

**Enquiry Report on the Human  
Rights Issues Arising from the  
Operation of a Residential and  
Day Care Centre for Persons  
with a Severe to Profound  
Intellectual Disability**

**March 2010**



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## Abbreviations

<b>AAQs</b>	Accessible, appropriate, acceptable and quality health care
<b>AIRS</b>	Accident and Incident Reporting Systems
<b>CAS</b>	Capital Assistance Scheme
<b>CB System</b>	Challenging Behaviour Scoring System
<b>CESCR</b>	Committee on Economic, Social and Cultural Rights
<b>CPT</b>	European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment
<b>CQL</b>	Council on Quality and Leadership
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>ECHR</b>	European Convention on Human Rights
<b>ECPT</b>	European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment
<b>ECSR</b>	European Committee of Social Rights
<b>EPSEN</b>	Education for Persons with Special Educational Needs Act 2004
<b>ERHA</b>	Eastern Regional Health Authority
<b>GP</b>	General Practitioner
<b>HIQA</b>	Health Information and Quality Authority
<b>HSE</b>	Health Service Executive
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ICESCR</b>	International Covenant on Economic, Social and Cultural Rights
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>MAIP</b>	Multi-Annual Investment Programme
<b>NCSE</b>	National Council for Special Education
<b>NDA</b>	National Disability Authority
<b>NEMU</b>	National Employment Monitoring Unit
<b>NIDD</b>	National Intellectual Disability Database
<b>NSP</b>	National Service Plan
<b>RESC</b>	Revised European Social Charter
<b>UN</b>	United Nations
<b>UNCAT</b>	United Nations Convention against Torture and all Forms of Cruel, Inhuman and Degrading Treatment or Punishment
<b>UN Principles</b>	United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care
<b>UN Standard Rules</b>	United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities
<b>VFM</b>	Value For Money
<b>WHO</b>	World Health Organization
<b>WTE</b>	Whole Time Equivalent



## Preface

One of the functions of the Irish Human Rights Commission is to conduct enquiries. It may do this of its own volition or at the request of any person who considers the conducting of such an enquiry to be necessary or expedient for the performance of certain other specified functions of the Commission.<sup>1</sup>

At its plenary meeting on 29 July 2004, the Commission delegated to the Chief Executive its function of conducting an enquiry at the request of a person. The delegation is subject to the requirement that before a decision is taken to conduct an enquiry the Chief Executive consult with the Commission's Casework Committee and take the Committee's views into consideration.

This is a report on the third enquiry conducted by the Irish Human Rights Commission. It relates to the important issue of the rights of persons with severe to profound intellectual disabilities and how the law and practice concerning these members of society operates in Ireland.

As noted, the Commission is empowered to conduct an enquiry where it is considered "necessary or expedient" for the performance of a number of the Commission's other functions. Among these other functions are the "keep[ing] under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights" and the "mak[ing of] such recommendations to the Government as [the Commission] deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights in the State".

It is important to note that an enquiry cannot therefore be a stand alone investigation but must be linked to the general functions of the Commission referred to. It is also important to note that in the exercise of its enquiry function, the Commission does not act as an adjudicatory body in respect of the

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<sup>1</sup> This report has been drawn up pursuant to Sections 9, 13 and 19 of the Human Rights Commission Act, 2000.

determination of rights or as a source of remedy. The Commission may, however, conclude that the enquiry has revealed a deficiency in the law/ practice in the State relating to the protection of human rights and this conclusion may in turn form the basis of a recommendation on the measures required to address the situation.

Accordingly, with due regard to the fact that by its nature an enquiry is not designed to adjudicate upon whether a human rights violation has occurred in a particular case, this enquiry has been directed to keeping under review the applicable law and practice in the State relating to the protection of the human rights of the individuals in the John Paul Centre and persons in a similar situation and to making recommendations on the measures required in order to strengthen, protect and uphold human rights in the State.

The fact that the enquiry function is not intended to adjudicate upon alleged human rights violations has allowed the Commission to take advantage of the cooperation of all the stakeholders to the enquiry in ascertaining how the situation in the Centre is a consequence of the strategies, legislation and policy frameworks set at the national level and how this has impacted on the individuals in the Centre. During the enquiry, this was done through research, correspondence, examination of documentation, reports and responses, interviews and meetings with the relevant stakeholders. The original intention had been to involve a number of experts in advising the Commission on aspects of the enquiry and to hold public hearings. However, it was decided not to proceed with these initiatives due to funding cuts to the Commission's budget during 2008 and 2009.

The enquiry report thus aims to set out the situation of the Centre against the national frameworks for the provision of disability services, before considering the international human rights standards applicable to the enquiry. The enquiry report then provides an analysis of the issues raised in the enquiry against those

standards. It then draws conclusions and makes recommendations and suggestions for follow-up action.

As stated, human rights enquiries are designed to identify whether there are any deficiencies in the law and/or practice relating to human rights in the State and, as such, the present report does not attempt to review medical standards from a clinical perspective. In enquiries such as the present one, which may span a period of time, our key task is to evaluate whether changes to laws and practices may remedy any deficiencies that previously existed in those laws or practices or whether more is needed to meet human rights concerns. I am confident that this report fulfils this purpose. However, the Commission would benefit from additional resources for its enquiry function e.g. in order to engage supplementary professional tailored advice and to conduct public hearings where warranted. In presenting this enquiry report, I would again call on Government to ensure adequate funding of such processes which are so essential to improved accountability in this jurisdiction.

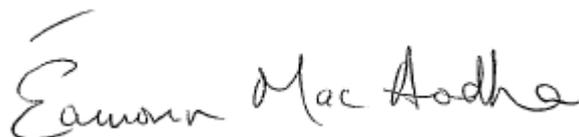
The issues raised by the parents of a group of adults with a severe to profound intellectual disability in the John Paul Centre, a residential, respite and day service centre in the State are thus considered against the national context. In this way, the report considers the situation facing these individuals, their parents and families, their carers and the charity which runs the Centre against the backdrop of a changing legislative and policy framework for the provision of services to persons with disabilities in the State. It then makes recommendations for improvements in the system.

I wish to acknowledge the courage and dedication of the parents of the individuals in the John Paul Centre, not least for their consistent engagement and assistance with the enquiry team. I would also like to acknowledge the excellent co-operation of the charity which runs the John Paul Centre, the Brothers of Charity Services Galway.

The Commission is mindful that its detailed requests for information and documentation throughout the enquiry created additional work for the charity and it extends its gratitude not only for the cooperation with the enquiry, but also the welcome afforded to the enquiry team by the Brothers of Charity during their trips to the Centre.

I would further like to thank the Health Service Executive (“the HSE”), the Department of Health and Children, the Department of Education and Science and the Health Information and Quality Authority for their exemplary cooperation with the Commission in the conduct of this enquiry. It is our common endeavour to secure human rights protection in the State, a fact recognised in the commitment of the HSE to produce and publish a detailed series of Actions to be undertaken in response to this enquiry report. An enquiry is not intended to be an adversarial process and, as with our previous enquiries, the current enquiry process is testimony to that fact.

Finally I would like to acknowledge the substantial work carried out on the enquiry and in the preparation of the report. In this regard, I would like to record my thanks to Des Hogan, Deputy Chief Executive of the Commission and Director of the Enquiries, Legal Services and Administration Division, for his exemplary commitment to the work on this report. I also wish to pay tribute to the staff of that Division for their efforts and to the volunteers in the Commission’s professional placement programme who assisted. Finally, I am indebted to the President of the Commission and the Commissioners for their advice and input in respect of this enquiry report.

A handwritten signature in black ink that reads "Éamonn Mac Aodha". The signature is written in a cursive, flowing style.

Éamonn Mac Aodha

Chief Executive

March 2010

## Executive Summary

A group of concerned parents (“the Parent Group”) contacted the Commission in relation to the care and welfare of their adult children living in a residential centre for persons with a severe to profound intellectual disability (“the Centre”). In 2007 the Commission decided to accede to their request for an enquiry into the human rights issues raised and the enquiry commenced in 2008. The terms of reference of the enquiry related to whether, *inter alia*, the State had fully respected the human rights of the individuals in the Centre, including through reference to whether the State had provided adequate facilities and/ or services for the individuals concerned. All the individuals at the Centre, who are the subject of the enquiry, have severe to profound intellectual disabilities and are adults aged in their twenties to early fifties. Many have lived in the Centre since they were children.

**Chapters 1-3** of the report set out the Commission's enquiry function, describe the background to the enquiry and provide a detailed account of the Commission's conduct of the enquiry.

**Chapter 4** of the report sets out the contextual factors arising from this enquiry and some of the complexities involved.

**Chapter 5** of the report provides an overview of the legal framework relevant to persons with intellectual disabilities living in residential, respite and day care settings such as, for example, their eligibility for health and personal social services, in-patient charges and social welfare entitlements. This chapter also describes recent legislative and policy developments including, for example, the National Health Strategy 2001, the Disability Strategy 2004, the Disability Act 2005, the Education for Persons with Special Educational Needs Act 2004 and the Citizens Information Acts 2000 and 2007, including the extent to which these various legislative enactments have been implemented.

**Chapter 6** of the report considers the actual service provision to the individuals in the Centre, in terms of residential, respite and day services. This includes an examination of personal outcome programmes, day programmes, medical and multidisciplinary supports. This chapter also highlights recent national initiatives regarding moving persons with intellectual disabilities from residential centres to community housing, which has also occurred in the Centre. The chapter considers the progress made in service delivery to individuals in the Centre in recent years. However, it also considers the ongoing concerns of the Parent Group in terms of the adequacy of the services, including for example the issue of multidisciplinary supports.

**Chapter 7** of the report examines the 2008 HSE Review into the Centre which was initiated following the Commission's decision to conduct this enquiry. This chapter considers the 18 HSE Review report recommendations and the subsequent response and follow-up of both the Brothers of Charity and the HSE to the review's recommendations.

**Chapter 8** of the report sets out the framework for the provision of funding to the Brothers of Charity Services Galway and how it is drawn down to the Centre. This chapter outlines the funding concerns as raised by the Brothers of Charity and members of the Parent Group; provides an overview of how funding is transferred from the Exchequer through the Department of Health and Children, the HSE and the Department of Education and Science, respectively, to the Brothers of Charity; provides for an overview of other funding provided to the Centre and other income generated by the Brothers of Charity.

**Chapter 9** of the report describes the accountability structures in place in the State which are of relevance to individuals with intellectual disabilities, including, the organisational oversight afforded through statutory or other reporting mechanisms, and the accountability mechanisms as provided for under the Health Acts of 2004 and 2007.

**Chapter 10** of the report sets out the standards for individuals with a severe to profound intellectual disability, as set out by the World Health Organization and also as set out at national level by the National Disability Authority and the Health Information and Quality Authority. In particular, this chapter considers the National Quality Standards for Residential Services for Persons with a Disability and their relevance to this enquiry. It also considers other good practice guidelines regarding consent, physical restraint and recent legislation providing for statutory registration of care professionals.

**Chapter 11** of the report sets out the international human rights standards relevant to the matters considered in the enquiry. The rights considered include the rights to health and bodily integrity for persons with disabilities; the rights to guidance, education and vocational training; the right to equality before the law and non-discrimination in the enjoyment of rights; the right to an effective remedy where a violation occurs; the right to freedom from arbitrary detention and the right to freedom of movement; the right to be free from inhuman or degrading treatment or punishment; and the rights to private life and to be treated with humanity and respect.

**Chapter 12** of the report provides an analysis of the issues raised in the previous chapters and identifies the international human rights that are applicable to this enquiry. It then sets out the Conclusions and Recommendations of the enquiry.

**Chapter 13** summarises the Recommendations of the enquiry where the Commission makes the following general and specific recommendations to the parties:

## *Summary of Recommendations/ Suggestions for Action*

### **To the Department of Health and Children**

#### ***General:***

- The Department should review the recommendations in this report carefully to identify those areas where existing legislation and practice may not fully reflect the State's human rights obligations as raised in this report. Where a gap in human rights protection exists, steps should be taken to remedy the situation within a short time frame.
- The Department, in conjunction with the Department of Justice, Equality and Law Reform and the Department of Foreign Affairs, should take steps to enable the State to ratify the UN Convention on the Rights of Persons with Disabilities without delay.
- The Department should introduce a clear and comprehensive definition of "health and personal social services" in primary legislation.
- The Department, in conjunction with the HSE, should review the imprecise nature of service agreements governing the quantum and quality of services to be provided under State funding, including their accountability structures. These agreements should be redesigned so that funding levels and accompanying protocols are delivered "bottom up" rather than "top down"; insofar as individual needs assessments, informed by personal outcome plans or similar programmes, inform the service levels, staffing levels and the capital funding levels required to ensure private life and dignity and the highest attainable standard of health. A "core" funding contingent should be identified to ring-fence front line services.

- The Department should convene a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, respite and day services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery. The recommendations of this working group should inform the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland.
- The Department should revise the workings of the National Intellectual Disability Database to ensure that it provides appropriate reliable data on service needs for persons with an intellectual disability in the State.
- The Disability Act 2005 should be fully commenced without delay.
- The Department should ensure that the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland be informed by a “bottom up” approach whereby individual assessments inform service level funding. Both this review and ongoing budgetary decisions should ensure that retrogressive measures in relation to the provision of core services in the Centre are guarded against.
- The Department should set out clear guidelines, possibly in the form of regulations, on the required staff-to-client ratios for centres caring for persons with an intellectual disability, taking into account adequate living space, socialisation, habilitation and night and weekend cover.
- The Department should introduce protocols governing HSE Reviews. There should be a statutory requirement on the HSE to report on such reviews including their terms of reference and their implementation by way of written report to the Houses of the Oireachtas.

- The complaints mechanisms currently available under Part 9 of the Health Act 2004 should be reviewed.
- The Department, in conjunction with the Department of Justice, Equality and Law Reform, should enact without any further delay, legislation and enforceable codes of practice concerning assessment of capacity and supported decision making for persons with an intellectual disability, in addition to protocols for next friend/ relatives giving of consent to placement in residential services and to medication or other forms of treatment. These protocols should also be introduced into service agreements.
- The Department, in consultation with the HSE and relevant statutory bodies, such as the Health Information and Quality Authority and the National Disability Authority, should set out clear protocols for the prevention of foreseeable risks to vulnerable persons with an intellectual disability living in institutions or residential centres through timely and appropriate intervention strategies.
- The Department should review the Government's 2003 Report to the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment ("CPT") and the commitments made in that report. The Department should ensure that all CPT recommendations on foot of its 2002 report concerning centres for persons with an intellectual disability are met, including those aspects that refer to detention in psychiatric institutions and that refer to multidisciplinary training and recruitment needs.
- The Department should ensure that the Health Information and Quality Authority's inspection and monitoring role as provided for in the Health Act 2007, are immediately introduced and that the Authority receives

adequate resourcing to carry out inspections and monitoring in all residential centres for persons with an intellectual disability.

## **To the Health Service Executive (“HSE”)**

### ***General***

- The HSE should review its public-private frameworks to ensure that service agreements are “bottom up”, being based on individual assessments. The HSE should stipulate in the agreements the precise nature of accountability structures in place, not only those governing financial accountability, but also in relation to the quality and quantity of services to be provided.
- The HSE should work closely with the Department of Health and Children in driving a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, respite and day services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery.
- The HSE should stipulate in its individual service agreements the precise level of multidisciplinary services available to the individuals in every residential, respite or day centre to meet the standards of accessible, appropriate, acceptable and quality health care. Any retrogressive measures in relation to the provision of core services in the Centre should be guarded against.
- The HSE should ensure that service agreements reflect sufficient control and accountability mechanisms to ensure that the State’s human rights obligations can be met in the delivery of health, habilitation and social care in the Centre and similar centres. Service agreements should be available

to the persons who avail of the services outlined therein and to their families.

- The HSE should introduce protocols so that HSE Reviews planned from 2010, have their recommendations implemented over a stipulated period of time. The HSE should also introduce the practice of providing written reports on its reviews to both the Department of Health and Children and the Oireachtas Committee on Health and Children and the findings of all such Review reports should be circulated to the individuals in the relevant centre and to their parents.
- The recommendations in this report on individualised assessments informing service needs should be applied by the HSE in the five demonstration sites being explored in 2010 for a recommended community living model. Specifically the Day Services component should be informed by individualised need assessment and that a form of personal outcome programme for the individuals concerned be put in place and monitored. Further, the residential, day and any respite services components in the demonstration sites should inform the deliberations of a Working Group on national average costings which is recommended in this report. A communication model between the service provider and the families of the individuals in the centres as suggested in this report should also be put in place.
- The HSE should instigate investigation and prevention strategies where areas of foreseeable risk (such as, overcrowding, staff shortages, challenging behaviour) may lead to situations of harm or neglect in centres for persons with intellectual disabilities. Recommendations should be followed up in a short timeframe. Reports of investigations and reviews should be laid before the Houses of the Oireachtas.

- The HSE should explore its system of non-judicial remedies in relation to situations currently outside the remits of the Ombudsman and Ombudsman for Children with a view to identifying whether other non-judicial remedies can be introduced which would address issues such as multidisciplinary services, health care provision and overcrowding in residential care settings for persons with an intellectual disability.

### *Specific*

- The HSE should ensure that adequate speech and language therapy and occupational therapy is available to the individuals in the Centre and others in a comparable situation. It should immediately fund the Brothers of Charity to engage an additional full-time Speech and Language therapist and an additional full-time occupational therapist. It should also make provision for an additional Consultant Psychiatrist to work with the present Consultant in the Centre on a needs basis.
- The HSE should provide an adequate level of capital funding to the Brothers of Charity for the development of appropriate residential services for the individuals in the Centre or in community group homes.
- The HSE should immediately provide the twelve individuals in the Centre who have been on a residential waiting list for between 1 and 12 years, with a full time service to meet their needs. Sufficient funding for respite services should be ring fenced to allow for at least a minimum service to continue to be available in the future.
- The HSE should immediately undertake a review of its Guidelines on in-patient charges to remove any disparity in personal income left to persons residing in congregated settings and hostels or community homes after in-patient charges have been deducted from a person's Disability Allowance. The said review should seek to ensure that each individual has sufficient

income left from their Allowance or other social welfare payment, after paying any in-patient charges, to allow them achieve optimum independence and to avail of opportunities for socialisation and integration with the community. The HSE should maintain an oversight function in relation to the assessment of the level of in-patient charges that each individual is liable to pay.

- In the event that the HSE imposes cuts to funding for the Centre in the future, it should be in a position to clearly demonstrate that any such measures can meet the international human rights standards set out in this report.

## **To the Department of Education and Science**

### ***General***

- The Department of Education and Science should ensure that educational provision is explicitly made for persons with an intellectual disability in adulthood; and that this educational provision is tailored to the individual's learning capacity. Separately, the Commission recommends that the Department of Education and Science ensures that provision be made for further educational guidance and vocational training for all adults with intellectual disabilities. In the interests of clarity, the Department should consider setting out such provision in legislation.
- The Department of Education and Science should ensure that these educational facilities should be guided by accessibility protocols.

### ***Specific***

- The Department of Education and Science should ensure that a review takes place as to the educational services currently available in the Centre

with a view to augmenting these services to ensure at least a minimal level of educational facilities for all individuals in the Centre.

### **To the Brothers of Charity**

- The Brothers of Charity should continue to review its protocols dealing with investigations and those preventive and remedial measures required in response to any challenging behaviour incidents that may arise at least on an annual basis and in advance of its annual service agreement meeting with the HSE. The Brothers of Charity should clearly document, on an ongoing basis, situations where foreseeable risks arise and it should draw such foreseeable risks to the attention of the HSE in writing, noting the causes for the risk (for example, individual behaviour, staffing levels, overcrowding etc.) and any measures taken or which in its view, should be taken.
- Pending the introduction of protocols matching individualised assessments to funding for the individuals in the Centre, the Brothers of Charity should explore ways of identifying individual needs, possibly through the personal outcome plan process. These individual needs and the quantum of funding associated with same should be drawn to the attention of HSE as part of its annual service arrangements.
- Pending the introduction of mental capacity legislation, the Brothers of Charity should formalise a system of supported decision making for each individual in the Centre and where necessary any substituted decision-making by parents for individuals in appropriate forms and that consent to medication and medical treatment continue to be regularly recorded in this manner.
- In relation to multidisciplinary services, the Brothers of Charity should follow up with the HSE in respect of the specific recommendations made

concerning speech and language therapy, occupational therapy and psychiatric services made in this report.

- In relation to individuals' accounts managed by the Brothers of Charity, the Brothers of Charity should introduce more formalised consent procedures to govern its handling of individual monies, to promote the autonomy and self-determination of the individuals concerned, in the context of the introduction of mental capacity legislation.
- Concerning the proposed move to community group homes, the Brothers of Charity should work with the Parent Group in a project team with clear terms of reference. The Brothers of Charity should work with parents to ensure that appropriate consultation and consent to any planned moves occurs, with concrete steps being taken to guard against isolation and to ensure that the individual is the centre of service provision in the new setting. A qualitative survey of the individuals who have already moved to community group homes should take place in order to inform this ongoing process.
- Any individual residing in a community group home should be provided with an appropriate tenancy agreement.
- The Brothers of Charity should continue to engage with the parents of the individuals in the Centre. New protocols should be devised to ensure accessible and transparent communication between Centre management, care staff and the parents which may include a more formal approach of meetings and consultations to supplement the informal approaches which are already working. Parents should be clearly informed in relation to their opportunities for engagement in relation to decisions concerning their children. Where parents or advocates engage in supporting individuals in the Centre to make decisions or where necessary substituted decision-

making occurs, the process of decision-making should be approached in a consultative and engaged manner and be documented where possible.

### **To the Parent Group and the Individuals in the Centre**

- The Parent Group should engage with the Centre Management and care staff in devising communication protocols that suit all parties.
- The Parent Group should continue to liaise with the Brothers of Charity in reviewing multidisciplinary needs on an ongoing basis and ensure that their input (and by definition the input of the individuals in the Centre) forms part of the annual review of multidisciplinary needs recommended to the Brothers of Charity; so that it can feed into the Brothers of Charity's annual service meeting with the HSE.
- In relation to any transfer to community group homes, the parents of the individuals concerned should engage in consultations on this issue with the Brothers of Charity as part of the project team referred to.

## Chapter 1            General Introduction

### Persons with a severe to profound intellectual disability

1.1     In recent years, Ireland has been at the forefront of international efforts to promote and advance the rights of persons with disabilities.<sup>2</sup> To this end, Ireland actively promoted the adoption of the new UN Convention on the Rights of Persons with Disabilities (“CRPD”) which was adopted by the UN General Assembly on 13 December 2006,<sup>3</sup> which fittingly, was the first comprehensive human rights treaty of the 21<sup>st</sup> Century. Ireland signed this treaty, commonly viewed as the new universal standard, in 2007 and has undertaken to ratify it swiftly. Many of the principles in the CRPD are already to be found in international conventions to which the State is a party. It is the task of national authorities, national human rights institutions, civil society and advocacy groups to ensure that the rights of persons with disabilities as enunciated in the CRPD are promoted and protected.

1.2     The most recent census (2006) statistics record 393,785 persons with disabilities living in Ireland.<sup>4</sup> More recent data provide that there are 26,023 persons registered as being persons with intellectual disabilities in the State.<sup>5</sup> Of this group, 4037 (15.5%) are persons with a severe intellectual disability and 1001 (3.8%) are persons with a profound intellectual disability.<sup>6</sup> As discussed in this enquiry report, the proper supports required by these most vulnerable and invisible of our citizens are substantial. As also discussed, the range of their rights is also considerable. The task of this enquiry report has been to consider the

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<sup>2</sup> Article 1 of the United Nations Convention on the Rights of Persons with Disabilities states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

<sup>3</sup> Adopted at the 61<sup>st</sup> Session of the General Assembly on 13 December 2006, the Convention was opened for signature on 30 March 2007. On 3 April 2008 it received its 20th signatory triggering the entry into force of the Convention and its optional protocol 30 days later.

<sup>4</sup> Central Statistics Office, *Census 2006: Vol 11, Disability, Carers and Voluntary Activities*, Table 1A, p. 13.

<sup>5</sup> Health Research Board, *National Intellectual Disability Database 2008*, p. 21.

<sup>6</sup> Health Research Board, *National Intellectual Disability Database 2008*, p. 12.

situation of one group of persons with severe to profound intellectual disabilities living today in the same residential centre many have lived in since early childhood.

1.3 International human rights law and best practice standards for persons with severe to profound intellectual disabilities recognise the huge challenges facing these individuals, their parents and family members, their carers, health care providers, health care professionals and administrators in formulating principles and practices that can deliver the best possible health care and habilitation facilities for these persons. Emerging international best practice, based on the presumption of ability and capacity in the CRPD, suggests that national authorities should consider how to best organise facilities and services around the citizen who has a severe to profound intellectual disability, rather than attempting to “fit” the person into a system which may be unsuited or inappropriate to their ability and potential. Ultimately the objective is to facilitate the persons concerned to live with maximum independence and autonomy within the community, and to be recognised as bearers of rights and acknowledged as equal citizens.

1.4 There can be no doubt that there has been significant public spending in recent years in the area of disability, with both capital and non-capital funds being made available, while a reconfiguration of services for children with intellectual disabilities has also occurred. These changes have been taking place against the backdrop of both substantial revenue for health services and a significant reorganisation of the health services particularly under the Health Act 2004 and the creation of the HSE. However, such development and investment must also be understood in a context where services for persons with disabilities have been historically chronically underdeveloped and under funded.

1.5 Also of relevance to this enquiry is the significant array of policy, legislative and accountability mechanisms introduced in recent years, including the National Health Strategy (2001), the National Disability Strategy (2004), the Education for

Persons with Special Educational Needs Act 2004 and the Disability Act 2005 and the creation of the Health Information and Quality Authority, incorporating the Social Services Inspectorate under its auspices. Building on the excellent work undertaken by the National Disability Authority in recent years, these mechanisms have made a significant contribution to disability rights.

1.6 Nonetheless, it remains the case that many of our citizens with an intellectual disability remain accommodated in inappropriate settings, including in or near psychiatric institutions. Many more are accommodated in residential centres where a constant effort is required of parents, family members and professional carers to seek the necessary funds to provide adequate services for these individuals.

1.7 This enquiry focuses upon the experience of a group of persons with a severe to profound intellectual disability in one residential centre and considers their experience against the law and practice relevant to persons with a severe to profound intellectual disability in the State. It then examines the extent to which that law and practice relevant to persons with a severe to profound intellectual disability in the State complies with Ireland's human rights obligations.

### **The nature of an enquiry**

1.8 The Irish Human Rights Commission ("the Commission") is the State's national human rights institution and an independent statutory body. The Commission may, at its discretion, decide to conduct an enquiry into any relevant matter at the request of any person who considers the conducting of such an enquiry to be necessary or expedient for the performance of any of the following functions of the Commission, namely:

- to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights;
- to consult with such national or international bodies or agencies having a knowledge or expertise in the field of human rights as it sees fit;

- either of its own volition or on being requested to do so by the Government, to make such recommendations to the Government as it deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights in the State;
- to promote understanding and awareness of the importance of human rights in the State and, for those purposes, to undertake, sponsor or commission, or provide financial or other assistance for research and educational activities.<sup>7</sup>

1.9 The Human Rights Commission Act of 2000 defines the term “human rights”:

In this Act (other than section 11), “human rights” means-

- (a) the rights, liberties and freedoms conferred on, or guaranteed to, persons by the Constitution, and
- (b) the rights, liberties or freedoms conferred on, or guaranteed to, persons by any agreement, treaty or convention to which the State is a party.<sup>8</sup>

1.10 The enquiry function of the Commission is therefore not free-standing. It serves as an aid to the performance of the other four specified functions.<sup>9</sup>

1.11 It is also important to note that, in the exercise of its enquiry function, the Commission does not act as an adjudicatory body. It does not decide on the merits of a particular alleged violation of human rights; nor is it for the Commission to afford a remedy to a person or persons who believe that their human rights have been violated. When a matter is brought to its attention, the Commission may however enquire into the matter in order to carry out one or more of the other four specified functions. For example, on foot of an enquiry, it may make recommendations for the strengthening of human rights in the State, or it may conduct an enquiry to aid it in a review of practice in the State relating to the protection of human rights.<sup>10</sup>

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<sup>7</sup> Sections 8(f) and 9(1)(b) of the Human Rights Commission Act, 2000. The other four specified functions are set out in Sections 8(a), (c), (d) and (e) of the Act.

<sup>8</sup> Section 2 of the Human Rights Commission Act, 2000.

<sup>9</sup> See further for an explanation of the enquiry function of the Commission, Appendix 2 of the Commission's *Annual Report 2003*.

<sup>10</sup> The competence of the Commission to conduct an enquiry is circumscribed by the Human Rights Commission Act, 2000, and the Commission has adopted guidelines in respect of the exercise of the discretion afforded to it by the Act: see Appendix I.

## Chapter 2            Background to the Enquiry

### The request for an enquiry

2.1     The request that the Commission conduct the enquiry came from a group comprising the parents and some siblings of adult persons with a severe to profound intellectual disability who reside in the John Paul Centre (“the Centre”) which is run by the Brothers of Charity Services Galway (“the Brothers of Charity”) in Galway City. The enquiry request from the group (“the Parent Group<sup>4</sup>”) related to the services and facilities available for their adult children within the Centre.<sup>11</sup>

2.2     The Parent Group informed the Commission that the Centre was opened in 1980 to provide a day and residential service to children with intellectual disabilities. Although originally established to provide services to children, these children have now grown up and continue to reside in the Centre. According to their parents, the Centre is unsuitable to meet the needs of their children who are now adults. The Parent Group was generally supportive of the Brothers of Charity and viewed the problem as one of funding and not one of commitment.

2.3     The main concerns of the Parent Group focus on historic underfunding, overcrowding, inadequate staffing, and a lack of occupational and other activities and therapies, most notably speech and language therapy. The Parent Group contended that these issues led to deterioration in the physical and mental health of their children, in turn leading to an increase in incidents and accidents between residents and between residents and staff, and to increased usage of medication as a means of controlling this type of challenging behaviour. More fundamentally, the Parent Group argued that the lack of multidisciplinary therapies was having a profound negative impact on their children. Concerns were expressed regarding

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<sup>11</sup> The term “Parent Group” is employed as it is the name the group refers to. However, it should be noted that a separate group is named *The Association of Parents and Friends of the John Paul Centre*. This group is comprised of parents who fundraise for the Centre: see Chapter 8.

the manner in which decisions affecting the individuals in the Centre were taken and the accountability of State authorities.

2.4 The Parent Group indicated that they had been involved in communications over an extensive period in relation to their concerns with a number of elected representatives, with Government Departments, particularly the Department of Health and Children and the Department of Education and Science and with the HSE and its predecessor, the Western Health Board.

2.5 With the abolition of the Health Boards in 2004, the HSE has statutory responsibility to ensure the provision of services (including residential and day care) to persons with intellectual disabilities. It does this by subcontracting responsibility to voluntary bodies which are not for profit organisations, as permitted under the Health Acts. Thus, since assuming responsibility from the Sisters of Charity in 1989, the Brothers of Charity has provided services to the residents of the Centre who were then children or young adults. This has occurred under contractual arrangements most recently set out under a service level agreement with the HSE to provide services for intellectual disabilities in the Galway region.

### **Issues raised**

2.6 The issues raised by the Parent Group thus relate to the adequacy and effectiveness of the law and practice in the State relating to services for persons with intellectual disabilities and in particular whether both law and practice in the State respect the human rights standards the State has committed itself to.

2.7 The relevant domestic law governing the provision of health and habilitation services for persons with intellectual disabilities are set out in the Health Acts and Disability Acts (see Chapter 5 below).

2.8 The term 'relevant practice' refers to the processes actually followed by both State agencies and private bodies in a number of respects: in assessing and allocating resources to cater for the service needs of persons with intellectual disabilities, in taking administrative decisions to grant or refuse funding for certain services, in the accountability of both State and voluntary bodies for what occurs in residential and day centres and in the actual treatment and care of persons such as the residents of the Centre the subject of the enquiry. Reviewing relevant practice includes consideration as to whether the State's service provision to persons with intellectual disabilities may involve ill-treatment or may not fully respect the dignity of the individual.

### **Consideration of the enquiry request – pre-enquiry stage**

2.9 In April 2004, the Parent Group confirmed that the group's request to the Commission was that it conduct an enquiry into the matter. In a meeting with the Commission in May 2004, members of the Parent Group indicated that they were seeking increased funding from the former Western Health Board (now the HSE) so that the Brothers of Charity could provide an improved level of service for their adult children. In addition, the Parent Group stated that it was in favour of individual needs assessments for all persons with a disability and for rights-based legislation to secure the delivery of necessary services. While describing the staff of the Centre as "heroic", the group again highlighted a number of concerns in relation to the ongoing deterioration of the mental and physical health of their children, staffing and accommodation issues, the need for a programmatic approach to life-skills and inadequate support services.

2.10 Before taking a decision on the enquiry request, the Commission sought to satisfy itself in relation to a number of matters. Following the May 2004 meeting, it engaged in detailed correspondence with the Parent Group, the Brothers of Charity, the Department of Education and Science ("Department of Education"), the Department of Health and Children ("Department of Health") and the HSE.

2.11 In November 2004, the Commission wrote to the Parent Group seeking clarification on a number of matters, including in relation to the formal and informal arrangements between the Centre, the Western Health Board, the Department of Health and the Department of Education. The Commission also sought details of other disability services run by the Brothers of Charity in the Western Health Board region. In addition, the Commission requested further details regarding the planned relocation of residents to alternative living arrangements and a number of incidents of challenging behaviour reported in the Centre. Finally, the Commission requested further information in relation to 'best practice' guidelines and any recent correspondence between the Brothers of Charity and the Health and Safety Authority.

2.12 In February 2005, the Parent Group confirmed that it had not received a copy of any recent correspondence between the Brothers of Charity and the Health and Safety Authority and that there were no ongoing or planned legal proceedings in relation to the matters raised in its enquiry request to the Commission.

2.13 In April 2005, the Parent Group again wrote to the Commission enclosing the Service Level Agreement between the Brothers of Charity and the HSE. In addition, the Group enclosed documents relating to Department of Education funding, to service needs, to other Brothers of Charity services, to the planned relocation of residents to larger premises and in relation to the incidence, reporting and management of challenging behaviour. In addition, the Parent Group enclosed a number of documents relating to best practice guidelines and a number of designs and plans for buildings in the Centre.

2.14 In addition to the various enclosures, the Parent Group noted that comprehensive details of services required by the individuals in the Centre on the basis of professional recommendations had been forwarded for many years to the appropriate authorities. The Parent Group also highlighted the fact that the relevant health and safety legislation only refers to staff and not to the individuals

in the Centre and stated its view that the right to liberty and security were compromised by the inadequacy of staffing levels. Finally, the Parent Group again emphasised that its comments were not directed at the staff or management of the Centre whose work “under difficult circumstances” was commended. Following this letter, the Commission received a number of telephone calls and letters from individual members of the Parent Group providing further details concerning the situation of their adult children at the Centre.

2.15 In December 2005, the Commission wrote to the Brothers of Charity, the Department of Education, the Department of Health and the HSE. In the letters to the two Departments and the HSE, the Commission sought to ascertain, among other matters, whether in their view a link existed between the provision of health and educational services and the levels of challenging behaviour at the Centre and if such a link existed, the measures taken by the State to address this.

2.16 In its letter to the Brothers of Charity, the Commission sought clarifications in relation to a number of “incidents of challenging behaviour” in the Centre between 2000 and 2005, whether these incidents had increased or decreased in that time, whether they had been brought to the attention of the HSE and whether, in the view of the Brothers of Charity, the physical and mental health of the individuals in the Centre had deteriorated in recent times.<sup>12</sup> In addition, the Commission asked detailed questions concerning the HSE Service Level Agreement with the Brothers of Charity, including in relation to staffing, funding needs and the precise legal obligations under which the Brothers of Charity ran the Centre.

2.17 The Brothers of Charity responded in January 2006 with detailed clarifications in relation to incidents of challenging behaviour for the period 2000 to 2005. It confirmed that the health of both individuals and staff may well have deteriorated due to the high level of such incidents. However, it pointed out that these incidents had decreased since 2004 after a 24 hour intensive ‘wraparound’

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<sup>12</sup> “Incidents of challenging behaviour” refers to incidents between individuals in the Centre.

staffing was introduced for two individuals.<sup>13</sup> The Brothers of Charity also indicated that covering the cost of providing the wraparound staffing service caused it serious budgetary difficulties as funding had not been secured from the HSE for the service.<sup>14</sup>

2.18 The Brothers of Charity provided data in relation to staff and the individuals in the Centre and expressed serious concerns regarding the adequacy of its resources. In particular, the view was expressed that the baseline staffing in residential services was “grossly inadequate” and that there were insufficient resources to provide suitable accommodation for the individuals in the Centre and support for those individuals with challenging behaviour. Finally, it was clarified that the relevant statutory and legal obligations referred to in the Service Level Agreement were not prescribed in a comprehensive manner. Instead, the Department of Health or the HSE informed voluntary organisations as to the introduction of relevant legislation by way of circular letters and in some instances, by way of a training workshop.

2.19 In April 2006, the Commission wrote again to the Brothers of Charity in relation to the extent to which either the former Western Health Board or later the HSE had conducted any inspections of the Centre in the past. The Brothers of Charity clarified that the Centre had been visited on two occasions since 1989 by the Western Health Board. However, no independent inspections had occurred.

2.20 In its letter of December 2005 to the Department of Education, the Commission sought information on any budgetary allocations made by the Department to the Brothers of Charity specifically for the provision of services at the Centre. The Commission also sought details regarding the nature and level of services for adults with severe to profound intellectual disabilities provided by the Department in the State. In addition, the Commission requested copies of

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<sup>13</sup> The wraparound staffing service is a “one-on-one, or two on-one” staffing ratio provided for an individual exclusively in their own accommodation including waking night staff.

<sup>14</sup> Discussed in Chapters 6 and 8 of this report.

standard guidelines for assessing the educational or vocational needs of adults and children with a severe to profound intellectual disability and best practice guidelines for assessing accommodation and day programme needs.

2.21 In its response to the Commission of February 2006, the Department of Education provided figures in relation to the level of funding provided to the Brothers of Charity between 2000 and 2005 and clarified that the primary responsibility for the provision of services to adults with an intellectual disability and for the assessment of accommodation and day care needs for persons with severe and profound disabilities lay with the relevant health authorities (the HSE), although the Department did provide some funding for an educational element to health programmes of adults with intellectual disabilities on a case by case basis. In relation to the question of any possible link between service provision and the levels of challenging behaviour at the Centre, the Department stated that it did not have sufficient detail on the circumstances at the Centre to comment.

2.22 In its letter of December 2005 to the Department of Health, the Commission asked about any best practice standards and statutory provisions concerning safety and any best practice guidelines concerning staff to client ratios, space and accommodation or day programme activities. It also sought information regarding any link between service provision and levels of challenging behaviour. Finally, the Commission requested copies of all documents pertaining to government policies and objectives regarding intellectual disability services, as referred to in the Service Level Agreement.

2.23 The Department of Health responded in February 2006. The Department explained that it had no direct function in relation to the provision of health services to individuals and that the management and delivery of services was the function of the HSE. The Department provided general information on its investment in service provision for persons with intellectual disability and stated that to date there has been very little formal engagement by the educational

services with adults with significant intellectual disabilities once they reach 18 years of age.

2.24 In relation to the question of a possible link between service provision and levels of challenging behaviour at the Centre, the Department of Health confirmed that challenging behaviour in those affected by severe to profound intellectual disability can result from or be exacerbated by overcrowding, lack of recreational opportunities or inadequate staffing. The Department stated that dealing with challenging behaviour was one of the identified areas within existing services for which additional funding had been provided by the Government.

2.25 The Department of Health also clarified that it was not aware of specific statutory provisions relating to the safety and welfare of persons with an intellectual disability other than the health and safety legislation that applies to all employers. In addition, it stated that a joint management/ union group had recently been established by the HSE to examine violence against health care staff across all healthcare settings. The Department explained that it had not issued guidelines in relation to staff to client ratios and that such arrangements were a matter for local management. Finally, the Department enclosed relevant policy documents and a copy of the Health (Eastern Regional Health Authority) Act 1999 as background to the Service Level Agreement.

2.26 In its letter to the HSE, the Commission sought to ascertain whether the HSE was aware of the number of incidents of challenging behaviour at the Centre and of any measures taken by the State to address such incidents. In addition, the Commission also sought information on the recommended staff-to-client ratio employed by the HSE, a breakdown of annual budgetary allocation to the Centre and for documents referred to in the Service Level Agreement to be forwarded, including those containing the agreed policies and objectives for Intellectual Disability services in the functional area of Health Boards.

2.27 In its response to the Commission in January 2006, the HSE confirmed that it was aware of the concerns voiced by the Brothers of Charity in relation to inadequacy of resources and that HSE officials had visited the Centre. The HSE stated that the level of development funding for the Centre was inadequate to meet all of the needs identified and that it was aware that 'risk funded' services had been put in place in relation to individual emergencies. The HSE made reference to its ongoing representations to the Department of Health for additional funding in respect of the Centre. In addition, the HSE drew attention to a Department of Health policy that only a maximum of 30% of new development funding could be allocated to those already in receipt of a residential place and that the requirement of enhanced supports had impacted negatively on resources allocated to the Centre.

2.28 The HSE stated that there were no specific HSE procedures or protocols to address the level of challenging behaviour and that protect the rights of persons with disabilities in such an environment as the Centre. However, it outlined the work carried out to-date to address this issue, including the recording of people's needs on the National Intellectual Disability Database. In relation to the question of a possible link between service provision and levels of challenging behaviour at the Centre, the HSE referred to research indicating that a continuum of service provision is required and referred to the soon-to-be-introduced mechanism under the Education for Persons with Special Educational Needs Act 2004 as a framework for future developments regarding educational needs (see Chapter 5).

2.29 The HSE also confirmed that no standard staff-to-client ratio had been set down by the Department of Health, Health Boards or the HSE. In addition, the HSE provided a breakdown of allocations to the Brothers of Charity Service, Galway, for the years 2000 to 2005. Finally, the HSE enclosed a number of policy documents and copies of legislation relevant to the agreed policies and objectives for Intellectual Disability services referred to in the Service Level Agreement.

2.30 In May 2006, the Commission wrote a further letter to the HSE in relation to an inquiry set up in 1999 by the Western Health Board on foot of a request by the Brothers of Charity to investigate allegations of sex abuse of clients by adults which may have occurred in other centres and to examine policies and procedures in place in the Brothers of Charity's Services. The HSE confirmed in June 2006 that a report of the Inquiry was expected to be completed in September 2006.

2.31 During 2006, the Commission continued to receive individual representations from members of the Parent Group in support of their request that the Commission conduct an enquiry into the care and treatment of their children at the Centre. The Commission's preliminary assessment of the issues arising from the enquiry request and the responses received from the Brothers of Charity and the State respondents continued during this period.

2.32 In early April 2007, the then-Chief Executive of the Commission and a staff member visited the Centre and met with management, staff and residents in order to examine at firsthand the facilities in the campus.

2.33 Before proceeding to take a decision on the request for an enquiry, the Commission reviewed the information supplied to it by the Parent Group, the Brothers of Charity, the Departments and the HSE. It also identified a number of human rights issues raised by the request.

### **Preliminary Review**

2.34 On a preliminary review of the matters raised by the enquiry request, it seemed that a number of rights guaranteed to persons by international conventions to which the State is a party were relevant to the situation of the individuals in the Centre.

2.35 At this point it appeared to the Commission that:

- the complainants were a group of parents of adult persons with a severe to profound intellectual disability whose children are residing in the John Paul Centre, in Ballybane in County Galway, which is run by the Brothers of Charity;
- although the Centre was established in 1980 to provide services to children with intellectual disabilities, these children had now grown up and it was argued that the Centre was unsuitable to meet the needs of the individuals in the Centre;
- the available service provision was viewed as inadequate to meet the needs of the individuals by the Parent Group, the Brothers of Charity and the HSE;
- there had been an escalation of incidents of violence in the Centre, possibly linked to the lack of adequate services, and this had only been remedied by expenditure of core funding on the part of the Brothers of Charity for what was arguably a short-term solution;
- the Parent Group had for a number of years communicated with State authorities in relation to the service needs of their children and had furnished the authorities with professional assessments and recommendations;
- there was no statutory entitlement which provided for a right to a certain level of services for the residents. At the same time, the scope of the legal obligations on the Brothers of Charity under its Service Level Agreement with the HSE appeared unclear - in that the agreement appeared to neither specify nor secure the relevant resources that may have been required;
- the relevant health and safety legislation only appeared to cover the safety of staff rather than the individuals in the Centre, while no independent standards or inspection mechanisms appeared to be in place;
- neither HSE nor Department of Health policies in relation to best practice service provision for persons with disabilities stipulated a minimum staff to service user ratio;
- the treatment of the individuals in the Centre by the State potentially raised a number of human rights issues under international conventions to which the State is a party.

## Chapter 3            Decision to Conduct the Enquiry and the Conduct of the Enquiry

### The decision to conduct the enquiry

3.1 On 5 April 2007, having considered the nature of the enquiry request, the law on the matter, the responses to the Commission's queries, the human rights issues involved and its legislation and guidelines, the Commission decided to accede to the request for an enquiry. The Commission was of the view that conducting an enquiry could be considered as expedient for the performance of two of its functions, as specified in the Human Rights Commission Act 2000, namely:

- to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights; and
- to make such recommendations to the Government as it deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights in the State.

3.2 The terms of reference set by the Commission for the enquiry were:

- to enquire into whether the State fully respected the human rights of the residents of the centre the subject of the enquiry, including through reference to whether the State provided adequate facilities and/ or services for persons with intellectual disabilities;
- to enquire into the extent to which persons with intellectual disabilities are entitled to and receive the necessary services to meet their human needs and human rights;
- to enquire into the extent to which the State's service provision to persons with intellectual disabilities has impacted on the residents of the centre the subject of the enquiry;
- to enquire into the legal bases, rationales and justifications advanced for decisions to grant or to refuse certain services to the residents of the centre;
- to consider what recommendations, if any, may be made to improve the human rights of the residents concerned.<sup>15</sup>

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<sup>15</sup> The Terms of Reference for the enquiry are set out in Appendix II.

## Procedure

3.3 The Commission's founding legislation provides that, for the purposes of an enquiry, the Commission may require a person to furnish relevant information, documents and things to it and, where appropriate, require such person to attend before it for that purpose.<sup>16</sup> It also provides that an enquiry may be conducted in public or in private as the Commission, in its discretion, considers appropriate.<sup>17</sup> Furthermore, subject to the provisions of the legislation, the procedure for conducting an enquiry shall be such as the Commission considers appropriate in all the circumstances of the case.<sup>18</sup>

3.4 The Commission decided that the enquiry would be held mostly in private but that there would also be public hearings in relation to aspects of the enquiry. However, in the course of the enquiry, the Commission suffered a serious funding cut which resulted in it not being able to hold public hearings. Accordingly the enquiry was held in private with its results to be made public.

3.5 The enquiry procedure adopted in the enquiry is set out in Appendix III.

## The conduct of the enquiry

3.6 In April 2007, the Commission notified the Parent Group, the Brothers of Charity and the following statutory bodies of its decision to conduct an enquiry: the Department of Education, the Department of Health and the HSE. The conduct of the enquiry commenced in 2008.

3.7 In February 2008, the Commission wrote to the Parent Group, the Brothers of Charity and the three statutory bodies outlining the enquiry procedure. In addition, the Commission wrote to the newly established Health Information and Quality Authority ("HIQA") in order to notify it of the enquiry as well as to outline

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<sup>16</sup> Section 9(6) of the Human Rights Commission Act, 2000.

<sup>17</sup> *Ibid.*, at Section 9(12).

<sup>18</sup> *Ibid.*, at Section 9(13).

the enquiry procedure. It put a number of detailed questions to all bodies in relation to the issues raised, as well as seeking further particulars from the Parent Group. A deadline of 28 days for responses was set. The Commission put 6 questions to the Parent Group, 10 additional questions to the Brothers of Charity, 5 questions to the Department of Education, 6 to the Department of Health, 8 to the HSE and 3 to HIQA.

3.8 In March 2008, the Commission received detailed responses from the Parent Group and four of the relevant bodies. One body responded in early April 2008. In September 2008, after analysing and cross-referencing the responses received to its first formal set of questions, the Commission sought additional information from the parties. Thus it put 11 additional questions to the Brothers of Charity, 4 to the Department of Health and 7 to the HSE with a further 28 day deadline. Responses were forwarded to the Commission within the specified timeframe by most parties, with the Department of Health responding in December 2008.

3.9 In early 2009 the Commission confirmed that no public hearings would take place and that the enquiry would conclude in private, with its results to be made public. After receiving further communications from the Parent Group, the Commission travelled to Galway in May 2009 at which time it met with the Brothers of Charity and with the Parent Group. It was also brought on a tour of the Centre and introduced to several residents and their care workers. In June 2009 the Commission engaged in a number of follow-up communications with parents, mostly by telephone. In July 2009, the Parent Group met with the Commission in the Commission's offices in Dublin. In July the Commission also conducted a number of telephone interviews with individual parents. The Commission sought further information and documentation from the Brothers of Charity in June and August 2009. It also sought further information and documentation from the HSE in August 2009. This information and documentation was received from both parties in September 2009.

## Information sought during the Enquiry

3.10 In addition to the information sought at pre-enquiry stage, the questions put to the Parent Group during the enquiry focussed on whether there had been any change in the situation previously advised regarding the conditions for their adult children at the Centre, on plans to move them to alternative community based homes, on its views on the administration of drugs at the Centre to manage or control behaviour and the relevant consent protocols attaching and on personal outcome programmes for their children.

3.11 The questions put to the Brothers of Charity during 2008 and 2009 (in addition to follow-up questions on previously raised issues) related to the wraparound staffing service, details of any negotiations with the HSE or proposed mechanism to ensure the adequate funding of their services, details of plans to move the individuals in the Centre to community based residential services and clarification of an inquiry into sex abuse in the past at another centre. The Commission also requested details concerning occupational and other therapy activities provided to the individuals in the Centre, the administration of medication at the Centre and any consent procedures in place. The Commission later sought information on the extent to which the recommendations of a 2008 HSE report on services in the Centre had been implemented and how complaints are dealt with.

3.12 Information was also sought on the process for assessing the medical needs of the individuals in the Centre, including the consent and capacity determination procedures for same, and the process for developing care plans and personal outcome programmes for the individuals in the Centre, with copies of nine personal outcome plans also requested. The Commission further sought information regarding the prioritisation of speech and language therapy within the Brothers of Charity Services generally, new Service Development Funding, community group homes, cuts to the Brothers of Charity's funding and staffing embargoes. It sought information on protocols governing the use of "restrictive

practices” in the Centre. It sought information on the registration of the individuals in the Centre with the National Intellectual Disability Database and the protocols required by the State in relation to the collection of individuals’ Disability Allowance. It also sought information on the levels of Department of Education funding for education in the Centre.

3.13 Additional questions put to the Department of Education during the enquiry (in addition to follow-up questions on previously raised issues) related to its progress on implementing provisions of the Disability Act 2005 and the Education for Persons with Special Educational Needs Act 2004 (“EPSEN Act”) which relate to the delivery of educational services, the education of a child with a disability coming into adulthood and the submission of an implementation report to the Minister for Education. In addition, the Commission requested details as to the assessment of applications from the HSE, other health authorities or service providers to the Department of Education for support for an educational element to the health programme of an adult. Finally, the Commission requested any relevant guidelines in relation to the teaching of adult students with a severe to profound disability.

3.14 The questions put to the Department of Health during the enquiry (in addition to follow-up questions on previously raised issues) focussed on ascertaining what additional resources had been provided by the Department with respect to services for people with disabilities since previous correspondence. In this regard, the Commission requested all relevant information concerning Department of Finance/ Department of Health protocols governing the funding of services for persons with disabilities. The Commission also asked what progress had been made in relation to the working group examining violence against health care staff. The Commission requested all information concerning specific obligations on the HSE and safeguards to prevent violence or ill-treatment of persons with disabilities living in residential settings. The Commission sought information on specific aspects of the oversight role of the Minister for Health and Children (“Minister for Health”) in respect of

the provision of services to persons with intellectual disabilities in residential settings.<sup>19</sup> The Commission also sought further clarifications regarding practical aspects of the funding process for the Brothers of Charity.

3.15 The questions put to the HSE during the enquiry (in addition to follow-up questions on previously raised issues) related to the progress of a review of services at the Centre commissioned by the HSE and any findings to-date. The Commission also requested copies of certain best practice guidance documents. In addition, the Commission asked whether there had been any reports or allegations of abuse since 1998, the period examined in a HSE-commissioned report by Dr. Kevin McCoy published in November 2007 (see Chapter 7). Detailed data was requested in relation to the funding of the Centre since 2000, including whether protocols were still in place that stipulated that a ceiling of 30% additional new development funding be applied to enhancing existing residential services. Further information sought related to whether any additional funding had been allocated to the Centre to support its wraparound staffing.

3.16 In relation to arrangements between the HSE and the Brothers of Charity, the Commission requested copies of the new Service Level Agreement, the Service Plan and any other contractual arrangements. The Commission also requested copies of any relevant protocols or arrangements between the HSE and service providers, including the Brothers of Charity which governed the reporting and management of incidents of violence and abuse. The Commission requested details on assessments of persons with severe and profound disabilities by multi-disciplinary teams working for the health authorities prior to funding applications to the Department of Education being made and all relevant information regarding such assessments at the Centre. The Commission later sought information on the engagement by the HSE with the Brothers of Charity regarding the implementation of the recommendations of the HSE Review Report (2008) and further clarifications were requested regarding the latest Service

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<sup>19</sup> This includes the making of directions to the HSE under section 10 of the Health Act, 2004. See further Chapter 9 on accountability mechanisms.

Level Agreement. In 2009, it sought sight of recent HSE Reviews on Adult Services and Congregated Settings, respectively, information on New Development Funding and speech and language therapy provision. The Commission also sought information on the HSE's knowledge of the complaints procedures operating in the Centre.

3.17 The questions put to HIQA related to whether it had any initiatives in relation to the services for or care of adults with intellectual disabilities in residential care. In addition, clarification was sought as to whether HIQA had any inspections planned for residential centres for persons with disabilities, any planned timescales for such inspections and as to whether HIQA was aware of or was planning any initiatives with respect to best practice in this area.

### **HSE Review**

3.18 The Commission was informed by the HSE in April 2008 that the HSE had conducted a review of services in the Centre following the Commission's decision to conduct an enquiry. That report issued in February 2008 and is discussed further in Chapter 7.

### **Draft Report**

3.19 A draft report was compiled by November 2009 and was sent, minus any conclusions and recommendations, to the Parent Group, the Brothers of Charity and to the four statutory bodies referred to in the enquiry for any views they had thereon prior to finalisation of the report.

3.20 All parties provided responses by December 2009 and all the responses received were taken into account in compiling this final report.

## **Final Report**

3.21 This final report is being concurrently submitted to the Parent Group, the Brothers of Charity and the four relevant statutory bodies. It is also being submitted to An Taoiseach in light of the cross-Departmental nature of the issues raised. This report is available in CD format on request from the Commission's offices (Jervis House, Jervis Street, Dublin 1 (tel: 01 858 9601)) and is also available on the Commission's website ([www.ihrc.ie](http://www.ihrc.ie)).

## Chapter 4 Context of the Enquiry

### The Individuals in the Centre

4.1 Opened in 1980 to cater for 55 residential and 26 day care children with intellectual disabilities, the accommodation in the Centre then consisted of 5 purpose built bungalows designed to cater for 10 children in each building. The 77 individuals who reside or receive a day service in the Centre today and who are the subject of this enquiry report, have a severe to profound intellectual disability. Although the Centre was designed to accommodate children, many of the child residents remained at the Centre as they progressed into adulthood, with 12 individuals now having resided at the Centre for over 25 years, one of whom arrived at the Centre at the age of three months.<sup>20</sup>

4.2 Now aged in their twenties to early fifties, the individuals in the Centre are the adult children of the Parent Group who requested the Commission to conduct the enquiry. Their parents have been their interlocutors with the Commission throughout the enquiry, along with the Brothers of Charity, the HSE and other statutory bodies. The reason for this is because practically all the individuals in the Centre cannot communicate verbally. Many have limited means to communicate with their parents or with their carers. In addition, because under Irish law there is no legal regime for assessing a person's legal capacity outside the Wards of Court system (see Chapter 5), while some individuals in the Centre may possess capacity to be able to take some decisions, in reality substituted decision-making takes place on their behalf. Practically all the individuals in the Centre have lived there since they were children. While the Centre was designed for children when it opened in 1980, it is now used only by adults. A policy has been adopted in agreement with the HSE where no new permanent admissions have been accepted into the Centre in the past 10 years, although recently one

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<sup>20</sup> HSE, *Review of Brothers of Charity Services, John Paul Centre, Ballybane, Galway*, February 2008, p. 6.

admission was made on a temporary basis to meet an emergency situation. In that time, 13 individuals have passed away.<sup>21</sup>

### **Severe to Profound Intellectual Disability**

4.3 As set out in Chapter 10, the International Statistical Classification of Diseases And Related Health Problems<sup>22</sup> defines intellectual disability using four classifications ranging from mild intellectual disability to profound intellectual disability. The American Psychiatric Association latest Diagnostic and Statistical Manual defines severe intellectual disability as representing an IQ level of 20-25 to 35-40 and profound intellectual disability as representing an IQ level below 20 or 25.

4.4 The World Health Organization has stressed the importance of individual assessments of the needs of people with intellectual disabilities.

Adults with intellectual disabilities can benefit from training of carers in health-related issues – particularly basic assessment skills. At the same time, adults who have basic communication skills need to be educated in the effective communication of pain or distress. Even in optimal circumstances – when the ill person with an intellectual disability is accompanied by knowledgeable carers – informant-based medical history taking requires time.<sup>23</sup>

4.5 The fact that the individuals the subject of this enquiry have difficulty communicating with family members and carers and the fact that they are mostly or wholly reliant on others for their care and well-being points to the fact that they represent one of the most vulnerable groups in society and one that cannot speak for itself. This fact brings a number of challenges to the conduct of an enquiry such as the present one. It means that the collation of information and evidence is based upon persons other than those whose human rights protection are at issue. It means certain claims can be difficult to test and that subjective interpretation of a person's condition and prognosis may differ between carers,

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<sup>21</sup> See Chapter 6.

<sup>22</sup> ICD-10: World Health Organisation, 1992.

<sup>23</sup> WHO, *Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing: Summative Report* (WHO, Geneva, 2000), at pp. 8-9.

between carers and family members, and between family members themselves. Chapter 10 will consider the condition of severe to profound intellectual disability and best practice in the area.

## **State Support**

4.6 As will become clear in the following chapters, responsibility for the provision of State support in the Centre is delegated from the Department of Health to the HSE and further from the HSE to a private not-for-profit body, the Brothers of Charity. Thus, the State's vindication of the human rights of the individuals in the Centre takes place firstly through a State agency but primarily through a private body which is a further context in which the current enquiry must be understood.

## **The Parent Group**

4.7 The Parent Group as the name suggests comprises a group of parents and some siblings of the individuals in the Centre.<sup>24</sup> As the age demographic of their adult children suggests, many of their parents are older persons who fear for the future wellbeing of their children. These parents have had to deal with a number of layers of bureaucracy over the years in their efforts to secure adequate resources for their children. It is clear that they communicate with the Brothers of Charity who care for their children, but in addition, they have also dealt with the Department of Health, the HSE and with local politicians and Ministers in trying to secure adequate resources.

### **Parent: Telephone interview with the Commission – 7 July 2009**

It is never clear to a parent who you should contact, from the Department of Health to the Department of Education to the HSE. One shoves responsibility onto the other, and they all say they have no money.<sup>25</sup>

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<sup>24</sup> As noted in Chapter 2, The 'Parent Group' which comprises 59 persons, is to be differentiated from the '*Association of Parents and Friends of the John Paul Centre*'.

<sup>25</sup> Parent 7, telephone interview with the Commission, 7 July 2009.

4.8 The courage and dedication of the parents is exemplary. Many have expectations that their children will learn to communicate with them and others through appropriate therapies and thus gain greater self-determination. Recent developments in intervention therapies for persons with intellectual disabilities, most notably for children, are monitored closely by these parents who believe their children should benefit from these therapies. This is in a context where many parents feel that their children missed out on opportunities for development earlier in life. In Chapters 4 to 8 of this report the Commission has included quotes from parents as to their concerns and as such relate to the perceptions of the parents of the adults in the Centre.

**Parent: Telephone interview with the Commission - 7 July 2009**

As well as parents, because of neglect in supporting services over the years, staff ended up with an impossible job, and as a result our children have regressed. We pay a very high price for lack of early diagnosis and intervention.<sup>26</sup>

**Parent: Telephone interview with the Commission - 2 July 2009**

There was so much good time lost. He was very bright if he had only got the services he needed. In fact his needs were never addressed until he became a problem.<sup>27</sup>

## The Brothers of Charity

4.9 The John Paul Centre was handed over to the Brothers of Charity by the Sisters of Charity in 1989.<sup>28</sup> In 2007, the Brothers of Charity Services Ireland<sup>29</sup>

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<sup>26</sup> Parent 7, telephone interview with the Commission, 7 July 2009.

<sup>27</sup> Parent 8, telephone interview with the Commission, 2 July 2009.

<sup>28</sup> The Congregation of Brothers of Charity is an international Roman Catholic religious organisation founded in Belgium in 1807. Founded by Canon Peter Triest and originally named the 'Hospital Brothers of St Vincent' after its patron saint, St Vincent de Paul, the Brothers of Charity, as they became popularly known, took their first religious vows in November 1811. Formed for the purpose of providing care to elderly men, by 1815 the Brothers of Charity were also providing care to persons with mental illness in Belgium. Today the Brothers of Charity provide services in 27 countries worldwide and its central administration is based in Rome. The Brothers of Charity opened its first services in Ireland in 1883 to provide for mental health needs and in 1938 it started to develop services for persons with an intellectual disability.

provided services to 3,600 persons with an intellectual disability, comprising 1,685 children and 1,945 adults, and employed 2,847 (whole time equivalent) staff members.<sup>30</sup> It had a total annual budget in 2007 of €183,462,598. Of this total, €159,608,589 was received from the HSE under Service Level Agreements with the Brothers of Charity Services Ireland's six regional service providers.<sup>31</sup>

4.10 One of the six regional service providers is the Brothers of Charity Services Galway.<sup>32</sup> In 2007, the Brothers of Charity Services Galway catered for 965 individuals with an intellectual disability (47% children and 53% adults), this number had risen to 1155 in 2009.<sup>33</sup> While it employed 811.42 whole time equivalent ("WTE") staff at the end of 2007, by 2009 this figure was 835.14 WTE employees.<sup>34</sup> The Brothers of Charity Services Galway is principally funded by the HSE and in 2009 it had an annual budget of €55.4 million.<sup>35</sup>

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<sup>29</sup> In January 2007, the Congregation of the Brothers of Charity in Ireland reorganised as a company limited by guarantee and became the Brothers of Charity Services Ireland, whose directors are Brother Members of the Congregation.

<sup>30</sup> Brothers of Charity Services Ireland, National Annual Report 2007, pp. 21 and 24.

<sup>31</sup> *Ibid.*, p. 29.

<sup>32</sup> As noted, in January 2007, the Galway region of the Brothers of Charity Services Ireland reorganised as a company limited by guarantee and became the Brothers of Charity Services Galway. In so doing, the Brothers of Charity Services Galway established its first Board of Directors and appointed a Chairperson. The Brothers of Charity Services Galway is also a registered charity: Company Registration No. 416984. The other five regional service are Clare, Limerick, Roscommon, South East, and Southern. Each region operates as an autonomous service under the auspices of the local company which owns and maintains the regional service. Each local company has its own annual budget which it receives mainly from the HSE. The management and executive functions of the local companies are the responsibility of the local Chief Executive.

<sup>33</sup> Brothers of Charity Services Galway, Annual Report 2007, p. 6, also Service level agreement 2009. It is noted of the 1155 people receiving a service in 2009, 930 were receiving a primary service from the Brothers of Charity while the remaining number were receiving their primary service elsewhere.

<sup>34</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>35</sup> Synopsis of Service Plan 2009. Of this sum, €48.2 million was an allocation from the Health Service Executive. As will be outlined in Chapter 6, the relationship between the Health Service Executive and the Brothers of Charity Services Galway is set out in Service Agreements between the parties, which are negotiated periodically. The Brothers of Charity Services Galway is a 'Service Provider' within the definition set out in the Health Act 2004 (see Chapter 5).

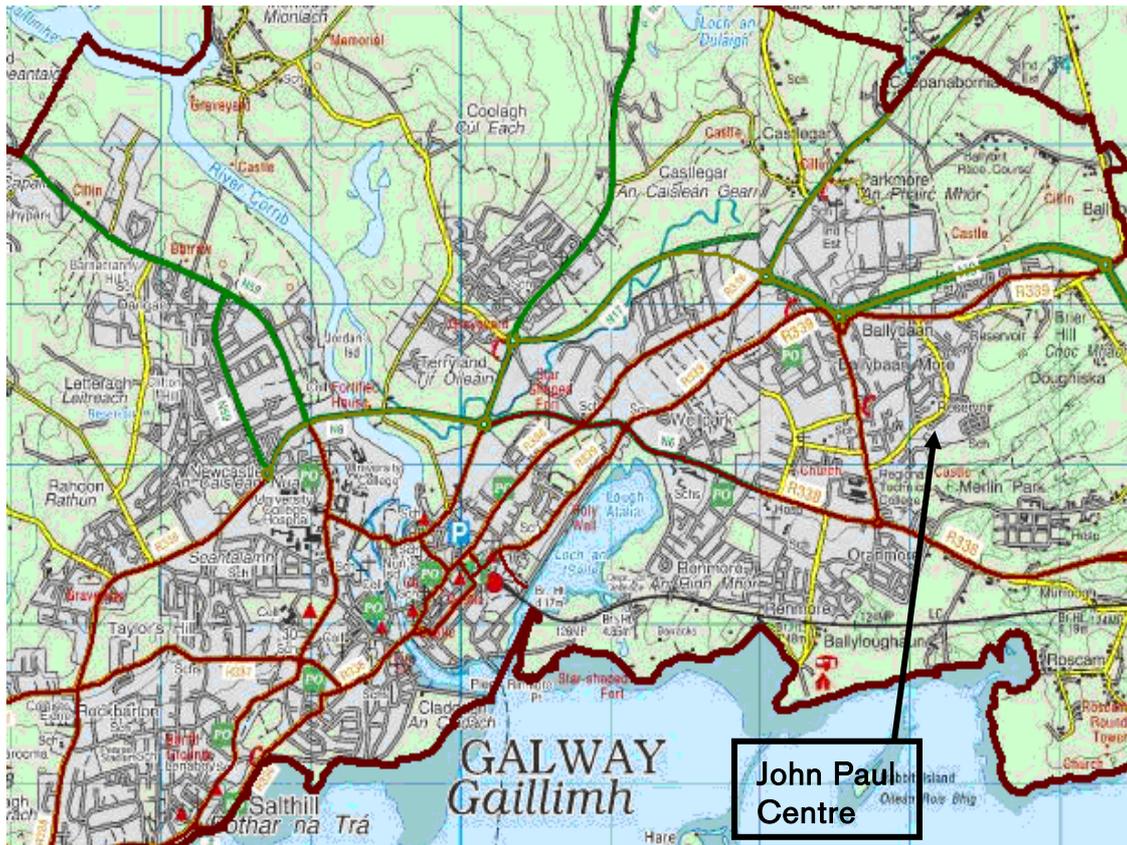
4.11 The Brothers of Charity Services Galway provides a range of services across the Galway region.<sup>36</sup> Both children and adults with an intellectual disability access these services through community, day, residential, respite and supported living arrangements services. These will be discussed further in Chapter 6. Adult services in Galway are divided into two sectors; East Galway and West Galway. The John Paul Centre is one of eight services for persons with intellectual disabilities provided by the West Galway Adult Services.

### **The John Paul Centre**

4.12 The Centre consists of campus accommodation and community group homes. The campus is situated in an urban residential area on the eastern suburbs of Galway City approximately two kilometres from the city centre, as can be seen on the map below. In addition there are a number of community group homes located around the Galway City area.

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<sup>36</sup> These include: Early Assessment Intervention; Health Related Support Services; Day Activation for Children and Adults; Advocacy Support; Personal Development Training; Family and Sibling support; Crisis Intervention and Respite Care Services; Staff Training and Development Services; Care of Elderly Persons with Intellectual Disability; Community School Age Support; Development and Pre-School Service; Educational Services; Vocational Preparation; Supported Employment Arrangements; Residential Care; Supported Employment Service; Service for Children and Adults with Autism; Pastoral Care and Chaplaincy Service; and Integrated Leisure Activities.



Source: Galway City Council, Ordnance Survey

4.13 As noted previously, the Centre was opened by the Irish Sisters of Charity in December 1980 to provide care for children between the ages of 3 and 18 years with a severe to profound intellectual disability. At that time, it catered for 55 residential individuals and 26 day individuals and the accommodation consisted of 5 purpose built bungalows designed to cater for 10 children in each building.

4.14 In 2007, total expenditure for the Centre was €9.371 million.<sup>37</sup> In 2009 this figure had risen to €9.531 million.<sup>38</sup> As noted, as of 1 January 2009, the Centre was catering for a total of 77 individuals through a combination of campus based residential services (37), day services (67), respite services (16, on a 7 bed basis<sup>39</sup>) and off-site community housing (21).<sup>40</sup> It is the stated intention of the

<sup>37</sup> Brothers of Charity Services Ireland; National Annual Report 2007, pp 21 and 24. The pay element of this expenditure was €8,144 million and the non-pay element of this expenditure was €1.227 million.

<sup>38</sup> Letter from the Brothers of Charity to the Commission, dated 7 September 2009.

<sup>39</sup> This arrangement means that the 9 persons cannot be accommodated at any one time.

Brothers of Charity Services Galway to move some residents in the Centre out of the campus over time and into off-site community based housing.<sup>41</sup> Some members of the Parent Group have had concerns about this proposal which are set out in Chapter 6.

## **Service Provision**

4.15 The concerns advanced by the Parent Group should be understood in the context of persons with severe to profound intellectual disabilities. Unlike other persons with disabilities, people with a severe to profound intellectual disability who have not had the benefit of life skill therapies and who have limited communication abilities, find it very difficult to perform basic life skills and to effectively communicate with others. Frustration is felt by parents and care workers where appropriate supports may be lacking. The challenges to all parties coping in this situation cannot be overestimated.

4.16 The extent of available therapies for individuals and the planned introduction and roll out of care plans and personal outcome programmes in recent years were also important issues raised in the enquiry. The education of a child with a disability coming into adulthood and their education in early adulthood was also raised. Concerns were raised that locked doors and over-reliance on medication may in the past have been used as a means of controlling challenging behaviour instead of addressing its underlying causes through intervention strategies. Concerns were also raised about the planned relocation of residents; the concern being that they may become isolated if in a non-campus environment. The lack of inspections or independent monitoring of residential homes was a theme also raised during the enquiry.

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<sup>40</sup> Letter from the Brothers of Charity Service Galway to the Commission, dated 7 September 2009. It should be noted here there can be an overlap between 'day' and 'residential' services as some individuals may be receiving both.

<sup>41</sup> *Ibid.* According to the Brothers of Charity Service Galway, community based housing for people with an intellectual disability has been regarded internationally as best practice since the 1980s when there was a paradigm shift in the organisational model of service from institutional/campus service to community integrated services.

## Irish Law

4.17 The law governing the delivery of health services in the State is spread across a number of statutes dating back to 1947, as outlined in Chapter 5. When the HSE was established in 2004, there was no attempt to consolidate the statutory functions of the new Executive, but rather it inherited the functions of the previous health boards, which in turn had been acquired from the previous health authorities, with only some additional elaboration of how those functions were to be carried out.<sup>42</sup> There is no clarity on the law governing mental capacity determination apart from the Wards of Court system administered by the President of the High Court (see Chapter 5). In addition, under the Health Act 2004 the HSE is understood to have the primary duty of delivering “health and personal social services” in the State, however there is no one definition of such services, and they must be understood from identifying elements from different statutes and from practice on the ground.

4.18 As a result, when examining the services being provided to the individuals in the Centre, there is no benchmark by which it is possible to determine what they are statutorily entitled to in terms of either health or personal social services. More recent statutory developments that should have moved towards clarifying this situation have not been fully implemented. In this regard, the Disability Act 2005 which should have directly addressed the situation of the individuals in the Centre, has only been partially implemented, namely in relation to children under five years of age.<sup>43</sup>

## Funding

4.19 At the outset of and throughout the enquiry, the Brothers of Charity agreed that serious underfunding was impacting on its ability to deliver proper

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<sup>42</sup> In the Annual Report of the Comptroller and Auditor General 2007, it was stated that: “Many health services are fragmented, disjointed and difficult for patients and service users to access and easily find their way through”; at p. 117.

<sup>43</sup> See Chapter 5.

services in the Centre. The Brothers of Charity, the Parents Group and indeed the HSE had all made representations in the past to the Department of Health seeking additional funds. Indeed over a number of years, the Parent Group had met with the Health Board, the Department of Health and Ministers seeking intervention on the service needs of their children and providing the authorities with professional assessments and recommendations linked to its requests.

4.20 At the outset of the enquiry, there was a sense of exhaustion on the part of the parents and some staff after years spent seeking additional State support for the Centre. During the course of the enquiry, some improvements in services occurred, including through increased funding after a HSE review was initiated following the Commission's decision to conduct the present enquiry (see below).

4.21 A further complexity in the enquiry derived from the fact that arguably the effective performance of the Service Level Agreement between the HSE and the Brothers of Charity was predicated upon funding which neither party could secure. During the course of the enquiry, the Commission was referred to the fact that a 30% "cap" existed in relation to enhancing existing residential services even if the original funding basis was inadequate.<sup>44</sup> Hence the Brothers of Charity, even where it agreed with the concerns of the Parents Group (which it usually did), was still hamstrung in its negotiations with the HSE for funding for two reasons. First, even if the HSE agreed with the Parent Group and the Brothers of Charity as to the need for additional funding, it was constrained by the Department of Health protocol on funding. Secondly, there was no mechanism to revisit the question whether the initial baseline funding assessment – presumably made circa. 1980 when the Centre opened and the residents were children, took into account the psychiatric, therapeutic and occupational needs of the individuals concerned, particularly when they were at the formative age as children who could have hugely benefited from speech and language therapy, from learning life skills such as continence, eating and drinking and speaking. Although other funding streams have injected further funds, the initial baseline

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<sup>44</sup> See Chapter 8.

funding assessment is still germane under the incremental determinial process (see Chapter 8).

4.22 The enquiry does not purport to conduct an in-depth financial analysis of the actual cost per residential, day or respite place for persons with severe to profound intellectual disabilities, but seeks to examine the mechanisms under which the individual needs of the persons in the Centre have been calculated and costed.

4.23 As persons with disabilities, all the individuals in the Centre are entitled to a Disability Allowance. However, most of this allowance is deducted for residents' maintenance in the Centre with a small sum being available for their own personal use. This is discussed further in Chapters 5 and 6.

4.24 It can thus be seen that a circular situation is in play: the State provides a sum of money for intellectual disability services to a private not-for-profit organisation, arguably against a baseline set for the delivery of those services when the end-users were children and arguably at a time when intervention therapies were uncommon. The manner in which funding is provided and directed are thus key issues of concern in the enquiry.

4.25 Prior to the enquiry, the Health and Safety Authority inquired into a number of incidents of challenging behaviour in the Centre. The fact of that investigation and the response to it was one of the matters that formed the subject matter of the request to the Commission for the current enquiry.

### **Other Developments**

4.26 During the course of the enquiry, a number of events have also occurred which have impacted on it.

## **McCoy Report**

4.27 In the period 1999-2007, the HSE conducted an inquiry into child abuse at the Holy Family School (which included the neighbouring Kilcornan Centre, see Chapter 7). While not a matter considered in the current enquiry, the long delay in that inquiry and the recommendations emanating from it did impact upon a number of parties to this enquiry, including the management team in the Brothers of Charity which had requested the HSE inquiry and sought an early report.

## **HSE Review Report**

4.28 In response to the Commission's decision to conduct the present enquiry, the HSE decided to review services in the Centre. A confidential report on this review was sent to the Brothers of Charity in February 2008. The Brothers of Charity did not fully agree with all the recommendations in the report which examined the organisational systems in the Centre, the 'physical structure' of the accommodation, the sufficiency of staff and individual service provision. However, the Report resulted in some additional funding to the Centre and by the end of 2009, most recommendations had been implemented by the Brothers of Charity (see Chapter 7). As can be seen, the scope of the review overlapped with a number of the main issues under review in the present enquiry, although the remit of the HSE review was different and many of the fundamental issues considered in this enquiry were not directly addressed.

## **Standards**

4.29 Until HIQA published national standards in May 2009, there were no formal quality standards in place for residential services for people with intellectual disabilities in the State. The HIQA standards refer to all persons with disabilities, both physical and intellectual. In addition, during the course of the enquiry it was clear that independent inspections by HIQA were expected to

commence from 2008/ 2009 following finalisation of its National Standards. However, in May 2009, it was announced that the standards would not be placed on a statutory footing and that independent inspections would not occur. This is discussed further in Chapter 9.

## **Cuts to Funding**

4.30 Since 2003, cuts to health funding have been made including through “Value for Money” protocols and the reduction of one off grants to assist the Brothers of Charity meet historic deficits (see Chapter 8). Such cuts to disability services made by the HSE have been recounted in a recent report of the Comptroller and Auditor General (see Chapter 8) and deepened in 2009. As a result, certain services in the Centre have been affected and it cannot be ruled out that this trend will continue. Consideration of funding threats and the protocols to minimise cuts from impacting on frontline services for the individuals in the Centre is thus also of relevance in this enquiry report.

## **Summary**

4.31 The contextual factors outlined in this chapter illustrate some of the complexities involved in conducting the present enquiry. These complexities include individuals who cannot communicate their concerns directly, and the multiple layers of bureaucracy through which the State provides services to persons with intellectual disabilities. In addition the absence of a clear statutory code and an established system of standards and inspections emphasises the magnitude of the issues facing the individuals in the Centre and their families in seeking to assert their human rights.

## Chapter 5      Legal Framework

### Introduction

5.1 The Health Acts 1947 to 2007 (“the Health Acts”) set out the legal framework for the delivery of what are currently referred to as “health and personal social services” in the State.<sup>45</sup> The term “health and personal social services” is not defined in legislation; however some constituent elements of the services referred to may be identified from a number of statutes. A background note prepared within the Department of Health provides the following working definitions:

#### Definitions of Health Services

The Health Act 1947 defines ‘institutional services’ as including:

- (a) *Maintenance in an institution,*
- (b) *diagnosis, advice and treatment at an institution,*
- (c) *appliances and medicines and other preparations,*
- (d) *the use of special apparatus at an institution.*

The 1970 Health Act refers to ‘general practitioner, medical and surgical services’, ‘drugs, medicines and appliances’ as well as more specialised services such as ‘home nursing’, ‘midwifery’, ‘dental’ etc. It does not attempt to define any of these services either by their nature or by what they are intended to achieve.

Section 2 of the Health (Corporate Bodies) Act, 1961 defined ‘health service’ as any service relating to the protection or improvement of the health of the people or the care and treatment of the sick and infirm;”. This was expanded on by section 22 of the Health (Amendment) (N<sup>o</sup>3) Act 1996 to include “any service relating to the protection, promotion or improvement of the health and welfare of people”.<sup>46</sup>

<sup>45</sup> Section 7(4) of the Health Act 2004.

<sup>46</sup> Letter from the Department of Health to the Commission, dated 8 December 2008.

### Definition of Personal Social Services - 1

Personal Social Services refer to those social services which essentially entail a personal relationship between client and provider as opposed to say social welfare benefits. Such services include for example social work services, supplementary to family care (domiciliary care such as home helps, child care workers with families), day care, and alternatives to family care (adoption, fostering, institutional care).<sup>47</sup>

### Definition of Personal Social Services - 2

Personal Social Services might be considered as separate from health services to the extent that they are aimed at improving the quality of life of individuals and families and assisting them to achieve their full potential. However, when this is set in the context of individuals or care groups (such as older people, persons with a disability or mental illness and children) the distinction is not so easily made. Care for these groups is a continuum linked to the level of dependency ranging from home help to institutional care and with potentially significant medical intervention.<sup>48</sup>

5.2 According to this definition the services provided to the individuals in the Centre are primarily personal social services with ancillary health services also provided within a residential setting. It is clear from the Departmental background note that personal social services remain an imprecise and somewhat vague concept. The Department indicated to the Commission that it was in the process of discussing a new legislative framework which would, *inter alia*, define these concepts more precisely.<sup>49</sup> The statutory framework within which the delivery of these services has developed is set out below.

## Responsibility for the provision of Health and Personal Social Services

5.3 The modern statutory health code was established with the Health Act 1947. Statutory responsibility for the provision of health services in Ireland was initially conferred on local authorities<sup>50</sup> (designated as health authorities) under that Act. The Health Act 1970 removed responsibility from the local authorities

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<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

<sup>49</sup> Letter from the Department of Health to the Commission, dated 8 December 2008.

<sup>50</sup> Namely County Councils, Town Councils, etc.

and created a system of health boards with responsibility for the provision of health services on a regional basis. The provision of health services was thus vested in regional health boards. This largely remained unchanged until 2004.<sup>51</sup> The Health Act 2004 was a radical transformation of the public health system. The Act dissolved the existing health boards (as well as the Eastern Area Health Authority, which was established in 1999) and transferred their functions and employees to a single executive body, the HSE.<sup>52</sup>

#### 5.4 The overall objective of the HSE is:

...to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.<sup>53</sup>

5.5 The Health Act 2004 provides the HSE with the statutory responsibility to manage and deliver, or arrange to be delivered *“health and personal social services”*. Such services are defined in the Act as those services provided under the Health Acts 1947 to 2001, before the establishment of the HSE.<sup>54</sup> This broad duty is understood to include services to persons with an intellectual disability but as already noted, there is no precise legal definition of such services. The reference to making arrangements for the delivery of such services is of significance to the present enquiry insofar as the HSE is not obliged to deliver the

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<sup>51</sup> The Health Act 1970 provided that the Minister for Health could establish by regulation such number of Health Boards as appeared to him or her appropriate. The Health Boards created by the 1970 Act were: The Eastern Health Board; The Midland Health Board; The Mid-Western Health Board; The North-Eastern Health Board; The North-Western Health Board; The South Eastern Health Board; The Southern Health Board and the Western Health Board; see the Health Board Regulations 1970 (S.I No. 170/ 1970). The Health (Eastern Regional Health Authority) Act 1999, created three new health boards in place of the previous Eastern Health Board established under the Health Act 1970. The Act also created a unified Eastern Regional Health Authority with the responsibility to provide health services within the area of the three new Health Boards, and with the power to delegate its function to those new health boards.

<sup>52</sup> See Sections 56 to 72, Health Act 2004. The Department of Health has drawn attention to the fact that child welfare and protection services are provided by or on behalf of the Health Service Executive under the provisions of the Child Care Act, 1991. The Child Care Act, 1991 (Commencement) Order, 1995 and the Child Care Act, 1991 (Commencement) Order, 1996 were developed under this legislation and relate to child welfare and protection services including foster care and children’s residential care (welfare and protection only): letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>53</sup> Section 7(1) of the Health Act 2004. The HSE was established under Section 6(1) of the Act.

<sup>54</sup> Section 2 of the Health Act 2004.

services directly itself, but can contract out its functions to other bodies. Such arrangements will be examined in more detail below.

## **Residential/ Institutional Care under the Health Acts**

5.6 Prior to 1947, public health services, including services to persons with intellectual disabilities (insofar as such services existed at the time), were delivered by public assistance authorities, urban sanitary authorities and charitable bodies. Under the Health Act 1947 the primary provider of health care in any district became the local authority for the area.<sup>55</sup> The 1947 Act conferred on such local authorities the function of providing and maintaining “health institutions”.<sup>56</sup> An institution was defined as:

...a hospital, sanatorium, maternity home, convalescent home, preventorium, laboratory, clinic, health centre, first aid station, dispensary or any similar institution.<sup>57</sup>

5.7 While this definition does not appear to exclude an institution established for the care of persons with an intellectual disability, the first specific statutory reference to residential care services for persons with an intellectual disability is contained in the Health Act 1953 which expanded the definition of health institutions to include a “home for persons suffering from physical or mental disability”.<sup>58</sup> This extension of the definition was in turn repealed and replaced in the Health Act 1970 by a definition of “in-patient services” which again referred to services for persons with a physical or mental disability:

...‘In-patient services’ means institutional services provided for persons while maintained in a hospital, convalescent home or home for persons suffering from physical or mental disability or in accommodation ancillary thereto.<sup>59</sup>

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<sup>55</sup> Section 10(1) of the Health Act 1947, which was repealed and replaced by the Health Act 1970. Under The Health Authorities Act 1960 four separate health authorities were established for the cities of Dublin, Cork, Limerick and Waterford.

<sup>56</sup> Section 10 was repealed and replaced by the Health Act 1970.

<sup>57</sup> Section 2 of the Health Act 1947.

<sup>58</sup> Section 6 of the Health Act 1953.

<sup>59</sup> Section 51 of the Health Act 1970.

5.8 There was also provision for in-patient services to be provided for children with diseases or disabilities of a permanent or long-term nature under section 52 of the Health Act 1970.<sup>60</sup>

5.9 The present statutory responsibility of the HSE to deliver “*health and personal social services*” under the Health Act 2004 thus appears sufficiently broad to include residential services to persons with an intellectual disability where the residential element is ancillary or necessary to the provision of health and personal social services to such persons.

### **Rehabilitation and habilitation services**

5.10 The Disability Act 2005 provides for the HSE to undertake assessments of need in relation to persons with a disability.<sup>61</sup> Section 7 of the 2005 Act states that an “assessment” means an assessment undertaken or arranged by the Executive to determine, in respect of a person with a disability, the health and education needs (if any) occasioned by the disability and the health services or education services (if any) required to meet those needs. “Health service” under the Act is defined as a service, including a personal social service, provided by or on behalf of the Executive.<sup>62</sup>

5.11 Rehabilitation and habilitation are defined by the World Health Organization (“WHO”) as follows:

Rehabilitation and habilitation are processes intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function. Rehabilitation encompasses a wide range of

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<sup>60</sup> Separately under section 54 of the Health Act 1953 health authorities had the function of providing ‘institutional assistance’ to those who could not provide shelter and maintenance for themselves or their dependents in a county home or similar institution. While this appears to include a residential service, it does not appear to have been based on the disability or the health status of the person. The responsibility to provide such institutional assistance and in-patient services was transferred to the HSE under the Health Act 2004.

<sup>61</sup> At the time of writing the Disability Act 2005 had not yet been fully commenced and no assessments in relation to adults with a disability appear to have been carried out under that Act.

<sup>62</sup> Section 7 of the Disability Act 2005.

activities including rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services.<sup>63</sup>

5.12 Aside from the Disability Act 2005, the Health Acts 1947 to 2007 make very limited reference to the provision of rehabilitative or habilitative services to persons with a disability, and such services are not defined. Section 50(1) of the Health Act 1953 and section 68 of the Health Act 1970 (which repealed and replaced section 50(1)) refer to rehabilitation solely in the context of training for employment and making arrangements with employers to provide placements for people with a disability. For this purpose the 1970 Act placed the health boards under a mandatory duty to provide such services and enabled them to maintain premises, workshops, farms, gardens, materials, equipment and similar facilities. These functions have now been conferred on the HSE under the Health Act 2004. The WHO definition of rehabilitative and habilitative services encompasses significantly more than the duties referred to directly in Irish legislation but it is apparent that the Department considers that such broader services form part of the wide, but imprecise, definition of health and personal social services as referred to in the Health Act 2004. Therefore it follows that such services are also encompassed in the definition of health and education services in section 7 of the Disability Act 2005 which extend to a “personal social service”.

### **Arrangements with other bodies**

5.13 As stated prior to 1947 there was no unified statutory code for the provision of public health services.<sup>64</sup> The first provision of health services in the

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<sup>63</sup> WHO is the directing and coordinating authority for health within the United Nations system. See <http://www.who.int/disabilities/care/en/>

<sup>64</sup> The Minister for Health (Dr Ryan), in introducing the Health Bill to the Seanad in 1947 stated: “On the motion that the Bill be read a Second Time, I may say that the purposes of this Bill are, in short, to bring the law relating to the health services up-to-date, to simplify the administration of these services and to add to them where they have been found to be deficient. The law now governing the health services is very complex and is intertwined with the codes relating to such sanitary services as water supply, baths, washhouses and bathing-places and burial grounds, as well as with the general law dealing with local government. Senators who wish to study the intricacies of this law will find a convenient list of the various Acts and sections of Acts dealing with the health services in the First Schedule to the Health (Transfer of Departmental Administration and Ministerial Functions) Order, 1947, which has been presented to the House. That is the Order under which the functions proper to my office were transferred from the Minister

country began with the voluntary, philanthropic and private sector in the Eighteenth Century. In the Nineteenth Century the workhouse system was introduced by the British Government and in 1922 the Free State turned the workhouses into county homes catering for the poor with medical and social needs. The Department of Health was established in 1947 and local authorities, designated as 'health authorities', were made the primary duty holder for the provision of public health services.<sup>65</sup> However the role of voluntary and charitable organisations in providing such services was also recognised and this parallel system of both public and voluntary health services has been continued and significantly developed to the present day through the Health Acts.<sup>66</sup>

5.14 In addition to providing health institutions under the 1947 Act, health authorities could also provide for care in hospitals or institutions or in residential settings. This was done under agreements with other bodies for the use of an institution under the management of that body by a particular person, the inhabitants of an area or a class of persons.<sup>67</sup> As noted above, the Health Act 1953 explicitly expanded the definition of institution to include a home for persons suffering from physical or mental disability. This extension explicitly allowed for agreements with bodies providing similar institutional services.<sup>68</sup>

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for Local Government. Forty-six complete enactments and portions of 14 other Acts are listed in that Schedule. These include parts of the Public Health and Local Government codes and various Acts dealing with infectious disease, tuberculosis, maternity and child welfare, school medical services, medical registration and similar matters under a wide variety of titles. Some of these enactments are now out of date and the powers given by them have not been used for many years. Seanad Éireann - Volume 34 - 09 July, 1947 *Health Bill, 1947—Second Stage*.

<sup>65</sup> For a further account of the historical development of the health service in Ireland, see Brian Harvey, "Evolution of Health Services and Health Policy in Ireland", (Combat Poverty Agency, 2007)[http://www.cpa.ie/publications/EvolutionOfHealthServicesAndHealthPolicyInIreland\\_2007.pdf](http://www.cpa.ie/publications/EvolutionOfHealthServicesAndHealthPolicyInIreland_2007.pdf).

<sup>66</sup> See, *Provision of Disability Services by Non profit Organisations*, December 2005. Report of the Comptroller and Auditor General, at p. 18.

<sup>67</sup> Section 12 (1) of the Health Act 1947 was repealed by the Health Act 1970. To enter into such an agreement the health authority required the consent of the Minister for Health. Section 20 of the Health Act 1947 also allowed a local authority to provide land (either through sale or compulsory purchase) to the governing body of an institution providing 'useful service' to persons in need of institutional services. Section 40 of the Health Act 1970 replaced section 20 and conferred a similar power on the Health Boards.

<sup>68</sup> Section 10 of the Health Act 1953.

5.15 Section 10 of the Health Act 1953 is significant in the context of the present enquiry. Section 10 as it provided that a health authority could, with the consent of the Minister for Health, “carry out an arrangement” for the provision of institutional services to any persons or class of persons, entitled to receive such services from an institution not managed by the health authority. The Minister was entitled to establish a scale for payment for such services by the health authority, but could not otherwise regulate such arrangements. However, the reference to an “arrangement” in section 10 of the Act would suggest the possibility of a certain degree of formality between the health authority and the relevant body for the provision of such services.<sup>69</sup>

5.16 Section 65 of the Health Act 1953, also empowered health authorities, with the approval of the Minister for Health, to provide assistance to a body providing either direct health services, or other ancillary services, or proposing to do so. This could be done by providing facilities and/ or direct financial assistance. This section therefore created a relatively informal system for voluntary and charitable bodies to carry out those functions statutorily conferred on health authorities. The section contained very little regulation, however, as to how the assistance is to be provided; there were no requirements that the services would be supervised by the health authority, nor does it appear from the section that there was any requirement to put in place a formal contract for the delivery of the services.<sup>70</sup> The 1953 Act thus allowed for significant variance in the State’s approach to sub-contracting the delivery of health services to private institutions including voluntary and charitable bodies through ill-defined and poorly regulated “arrangements” or “assistance” under sections 10 and 65 of the

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<sup>69</sup> This provision was repealed by section 3 of the Health Act 1970.

<sup>70</sup> This section, as originally enacted, required the approval of the Minister before such assistance could be provided; however it was subsequently amended to remove the requirement for Ministerial approval, but allowed the Minister to make general directions in relation to the operation of this power. In tandem with sections 10 and 65 of the 1953 Act, a person entitled to an institutional service under the Act could elect to have the service provided otherwise than through a health institution, subject to arrangements being made by the health authority to make a financial payment to the service provider. This Section was repealed by Section 73 of the Health Act 2004, and replaced by section 39, which allowed the HSE impose such terms and conditions on the assistance as it sees fit, and subject to any directions given by the Minister under section 10 of the Health Act 2004 (*see below*).

1953 Act, respectively.<sup>71</sup> Section 26 of the Health Act 1970 repealed section 10 such that “arrangements” were henceforth to be subject to “conditions” specified by the Minister for Health for persons eligible for services, although in reality no Minister for Health has ever specified any such “conditions”.<sup>72</sup>

5.17 The ability of local authorities and later the Health Boards to provide arrangements or assistance to bodies providing health services under the 1970 Act was not repealed until the Health Act 2004. In reality however, it appears that many of those bodies were funded directly through the Department of Health rather than through health authorities and subsequently the Health Boards.

5.18 In 1994 the Department of Health published a national health strategy.<sup>73</sup> In 1997 it published a report entitled “Enhancing the Partnership”.<sup>74</sup> This report set out a strategy for transferring the responsibility for funding such services to the health boards and regulating grants by way of service agreements.<sup>75</sup>

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<sup>71</sup> See Section 25 of the Health Act 1953. Under Section 54 of the Health Act 1970, the hospital or institution in question was required to be approved for that purpose by the Minister for Health. See also generally “The National Federation of Voluntary Bodies - A Historical Context”, Tom Hogan, March 2006 - [http://www.fedvol.ie/National\\_Federation\\_Publications/Default.757.html](http://www.fedvol.ie/National_Federation_Publications/Default.757.html) Section 26 of the Health Act 1970 repealed section 10 such that “arrangements” were henceforth to be subject to “conditions” specified by the Minister for Health for persons eligible for services, although in reality no Minister for Health has ever specified any such “conditions”. Letter from the Department of Health and Children to the Commission, dated 8 December 2008. Section 26 of the Health Act 1970 and Section 65 of the Health Act 1965 were repealed by Section 73 of the Health Act 2004. In addition section 72 of the Health Act 1970, allowed the Minister to make regulations in relation to the manner and extent of services to be provided by health boards and the administration of those services and a number of regulations have been introduced under this section but primarily dealing with in-patient charges (see further below).

<sup>72</sup> Such arrangements were to be underpinned by conditions set out under section 72 of the Health Act 1970.

<sup>73</sup> “Shaping a Healthier Future, A Strategy for effective healthcare in the 1990s”, Department of Health, 1994.

<sup>74</sup> See Chapter 6.

<sup>75</sup> The then Minister of State at the Department of Health and Children in a written answer to a parliamentary Question on 27 February 2003 stated that: “In addition to providing funding in recent years to put in place new service developments to meet identified needs in relation to residential, respite, day and other support services, funding has also been provided by my Department to meet identified needs in existing services. These needs arise as a result of the changing profile of persons with an intellectual disability or those with autism in the services, and in particular the residential services, which has resulted in an increasing number of older and medically fragile persons. They would also relate to issues such as underfunding of base budgets, including the need to consolidate elements of services previously funded from sources such as fund-raising. My Department has sought over the years to address these issues as resources have permitted. It was agreed that this process should continue, albeit through new more appropriate mechanisms, as outlined in the reports “Enhancing the Partnership”, which dealt with

5.19 The dual system of public and voluntary provision of health services is again evident in section 2 of the Health (Amendment) (No.3) Act 1996, which listed a number of matters to which health boards had to have regard in carrying out their functions under the Health Acts, including the most beneficial, effective and efficient use of resources, the need for co-operation with voluntary bodies providing similar services to the health board, and relevant government policy.<sup>76</sup>

5.20 The Health (Eastern Regional Health Authority) Act 1999, although largely an administrative Act in that it created a new health authority for the greater Dublin region, also has significance in the present context. The Act specifically excluded the new Eastern Regional Health Authority (“ERHA”) from exercising the power of the health boards under section 65 of the 1953 Act (that is, to provide financial assistance to bodies for the provision of health services).<sup>77</sup> In its place the Act introduced a new statutory framework within which the new Authority could enter into arrangements rather than just dispensing monies, for the provision of health services, including a much more regulated form of relationship between the ERHA and voluntary service providers.<sup>78</sup>

5.21 In making arrangements under section 10 of the 1999 Act the ERHA was required to coordinate the provision of services, and more importantly put in place systems, procedures and practices to enable it to monitor and evaluate services

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the framework supporting the transfer of responsibility for the funding of former direct funded intellectual disability service providers from my Department to the health boards and “Widening the Partnership” which dealt with the application of that framework to voluntary intellectual disability service providers, such as Co-Action West Cork, funded by the health boards.” Mr T. O’Malley, Dail Debates Volume 562.

<sup>76</sup> Section 73 of the Health Act 2004 repealed Section 2(1) of the 1996 Act, but provided similar requirements for the HSE in Section 7(5) (*See also* above).

<sup>77</sup> Section 7(6) of the Health (Eastern Regional Health Authority) Act 1999.

<sup>78</sup> The arrangement was required to endure for a minimum of three years, and not exceed a maximum of five years. The arrangement had to include the principles by which both parties agreed to abide for the duration of the arrangement and was also required to include standards in relation to efficiency, effectiveness and quality of services to be provided as agreed between the parties. In addition to this arrangement there was a further requirement that a yearly agreement had to be entered into specifying the service to be provided under the arrangement and the funds to be made available for same. The Authority was required to make arrangements with the area health boards established under the Act or in the alternative with voluntary service providers for the provision of health services within its functional area. Section 7(6) of the Health (Eastern Regional Authority) Act 1999. This was repealed by Section 73 of the Health Act 2004, which also provides for arrangements for the provision of health services in Section 38.

provided under section 10 and report on these measures in its annual report.<sup>79</sup> In addition, the Authority was required to have regard in making such arrangements to the right of voluntary bodies to “manage their own affairs in accordance with their independent ethos and tradition”.<sup>80</sup>

5.22 Section 26 of the 1970 Act, section 65 of the 1953 Act and section 10 of the 1999 Act were all repealed by the Health Act 2004, which established the HSE.<sup>81</sup> In general terms the Act obliges the HSE in performing its functions to have regard to the services provided by voluntary and other bodies which are similar or ancillary to the services the HSE provides.<sup>82</sup>

5.23 Section 38 is the primary statutory provision by which the HSE enters into contractual agreements with the larger voluntary service providers in the State.<sup>83</sup> Although not specifically named in the Act, these agreements have become known as service level agreements.<sup>84</sup>

5.24 More specifically section 38 of the 2004 Act allows the HSE to enter into an arrangement with a provider of health or personal social services on such terms and conditions as it considers appropriate, subject to its available resources and any written directions issued by the Minister.<sup>85</sup> Before entering into such an arrangement, the HSE must determine the maximum amount of funding that it proposes to make available in that year under the arrangement and the

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<sup>79</sup> Section 8 (3)(b),(c) of the Health (Eastern Regional Authority) Act 1999. This was repealed by Section 73 of the Health Act 2004, which provided similar measures relating to monitoring in Section 37.

<sup>80</sup> Section 8(3)(f) of the Health (Eastern Regional Authority) Act 1999. This was also repealed by Section 73 of the Health Act 2004.

<sup>81</sup> Section 73 of the Health Act 2004.

<sup>82</sup> Section 7(5)(a). It is also required under Section 7(5) to have regard to the need to co-operate and co-ordinate with other public authorities, Government policies and objectives, available resources and their effective and efficient use, and, since the Health Act 2007 was enacted, any standards set down by the Health Information and Quality Authority (HIQA); see Part 4 of Schedule 2 (Amendments to Health Act 2004) of the Health Act 2007.

<sup>83</sup> Section 38 currently applies to the 26 non-statutory service providers that are currently within the HSE Employment Control Framework. (See *further* discussion of the Employment Control Framework in Chapter 8.)

<sup>84</sup> The precise content of Service Level Agreements will be examined further in Chapter 6.

<sup>85</sup> It appears that the Minister has issued no written directions under this provision to date: Letter Department of Health to the Commission, dated 8 December 2008. Section 38 was amended by section 21 of the Health (Miscellaneous Provisions) Act 2007.

level of service it expects to be provided for that funding. The HSE may request information from the service provider and this may be further supplied to the Minister. The service provider must supply the HSE with accounts if funded over a particular amount as specified by the Minister.

5.25 Under Section 39, the HSE retains the power to give assistance to any person providing a service similar or ancillary to a HSE service, whether or not the HSE is in an arrangement with that person under Section 38. Section 39 thus allows the HSE to provide financial assistance in the form of contributing to expenses or providing the use of premises to such a body, subject to any directions from the Minister and under such terms and conditions as the HSE sees fit to impose.<sup>86</sup>

### **Eligibility for Health and Personal Social Services**

5.26 The question of eligibility or entitlement to Health and Personal Social Services under the Health Acts 1947 to 2007, is another area that is unclear. For present purposes eligibility refers to a right to access such services *if available*, while entitlement may more properly be regarded as referring to the right of someone to have a particular service made available to them, which right has either been conferred on them by law or is inherent to them as persons or as a particular class of persons.

5.27 The Health Act 1947 largely left the imposition of financial charges for health services to the discretion of the health authority. It allowed health authorities to impose a charge of a “reasonable sum” for institutional services, which are assessed by reference to the financial circumstances of the person.<sup>87</sup>

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<sup>86</sup> The HSE has published the documentation in relation to contract agreements for funding under section 39 of the Health Act 2004.

See [http://www.hse.ie/eng/Publications/Non\\_Statutory\\_Sector/](http://www.hse.ie/eng/Publications/Non_Statutory_Sector/)

<sup>87</sup> Section 17 of the Health Act 1947, which was repealed and replaced by the Health Act 1953.

5.28 The Health Act 1953 had two significant sections dealing with eligibility. The first was section 14 which dealt with eligibility for general practitioner medical and surgical services, medicines, ophthalmic, dental and aural treatment and medical, surgical and dental appliances.

5.29 Section 15 provided that a health authority was obliged to provide institutional and specialist services to the following categories of persons free of charge:

- a) those covered by social insurance;
- b) adult persons with means less than six hundred pounds per year;
- c) farmers where the rateable valuation of their farm was less than fifty pounds and,
- d) any other person not specified but who in the opinion of the health authority could not pay for institutional and specialist services without undue hardship.<sup>88</sup>

5.30 Under the 1970 Act eligibility for services was again based on means. A person, or their dependants, had full eligibility for public health services including attending a General Practitioner if it would cause them undue hardship to pay for same out of their own means.<sup>89</sup> However those categories covered by section 15 of the Health Act 1953 (with the income thresholds modified), no longer had full eligibility under the Act.

5.31 Section 52 of the 1970 Act required health boards to provide in-patient services in general for persons with full and limited eligibility, including institutional services for persons maintained in a home for persons suffering from a physical or mental disability or in ancillary accommodation.<sup>90</sup> In-patient services

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<sup>88</sup> Section 25 of the Act, provided that a person entitled to services under section 15 of the Act, as outlined above, could elect to have such services made available to him or her, or their child in a hospital or nursing home approved of for that purpose by the Minister, rather than by the health authority. The section made provision for payment to the nursing home or hospital for the service by the health authority.

<sup>89</sup> Section 45 of the Health Act 1970. The Minister for Health could adopt regulations in relation to defining the category of persons with full eligibility under section 45(1). Section 45 was amended by the section 1 of the Health (Amendment) Act 2005.

<sup>90</sup> Section 51 of the Health Act 1970 states: "In this Part "in-patient services" means institutional services provided for persons while maintained in a hospital, convalescent home or home for

were also to be made available to children with diseases and disabilities of a permanent or long-term nature. The Minister was entitled to make regulations for the imposition of charges for such services in specified circumstances in relation to persons who did not have full eligibility.<sup>91</sup>

5.32 Section 56 of the 1970 Act placed a mandatory duty on health boards to make available outpatient services for those who were either fully eligible or with limited eligibility. In a similar manner to in-patient services health boards were also required to make available out patient services for children with a permanent or long term disease or disability as prescribed by the Minister.

5.33 In brief, the Health Acts establish a system of eligibility for unspecified health and personal social services, with provision to allow charges to be imposed for such services when they are provided on an in-patient basis. There are also certain mandatory duties on the HSE to provide health and personal social services, however this is not predicated on the individual needs of a person who applies for them, but rather is based on a generalised obligation to make such services available within the resources of the HSE. In other words it is not apparent that the Health Acts create any individualised entitlement to health or personal social services, such that they must be provided to a particular person in need of same.

### **In-Patient Charges**

5.34 General Practitioner services, drugs and medical supplies were only made available under the 1970 Act to persons with full eligibility.<sup>92</sup> This was subsequently amended to include persons and their dependents, who, in the opinion of the HSE would suffer hardship if not so provided.<sup>93</sup>

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persons suffering from physical or mental disability or in accommodation ancillary thereto.” Under Section 52 of the Health Act 1970, health boards were placed under a mandatory duty to make available in-patient services to both persons with full eligibility and those with limited eligibility.

<sup>91</sup> Section 53 of the Health Act 1970.

<sup>92</sup> Sections 58 and 59 of the Health Act 1970.

<sup>93</sup> Section 5 of the Health (Amendment) Act 2005.

5.35 Following the introduction of the Health (Amendment) Act 2005, the residents in the Centre have been subject to in-patient charges. In 2004 the Health (Amendment) Bill had sought to amend certain provisions of the 1970 Act in relation to the imposition of charges for in-patient services. The Bill sought to retrospectively make lawful maintenance charges which had been imposed on patients who had full eligibility, although individuals had an exemption from paying any charges under section 53 of the 1970 Act.<sup>94</sup> The Bill also sought to impose maintenance charges on a prospective basis. Until the 1970 Act, it appears that the Health Boards were applying charges pursuant to section 54 of the Health Act 1953 for the provision of “institutional assistance”, however a High Court decision found that in fact it was not permissible to regard a person as coming within section 54, where they were also in receipt of medical services over and above pure maintenance.<sup>95</sup> In considering the 2004 Bill, the Supreme Court found that the retrospective provisions of the Bill were unconstitutional, however, the prospective provisions of the Bill, which proposed imposing charges for in-patient services into the future irrespective of eligibility, were upheld.<sup>96</sup>

5.36 As a result of the 2004 Supreme Court decision section 4 of the Health (Amendment) Act 2005 amended section 53(2)(a) of the 1970 Act to remove the exemption from in-patient charges in respect of persons with full eligibility. The Minister is now under a mandatory requirement to make regulations imposing such charges for in-patient services on all persons to whom the in-patient services are provided irrespective of eligibility.<sup>97</sup> In-patient charges may be waived or reduced by the HSE if, having regard to the financial circumstances of that person, it is necessary to do so in order to avoid undue financial hardship in relation to that person.<sup>98</sup> The 2005 Act also limits the meaning of in-patient

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<sup>94</sup> Section 53(2) of the Health Act 1970 allowed the Minister by regulation to provide for the imposition of charges for in-patient services in specified circumstances where they did not have full eligibility under the Act.

<sup>95</sup> *In Re Maud McInerney, a Ward of Court* [1976-1977] ILRM 229.

<sup>96</sup> *In the Matter of Article 26 of the Constitution & In the Matter of the Health (Amendment) (No.2) Bill 2004* [2005] IESC7.

<sup>97</sup> The charges that may be imposed under the Act are capped at a maximum rate of 80% of the maximum of the weekly rate of the old age (non-contributory) pension within the meaning of the Social Welfare Acts. Section 4(6)(d) of the Health (Amendment) Act 2005.

<sup>98</sup> Section 4(4) of the Health (Amendment) Act 2005.

services to those institutional services that consist of the maintenance of a resident (rather than the provision of medical care). The effect of the 2005 Act is that persons who are deemed to be receiving in-patient services, such as those in the Centre and who, prior to the introduction of the Act, were exempt from in-patient charges are now subject to such charges.

5.37 The Health Act 2004 did not amend any statutory provisions in relation to eligibility for health and personal social services.<sup>99</sup> The level of in-patient charges is now determined on a periodic basis by Ministerial Order, which also establishes the criteria to be satisfied before such charges can be imposed.<sup>100</sup>

## Social Welfare

5.38 Section 50(5) of the Health Act 1953 required health authorities to provide a maintenance allowance to persons with a disability. This was repealed by the Health Act 1970. Section 69 of the 1970 Act required health boards to provide a maintenance allowance to disabled persons, over 16 years of age, where neither the person themselves nor their spouse were in a position to maintain that person.<sup>101</sup> Section 13 of the Social Welfare Act 1996 amended the Social Welfare (Consolidation) Act 1993 to include provision for the payment of a Disability Allowance to persons over 16 years of age with an intellectual disability. This, however, did not include persons who were then resident in an

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<sup>99</sup> It was noted *In the Matter of Article 26 of the Constitution & In the Matter of the Health (Amendment) (No.2) Bill 2004* (2005) IESC7, that no regulations had been made pursuant to section 45(3) of the Health Act 1970 and that the determination of who is entitled to full eligibility (i.e a medical card) is administered by a system of departmental circulars, with the relevant chief executive of each health board (now HSE) making the decisions.

<sup>100</sup> The most recent Ministerial Orders in relation to in-patient and out patient charges are Health (In- Patient Charges) (Amendment) Regulations, 2008 (S.I. 543/2008, Health (Out- Patient Charges) (Amendment) Regulations 2008 (S.I. 544/2008), Health (Charges for In-patient Services) (Amendment) Regulations, 2008 (S.I. 521/2008). A somewhat problematic aspect of the charges under the regulations, is that the rate of charge is determined by reference to the level of nursing care provided in a particular institution, with a higher charge applying to institutions with twenty four hour nursing care, whereas the 2005 Act refers to in-patient services as referring only to the maintenance element of the service, rather than the medical element. There are currently two rates of charge applicable as follows: Class 1 is €153.25, or the person's total weekly income less €44.70, whichever is less. Class 2 is €114.95 or the total weekly income of the person less €70.25 or 60% of the weekly income of that person, whichever is less.

<sup>101</sup> Section 69 of the Health Act 1970.

institution, including a home for people suffering from a physical or mental disability or ancillary accommodation.<sup>102</sup> The Social Welfare Consolidation Act 2005 established a Disability Allowance personal expenses rate of €35 which was payable to people in residential care if this was less than the Disability Allowance they would otherwise qualify for.<sup>103</sup> All persons with an intellectual or physical disability are now eligible for a Disability Allowance payment from the Department of Family and Social Affairs irrespective of whether they are in a residential centre or not, depending on their means and level of disability.<sup>104</sup> A person in prior receipt of Disability Allowance would not lose eligibility to receive such an allowance solely because they were subsequently admitted to an institution. This exception to the qualification for Disability Allowance for persons already resident in an institution was repealed by section 11 of the Social Welfare Act 2006. The maximum personal rate of Disability Allowance is now €196.<sup>105</sup>

5.39 Any person who is in receipt of a Disability Allowance will automatically be deemed to have full eligibility under the Health Acts, and thus be issued with a medical card by the HSE to confirm their eligibility for health and personal social services.<sup>106</sup>

## **National Health Strategy 2001**

5.40 The 2001 National Health Strategy is centred on a whole-system approach to tackling health in Ireland. In relation to disability services provision the strategy outlines provision for the implementation of the Disability Act 2005, an integrated approach to care planning for individuals, programmes to support informal caregivers through the development of informal networks, the provision

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<sup>102</sup> The 1993 Act was repealed and replaced by the Social Welfare Consolidation Act 2005.

<sup>103</sup> This figure is invariably less than the Disability Allowance.

<sup>104</sup> Section 210 of the Social Welfare Consolidation Act 2005.

<sup>105</sup> As of 1 December 2008; the Social Welfare (Miscellaneous Provisions) Act 2008 amended the rates for Disability Allowance (see section 4, Schedule 2). Budget 2010 reduced disability payments including the Disability Allowance by €8.30 per week from January 2010: [www.citizensinformation.ie](http://www.citizensinformation.ie)

<sup>106</sup> For a discussion of the interplay between the recoupment of in-patient service charges and the payment of Disability Allowance to persons with an intellectual disability receiving care in a residential setting, see Chapter 8.

of basic training and that greater availability of short-term respite care will be developed and implemented.<sup>107</sup> In addition, the remit of the Social Services Inspectorate was to be extended to include residential care for people with disabilities, national standards for residential care for people with disabilities were to be prepared and service agreements put in place between the health boards and the voluntary sector were to be introduced.<sup>108</sup>

5.41 In relation to actions for intellectual disability and autism, a programme of investment was to take place in expansion of day places, training, residential and respite care and other support services. Complete programmes were to be put in place to transfer people with an intellectual disability in psychiatric hospitals to appropriate accommodation not later than the end of 2006. Investment was to be made to provide appropriate support services for people with autism. An information system to provide accurate data on the numbers of persons with autism and their service needs was to be established as soon as possible.<sup>109</sup>

## **Disability Strategy 2004**

5.42 The aim of the National Disability Strategy is to underpin the participation of people with disabilities in society. In addition to legislation and sectoral plans,<sup>110</sup> this contained a commitment to a multi-annual Investment Programme to

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<sup>107</sup> National Health Strategy 2001 at p. 82.

<sup>108</sup> National Health Strategy 2001 at p. 143.

<sup>109</sup> National Health Strategy 2001 at p. 144.

<sup>110</sup> The Disability Act 2005, the Education for Persons with Special Educational Needs (EPSEN) Act 2004, The Citizens Information Act 2007, which equips the Citizens Information Board (formerly Comhairle) to provide a personal advocacy service for people with disabilities and Six Sectoral plans for the Department of Health and Children; the Department of Social and Family Affairs; the Department of Communications, Energy and Natural Resources; the Department of Transport, the Department of Enterprise, Trade and Employment and the Department of the Environment, Heritage and Local Government. The Disability Act also provides for a review of the Departmental Sectoral Plans. The Department of Health advised the Commission that it intends to complete this review by December 2009; letter from the Department of Health to the Commission, 11 December 2009. In the context of a strategic objectives document on the National Disability Strategy in 2009 the Government set out a number of goals to achieve its vision for persons with disabilities as follows: "(1) every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living; (2) every person with a disability would in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services; (3) every person with a disability would have access to public spaces; (4) buildings, transport, information,

be targeted at high-priority disability support services to run until 2009 estimated at €900 million.<sup>111</sup> A new Office for Disability and Mental Health was established in January 2008. From 2006 to 2008 over €550m was allocated to the HSE under the Multi-Annual Investment Programme, of which €425 million was for disability services and €125 million for Mental Health provision.<sup>112</sup> The Disability Act 2005 provides that a review of the Sectoral Plan would occur within three years of publication and the Department of Health advised the Commission that it intends to complete this review by the end of 2009, in conjunction with the 5 other Departments required to publish and review sectoral plans.<sup>113</sup>

5.43 Part 2 of the Disability Act 2005 (assessment of need) came into effect on 1 June 2007 in relation to persons under 5 years of age. As required by the EPSEN Act the National Council for Special Education (“NCSE”) in Ireland provided a report on its implementation which suggested additional investment over a period of years of up to €235 million per annum across the education and health sectors. The further implementation of the Disability Act 2005 and the EPSEN Act is dealt with further below.

## **Disability Act 2005**

5.44 As previously noted, section 8 of the Disability Act 2005 provides for the assessment of the health and education service needs of persons with a disability. The Disability Act provides that an individual who believes they have a disability may seek an assessment, which would be carried out by an assessment

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advocacy and other public services and appropriate housing; (5) every person with a disability would be supported to enable them as far as possible to lead full and independent lives to participate in work and in society and to maximise their potential and, (6) carers would be supported and acknowledged in their caring role.” In the Programme for Government agreed on 10 October 2009 it is stated that the Government will “publish a ‘NDS Recession Implementation Plan’ central to which will be the availability of accessible public and social services that promote independence and choice for people with disabilities.”, *Towards 2016: Strategic Document: National Disability Strategy Vision, Mission & Strategic Objectives*, April 2009, page 5.

<sup>111</sup> See *Towards 2016: Strategic Document: National Disability Strategy Vision, Mission & Strategic Objectives (Section 33.2, p. 66)*, April 2009, at p. 2.

<sup>112</sup> *Ibid.*, at p. 4.

<sup>113</sup> Letter from the Department of Health to the Commission, dated 14 December 2009.

officer.<sup>114</sup> Alternatively, a third party (a relative, guardian, legal representative or personal advocate) may also apply for an assessment to be carried out on a person who is considered to have a disability.<sup>115</sup> The Disability Act provides that an assessment will be carried out, without regard to the cost or the capacity to provide any service identified in the assessment as being appropriate to meet the needs of the applicant concerned.<sup>116</sup> In carrying out an assessment, an assessment officer is required to be independent in the performance of his or her functions.<sup>117</sup>

5.45 Following an assessment, an assessment report will be furnished which will outline whether, in the view of the assessment officer, the person has a disability, the nature and extent of such disability and a statement of the health and educational needs (if any) arising from the disability.<sup>118</sup> The report will also outline the appropriate services which the assessment officer considers are required to meet the needs of the person along with a timeframe within which such services should be provided. The report will also state a time as to when a review of the assessment should be undertaken.<sup>119</sup> Upon the identification of a need for disability related services, the person is entitled to a “Service Statement”. This statement will set out the health and educational services that will be provided to a person taking certain factors into account including financial resources.<sup>120</sup> Significantly, in preparing a service statement, where a service is to be provided by or on behalf of the HSE, regard must be had, *inter alia*, to not only the assessment report and the eligibility of the applicant for services, but also the

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<sup>114</sup> Section 8(2) of the Disability Act 2005 states that an Assessment Officer will carry out an assessment on behalf of the HSE or alternatively they will arrange for another HSE employee who has the requisite experience to carry out an assessment.

<sup>115</sup> Section 9(1) of the Disability Act 2005 states that a relative, guardian, legal representative or personal advocate may request an assessment.

<sup>116</sup> Section 8(5) of the Disability Act 2005.

<sup>117</sup> Section 8(4) of the Disability Act 2005.

<sup>118</sup> “Health services” are defined in Section 7, Disability Act 2005 as services provided by or on behalf of the HSE which includes personal social services. Section 7 also defines “Education Service” as education service for persons with disability over 18 years. Section 11(6) provides that a service statement shall not contain any provisions relating to education services where the subject of the statement is a child.

<sup>119</sup> Section 8(7) of the Disability Act 2005.

<sup>120</sup> Other factors to be taken into account are approved standards and codes of practice (if any) and advice of the National Council for Special Education.

“practicality” of providing those services and the need to ensure that the provision of the service would not result in any expenditure in excess of the amount allocated to implement the service plan of the HSE for that financial year.<sup>121</sup>

5.46 The Disability Act provides for a complaints procedure. A person can make a complaint about a determination by the assessment officer concerned that the person does not have a disability, the delay in the performance of an assessment, that the assessment was not conducted in a manner that conforms to the standards determined by HIQA, the contents of the service statement or if the HSE (or an education service provider) failed to provide or to fully provide a service specified in the service statement.<sup>122</sup> An employee of the HSE, known as a Complaints Officer, will attempt to resolve the complaint informally. However, if this is not possible the complaint will be investigated further and a recommendation will issue to the applicant and the HSE.<sup>123</sup> A person may lodge an appeal to this recommendation. The HSE or education service provider may also appeal the complaints officer’s recommendation. An appeal will be investigated by an independent appeals officer who is appointed by the Minister for Health.<sup>124</sup> If both parties agree, the matter can be resolved through mediation. Otherwise, an appeal hearing will take place and a recommendation will issue. The appeals officer’s decision is final and may only be appealed to the High Court on a point of law.<sup>125</sup>

5.47 At time of writing, the Disability Act has not yet been fully implemented. On 1 June 2007 the provisions of the Act outlined above came into effect in respect of children under five years of age only. It had been envisaged that provisions of the Disability Act dealing with persons between the age of five years and eighteen years would be rolled out in 2010 in tandem with the EPSEN Act (see below). It was envisaged that the statutory requirements of Part 2 of the Disability

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<sup>121</sup> Section 11(7) of the Disability Act 2005.

<sup>122</sup> Section 14(1) of the Disability Act 2005.

<sup>123</sup> If appropriate, the recommendation may also issue to the assessment officer, the liaison officer (the person who prepares the service statement) and the head of the education service provider.

<sup>124</sup> Appeal officers are appointed by the Minister for Health. Appeal officers are independent in the performance of their functions.

<sup>125</sup> Section 20 of the Disability Act 2005.

Act would be extended to adults no later than 2011. However, the Government took a decision in October 2008 that it was not possible to implement the legislation at that time due to financial circumstances.<sup>126</sup>

## **Education for Persons with Special Educational Needs Act 2004 (“EPSEN Act”)**

5.48 The Disability Act and the EPSEN Act are intrinsically linked. A child with a disability can be assessed under either the Disability Act or EPSEN Act.<sup>127</sup> Where an assessment officer is carrying out an assessment under the Disability Act and identifies the need for the provision of education service for the child, where the child is enrolled in a school the assessment officer must refer the matter to the principal of the school for a separate assessment under the EPSEN Act.<sup>128</sup>

5.49 The EPSEN Act refers to a five year implementation period. The NCSE implementation report envisaged that there will be a full implementation of the Act by 2010.<sup>129</sup> However, as already noted, implementation by that date will not now happen, rather the Government states it is committed to the full implementation of EPSEN “at the earliest possible date”.<sup>130</sup> The EPSEN Act

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<sup>126</sup> According to the Department of Health, this decision was taken in the context of Budget 2009: Letter from the Department of Health to the Commission, dated 14 December 2009. Subsequently in a strategy document on the National Disability Strategy, the Government stated that in light of current financial circumstances, it is not now possible to implement the legislation at this time: see *Towards 2016: Strategic Document: National Disability Strategy Vision, Mission & Strategic Objectives (Section 33.2, p. 66)*, April 2009 at p.3.

<sup>127</sup> Under Irish law, in the context of the provision of education, children with intellectual disabilities are treated differently to adults: see discussion of *Sinnott v The Minister for Education*, Supreme Court 2001 2 IR 545 below.

<sup>128</sup> Section 8(9) of the Disability Act 2005. The NCSE was formally established under the EPSEN Act. The NCSE has various powers and functions under the Act one of which includes the power to refuse the request to draw up an educational plan, section 20(1) EPSEN Act. There is an appeals process whereby the child’s parents or the school principal can appeal the Council’s decision to an Appeals Board under section 3(13) of the Act.

<sup>129</sup> Letter from the Department of Education to the Commission, dated 14 March 2008.

<sup>130</sup> *Towards 2016: Strategic Document: National Disability Strategy Vision, Mission & Strategic Objectives (Section 33.2, p. 66)*, April 2009, at p.3. The Renewed Programme for Government, of 10 October 2009 reiterates this commitment and states that the Government will develop in consultation with stakeholders a costed multi annual plan to implement priority aspects of EPSEN. See also reference in the Report of the Special Group on Public Service Numbers and Expenditure Programmes that “full implementation of the *Education Special for People with*

makes provision for children up to 18 years.<sup>131</sup> The EPSEN Act states that children with special educational needs shall be educated, where possible, in an inclusive environment.<sup>132</sup> It places an obligation on the role of schools and school principals in taking, “*such measures as are practicable to meet the educational needs of the student concerned*”.<sup>133</sup> However, if a child fails to progress following the implementation of such measures, the EPSEN Act provides for the formal assessment of the child to establish whether or not a disability exists. The assessment under the EPSEN Act gives an evaluation and statement of the services which the child requires in order to participate and benefit from education and to develop to their full potential generally<sup>134</sup>. Where an assessment establishes that the student has special educational needs an education plan will be devised for the “appropriate education of the student”. This is usually designed by the school principal.<sup>135</sup> However, if this education plan proves ineffective, the principal must request the NCSE to cause to be prepared a plan for the appropriate education of the child. The individual education plan must be reviewed by the school principal at least once a year.<sup>136</sup>

5.50 Section 7(1) and (2) of the EPSEN Act provides that the HSE shall provide to the child such of the services identified in the assessment in relation to the child as are necessary to enable him or her to participate in and benefit from education. Where, in performing its functions under subsection (1), the HSE is of the opinion that particular services can most effectively be provided for by the NCSE, it shall inform the NCSE of that opinion by notice in writing and, upon being so informed, the NCSE shall provide those services to the child concerned.

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*Special Educational Needs (EPSEN) and Disability Acts has been deferred due to the economic circumstances...*”; see Volume II: Detailed Papers, July 2009; at p. 56.

<sup>131</sup> See also the Education Act 1998.

<sup>132</sup> Section 2 of the EPSEN Act 2004.

<sup>133</sup> Section 3(2) of the EPSEN Act.

<sup>134</sup> This will generally be conducted by the Principal of the School. However, under 3(6) of the Act it provides that where the principal of a school considers that the arrangements for carrying out an assessment are impracticable he or she shall request the NSCE to arranger for an assessment.

<sup>135</sup> In the case of a child who is not a student, the HSE undertakes this.

<sup>136</sup> Section 11 of the EPSEN Act.

The Minister for Education and Science is responsible for providing the resources for the implementation of the individual child's education plan.

5.51 The EPSEN Act has no direct relevance to the individuals in the Centre, the subject of the enquiry, as they are all now over 18 years of age, but it is apparent that the education of children with intellectual disabilities before they reach 18 years of age will have an ongoing impact on their quality of life after they leave the formal education system. The Department of Health in commenting on the Disability Act 2005 and EPSEN Act 2004 stated:

Two key legislative elements of the National Disability Strategy are the Disability Act 2005 and the Education for Persons with Special Needs Act 2004 (EPSEN Act 2004). The provisions of both Acts are complementary and are designed, once implemented, to provide a framework within which the educational and specific health and personal social services needs of person with disabilities will be addressed.<sup>137</sup>

5.52 The Department of Education has informed the Commission that a Cross Sectoral Team which is representative of senior officials in the education and health sectors meet regularly to ensure that the implementation of the Disability and EPSEN Acts are progressed in a coordinated manner.<sup>138</sup> Insofar as children currently receiving services under the EPSEN Act may ultimately receive residential care or day services as adults, they will at least have received more structured educational services during their childhood than the current individuals in the Centre. However, although the Disability Act states that a person's health and personal social services will be described in the service statement, the extent to which the health and personal social services they receive will be integrated with the services under the Disability Act and the EPSEN Act remains to be seen, particularly given questions about the implementation date for the legislation and its operation thereafter.

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<sup>137</sup> Letter from the Department of Health to the Commission, dated 7 February 2006.

<sup>138</sup> Letter from the Department of Education to the Commission, dated 16 December 2009.

5.53 Under Irish law, adults with a severe to profound intellectual disability are entitled to education services until they attain 18 years of age.<sup>139</sup> In *Sinnott v The Minister for Education*<sup>140</sup>, the Supreme Court considered the extent of the State's duty to provide for free education to an adult with a severe to profound intellectual disability and found that the constitutional right to primary education ceases at 18 years of age.<sup>141</sup>

## **Mental Capacity and the Law**

5.54 Every person is presumed to have formal legal capacity to make decisions on their own behalf.<sup>142</sup> In the Irish context, the only exception to this formal legal position is where a person has been made a Ward of Court. Wards of Court have no formal legal capacity and jurisdiction over Wards of Court is exercised by the President of the High Court and by the Circuit Court, with decisions taken by the Committee of a Ward of Court.<sup>143</sup>

5.55 The Lunacy Regulation (Ireland) Act 1871 is the statutory provision governing wards of court. While recognising that wardship may be necessary because the person is considered to be incapable of managing his (or her) person or property, this Act deals mainly with the power of the court over property issues. It does not deal specifically with the issue of withholding consent to medical treatment, choice of residence, and other matters relating to personal autonomy and self-determination. There is no legislation dealing with how the Court is to determine issues related to the person, as opposed to the property, of the ward.

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<sup>139</sup> Article 42 of the Constitution.

<sup>140</sup> *Op. cit.*

<sup>141</sup> See Article 42(4) provides for free primary education. See also *JM Kelly: The Irish Constitution* para 7.6.287 et al. See also discussion in Chapter 11.

<sup>142</sup> For a general discussion of legal capacity, see O'Neill, A.M.; *Irish Mental Health Law*, 2005, Johnswood Press Ltd at pp.14-15 and 541 et seq.

<sup>143</sup> The powers of the High Court in relation to wards and their estates are set out in the Lunacy Regulation (Ireland) Act 1871 and the procedure in relation to applications is governed by Orders 65 and 67 of the Rules of the Superior Courts. The Wards of Court system originated in the crown prerogative for the purpose of acting as guardian for persons with legal disabilities – the *parens patriae* or guardian of the people.

5.56 In reality however, apart from Wards of Court, there are other persons, such as persons with a severe to profound intellectual disability who do not exercise personal autonomy in many areas of their lives. For such people, there is in reality, usually some form of supported or substituted decision-making taking place on their behalf. Such decision-making can best be described as taking place in a legal vacuum, and is a response to a lack of clear legislative guidance in this area.<sup>144</sup>

5.57 To address this situation the Scheme of the Mental Capacity Bill 2008 was published in September 2008. The main purpose of the 2008 Scheme is to reform the existing wards of court system, insofar as it applies to adults, and replace it with a modern statutory framework governing decision making on behalf of persons who lack capacity.<sup>145</sup> However, at the time of writing the Mental Capacity Bill had not yet been published and the law remains as discussed above.

### **Citizens Information Acts 2000 and 2007**

5.58 The Citizens Information Acts 2000 and 2007 make specific provision for advocacy services to be provided to persons with a disability.<sup>146</sup> There are a number of ways such services can be provided. The Citizens Information Board (“the Board”) may support, provide or arrange for the provision of advocacy services, including providing financial or other resources to a voluntary body providing social services.<sup>147</sup>

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<sup>144</sup> For a further discussion in relation to consent to medical treatment see Chapter 6. The Law Reform Commission in its Report: *Vulnerable adults and the Law*, 83-2006, stated “The area of assessment of capacity to make healthcare decisions is fraught with uncertainty” at p. 31.

<sup>145</sup> Press Release of the Department of Justice, Equality and Law Reform, “Minister Ahern Announces Proposals for a Mental Capacity Bill”, (15 September 2008), available at [www.justice.ie](http://www.justice.ie). See also *Observations on the Scheme of the Mental Capacity Bill 2008*, IHRC, November 2008, [www.ihrc.ie](http://www.ihrc.ie).

<sup>146</sup> Section 4 of the Citizens Information Act 2007, amends the functions of the Citizens Information Board (formerly Comhairle) under the Comhairle Act 2000.

<sup>147</sup> Section 7(1) of the Citizens Information Act 2000 and 2007. The Citizens Information Board has developed a Community and Voluntary Advocacy Programme for Persons with Disabilities, which consists of funding a range of community and voluntary organisations to provide independent representative advocacy to people with disabilities throughout the country. There are

5.59 To qualify for personal advocacy services a person must be over 18 years of age and by reason of their disability have difficulty accessing a particular social service. In addition, there should be grounds for believing that there is a risk of harm to his or her health, welfare and safety if he or she is not provided with the service.<sup>148</sup> The functions of a personal advocate are interconnected with the Disability Act and include:

1. Making or assisting in making an application for an assessment under Part 2 of the Disability Act 2005, and to assist, support and represent the person in relation to the application, assessment and service statement prepared in respect of the person under that Act;
2. Assisting, supporting and representing the person in relation to applying for and obtaining a social service, and pursuing any right of review, reference or appeal if the application for such a service is refused;
3. At any reasonable time entering any place where day care, residential care or training is provided for the person and making such inquiries in such place in relation to the person as appropriate;
4. Obtaining any information in relation to the person from a statutory body or voluntary body as necessary;
5. Attending and representing the person at any meeting consultation or discussion at which the interests of the person are being considered and which they would have attended if not for their disability.<sup>149</sup>

5.60 A statutory or voluntary body is under a legal duty to co-operate with a personal advocate and it is a criminal offence not to do so.<sup>150</sup> Although it was envisaged that the Personal Advocacy Service would be rolled out during 2007 and 2008, at the time of writing section 5 of the Citizens Information Act 2007

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currently 46 such projects around the country, with a limited service to persons in residential centres. The pilot phase for these projects will come to an end in 2010, and the Citizens Information Board hope that it will be in a position after that time to develop the initiative further; correspondence from the Board to the Commission, dated 9 October 2009.

<sup>148</sup> Section 7A(1)(3) of the Citizens Information Acts 2000 and 2007. Pursuant to Section 7B a person, or someone on their behalf must apply in writing or other form as provided for to the Director of the Personal Advocacy Service for the assignment of a personal advocate. There is provision for an appeal of a decision of the Director if it is decided to refuse the provision of a personal advocate

<sup>149</sup> Section 7D(1) of the Citizens Information Acts 2000 and 2007.

<sup>150</sup> Section 7D (5) of the Citizens Information Acts 2000 and 2007. Under this provision it is a criminal offence to obstruct or hinder a Personal Advocate in the performance of his or her functions.

had not been commenced and there is no indication that it would be commenced in the foreseeable future.<sup>151</sup>

5.61 The Citizens Information Board has developed a number of initiatives in collaboration with the voluntary sector to provide advocacy services at a local level, but these are not established on a statutory basis.<sup>152</sup>

### **The Equal Status Acts 2000 to 2004**

5.62 The Equal Status Acts 2000 to 2008 prohibit discrimination in the supply of goods and services, including educational services on nine grounds, one of which is disability.<sup>153</sup> Disability is broadly defined to include people with physical, intellectual, learning, cognitive or emotional disabilities and a range of medical conditions.<sup>154</sup> Discrimination is defined as the treatment of a person in a less favourable way than another person is, has been or would be treated in a comparable situation.<sup>155</sup> For the purposes of the Act discrimination includes a refusal or failure by the provider of a service, including persons responsible for the provision of accommodation and related service, to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities.<sup>156</sup> This is of course subject to exceptions within the Act, including that certain activities do not constitute discrimination<sup>157</sup> and that service

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<sup>151</sup> The Government has stated, however, that the advocacy service remains a priority for the Department of Social and Family Affairs: *Towards 2016: Strategic Document: National Disability Strategy Vision, Mission & Strategic Objectives* (Section 33.2, p. 66), April 2009, at p.4.

<sup>152</sup> See [www.citizensinformationboard.ie](http://www.citizensinformationboard.ie)

<sup>153</sup> Complaints under the Equal Status Acts are heard by the Equality Tribunal. In a recent decision of the Equality Tribunal, it was decided that the Minister for Education and Science could be a service provider within the terms of the Equal Status Acts. It was further determined that the policy of the Department of Education and Science that required students with disabilities attending special schools to cease attending such schools at the end of the year in which they reached eighteen years of age, even where they had not completed their formal education, was discriminatory as the same policy did not apply in mainstream schools, where students over eighteen could continue attending until such time as they had completed their formal education cycle (the Leaving Certificate or Applied Leaving Certificate): see *Mrs KH & Ors v The Minister for Education and Science*, Dec-S2009-050, 5 August 2009.

<sup>154</sup> Section 2 Equal Status Act 2000.

<sup>155</sup> Section 3 Equal Status Act 2000 amended by Section 48, Equality Act 2004.

<sup>156</sup> Section 4 (1) Equal Status Act 2000.

<sup>157</sup> Section 14 of the Act provides that anything done on foot of a requirement of an enactment shall not constitute discrimination. A further practical limitation in seeking a remedy under the

providers are not obliged to provide special facilities or treatment when this costs more than what is termed a nominal cost.<sup>158</sup>

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Equal Status Acts is that it is necessary to demonstrate discrimination by reference to a comparator either real or hypothetical. However in the case of disability and the provision of services it may not be possible to identify such a comparator as the service may be uniquely only relevant to a person with a disability; see for example *Mrs K v The Health Services Executive*, Dec S2009-007, 30 January 2009.

<sup>158</sup> Section 4 Equal Status Act 2000. All claims (except for claims in relation to discriminating clubs and in relation to certain complaints against licensed premises) under the Equal Status Acts 2000 to 2008 are brought to the Equality Tribunal which is the quasi judicial body established to investigate, hear and decide claims under the Equal Status Acts. A parent, guardian or other person acting in place of a parent can be the complainant where a person is unable by reason of an intellectual or psychological disability to pursue a claim effectively; see Information booklet on the Equal Status Acts 2000 and 2004 issued by The Equality Authority.

## Chapter 6            Service Provision in the Centre

6.1    It will be recalled that the Centre provides residential, respite and day services to 77 adults, aged between twenty four and fifty one years of age who have severe to profound intellectual disabilities within the Brothers of Charity West Galway Service area.

6.2    As set out in Chapter 5, under the Health Act 2004, the HSE has the statutory responsibility to deliver “*health and personal social services*” to persons with an intellectual disability in the State. The HSE may also enter into agreements with voluntary bodies to provide some or all of these services, and has entered into such an agreement with the Brothers of Charity. This arrangement is reflected in a contract called a “Service Level Agreement”. In carrying out the agreed services, the Brothers of Charity is accountable to the HSE in certain respects and relies on the HSE as its main source of funding.<sup>159</sup>

6.3    The agreements state that the Brothers of Charity will provide disability services to all persons within a specified functional area of the HSE. In other words, the Brothers of Charity replaces the HSE as the primary service provider for all disability services within a specified area.<sup>160</sup> Thus the individuals in the Centre, or family members of individuals in the Centre, have no direct relationship with the HSE, but rather the services they receive are negotiated through a voluntary body namely the Brothers of Charity in a service level agreement.

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<sup>159</sup> See Chapter 8 for further information. It is noted that although the Department of Health provides funding to the HSE, it has no direct role in relation to the provision of health services to individuals. Rather, one of its principal responsibilities is to advise and support the Minister for Health in determining national policy. The Department of Health informed the Commission that in terms of service provision to persons with intellectual disability and those with autism, this involves working closely with the HSE, the relevant service providers and other professionals and national representatives, including people with disabilities and parents/families of children and adults with disabilities: letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>160</sup> The service level agreements set out the catchment area for which the Brothers of Charity will provide services. The agreements provide that the Brothers of Charity Galway’s principal concentration is on the needs of person from the Galway Primary Community and Continuing Care service within the agreed geographic area.

Moreover, the agreements between the HSE and the Brothers of Charity confer no rights on individuals in the Centre to any particular service.<sup>161</sup>

### **Service Level Agreements between the HSE and the Brothers of Charity**

6.4 Prior to 1999, the Department of Health directly funded the Brothers of Charity to provide services to the persons with disabilities in the Centre.<sup>162</sup> Since 1999, the Western Health Board, and more latterly the HSE, has funded the Brothers of Charity on foot of four service level agreements with it.<sup>163</sup> The agreements set out the respective obligations of both the HSE and the Brothers of Charity in respect of staffing, funding and the standard of services to be provided to the individuals in the Centre.<sup>164</sup> The service level agreements also set out monitoring conditions that require the Brothers of Charity to submit annual and quarterly reports to the HSE in relation to finance, staffing and service activity.<sup>165</sup> It also requires the Brothers of Charity to keep correct and accurate data on each client who consents to be registered on the National Intellectual Disability Database and to additionally provide data to the HSE on all clients in receipt of services.<sup>166</sup>

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<sup>161</sup> It is noted that service level agreements stipulate that the voluntary provider must respect the individuality of each person with a disability availing of its services, however, the agreements do not confer explicit rights on individuals in the Centre.

<sup>162</sup> Since 1999, the primary contractual arrangement was between the Western Health Board and since 2005, the HSE and the Brothers of Charity. Funding is in turn provided on an annual basis by the Department of Health to the HSE. This change had been contemplated in 1994 in a health strategy published by the Minister for Health entitled "Shaping a Healthier Future, A Strategy for effective healthcare in the 1990s", Department of Health, 1994 (*"the Health Strategy"*). In 1996 the Working group on the implementation of the Health Strategy in relation to persons with an intellectual disability published *Enhancing the partnership: report of the working group on the implementation of the health strategy in relation to persons with a mental handicap*, Department of Health and Children 1997, (*"the Enhancing the Partnership Report"*), which set out the framework for service level agreements between the HSE and voluntary bodies. In 2009 the HSE introduced a new framework for the relationship between the HSE and voluntary providers, known as service arrangements.

<sup>163</sup> The first service level agreement refers to the period 2002-2006; the second refers to the period 2007-2008, the third refers to 2008 and the fourth to 2009. Each of the service level agreements to date have been a refinement on the previous document. The 2009 Service Agreement is set out in Appendix IV.

<sup>164</sup> See Chapter 8.

<sup>165</sup> For example, the service level agreement requires the Brothers of Charity to submit quarterly reports in relation to its service activity (detailing changes in circumstances of individuals in the Centre, such as, discharges, transfers or new admissions).

<sup>166</sup> The National Intellectual Disability Database is discussed further below.

6.5 Up to 2009, the service level agreements referred to the Brothers of Charity on an organisational level across the Galway region and did not identify the actual services to be provided at the Centre. For instance, all the service level agreements to date refer to a similar generic list of services that are to be provided by the Brothers of Charity, throughout all their services. The “quantum of services” provided in the 2009 service level agreement are:

- Early Assessment Intervention, Development and Pre-school service
- Health related Support Services for Educational Services
- Residential Care and Day Activation for Adults and Children
- Vocational Preparation, Personal Development and Independent Training
- Supported Employment Service
- Crisis intervention and Respite Care Services<sup>167</sup>
- Adult Counselling and After Care Service
- Service for Children and Adults with Autism (with/without Learning Disability)
- Care of Elderly Persons with Intellectual Disability
- Staffing Training and Development Service
- Pastoral Care and Chaplaincy Service
- Family Sibling Support.<sup>168</sup>

6.6 The service level agreements provided a breakdown of service provision by reference to the type of service, facilities and multidisciplinary services. However, they still remained in the form of gross numbers rather than being defined by reference to each individual in the Centre.

6.7 The report of the Comptroller and Auditor General (2005) on the “*Provision of Disability Services by Non-Profit Organisations*” (the 2005 Report of the Comptroller and Auditor) signalled its concerns about the lack of data provided within service level agreements, recommending:

Service agreements need to be precise and sufficiently comprehensive to enable effective management and monitoring of service delivery. Poorly drafted

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<sup>167</sup> This service was added to the 2008 and 2009 Service Level Agreements.

<sup>168</sup> The service level agreements recognise that “*the list of services is not exhaustive as persons with Intellectual Disabilities, Autism or Dual Disability will not always have needs identical to their peers*”. The service level agreements also state that services for persons with a disability may also be provided by the HSE and other voluntary bodies within the Galway area. Finally, the agreements recognise that it is the responsibility of the Brothers of Charity to provide the services in a “*comprehensive, effective and efficient manner*” and to ensure that individuals, who are not in receipt of a service, in fact receive a service appropriate to their needs.

agreements reduce the effectiveness of the contract management process and may result in both parties having limited recourse in the event of a dispute.<sup>169</sup>

## New Service Arrangements

6.8 In 2009, the HSE in consultation with a number of voluntary organisations, introduced a new governance framework to formalise the relationship between the HSE and each of its non-statutory service providers, including the Brothers of Charity. This new arrangement is intended to replace service level agreements and will commence in 2010.<sup>170</sup> The HSE advised the Brothers of Charity that this new arrangement would address the “governance and accountability deficiencies that have been identified as a feature of current arrangements, as pointed out, for example in the 2005 Report of the Comptroller and Auditor General.”<sup>171</sup>

6.9 It is noted that this new framework known as Service Arrangements sets out in contractual format certain requirements in relation to the quality of services and the standard of care for individuals within a service and also provides for self-monitoring of same.<sup>172</sup> Schedule 2 of the new service arrangement lists quality standards which service providers are to adhere to, including the Guidance Document on Residential Services that was prepared by the HSE in consultation with other voluntary service providers in 2008. Further, the HSE advised the Commission that from 2010, Schedule 2 will also include the requirement to implement the HIQA standards for residential services for people with disabilities.<sup>173</sup>

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<sup>169</sup> Report 52 – Comptroller and Auditor General Report on Value for Money Examination: Provision of Disability Services by non profit organisations, December 2005, p.27.

<sup>170</sup> The new arrangement sets out three standardised documents entitled: Section 38 Service Arrangement, Section 39 Service Arrangement and Section 39 Grant Aid Arrangement. See [www.hse.ie/eng/Publications/Non\\_Statutory\\_Sector/](http://www.hse.ie/eng/Publications/Non_Statutory_Sector/). Service providers that receive under €250,000 funding from the HSE will be required to complete a less detailed Grant Aid Agreement and those receiving over €250,000 will be required to complete the section 39 Agreement letter from the Department of Health to the Commission, dated 11 December 2009.

<sup>171</sup> Letter from the HSE to the Brothers of Charity, dated 12 March 2009. This was provided as an enclosure in the Brothers of Charity’s letter to the Commission, dated 8 September 2009.

<sup>172</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>173</sup> Letter from the HSE to the Commission, dated 11 December 2009. See also Chapters 9 and 10.

6.10 In terms of reviewing and auditing service arrangements, the HSE also advised that in early 2010 it will put in place a framework whereby service providers will carry out a self-audit against the HIQA Standards, with the results of the audit to be “reviewed at regular Service Arrangement monitoring meetings”.<sup>174</sup> The HSE further drew attention to the fact that the new service arrangements provide for ongoing review and monitoring by the HSE. In this regard, it advised that it intends to put in place capacity in each HSE region to allow it to carry out reviews of services “where required, either on a routine basis or in response to identified concerns”.<sup>175</sup> The HSE states that these reviews will be linked to ongoing monitoring of the implementation of the new service arrangements.<sup>176</sup> The Department of Health informed the Commission that the development of self-assessment tools, the providing of awareness training for service providers and the introduction of an appropriate level of external validation were being considered to support the implementation of the HIQA Standards. The HSE acknowledged that while the new service arrangements are not envisaged at present “to itemise the needs of individual clients”, they identify the processes and quality management systems required “to ensure the needs of each individual are both identified and being addressed”.<sup>177</sup>

6.11 In March 2009, the Brothers of Charity entered into a “Service Arrangement” with the HSE. As the Brothers of Charity had already signed a service level agreement with the HSE in February 2009, the Brothers of Charity advised the Commission that the year 2009 was in effect a transition year moving from the historical requirements, as provided by the service level agreement, to the new requirements, as provided by the new service arrangements.<sup>178</sup>

6.12 It is too early to assess whether this new framework will improve the governance and accountability of service provision between service providers and

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<sup>174</sup> *Ibid.* This was also confirmed to the Commission by the Department of Health in its letter to the Commission, dated 14 December 2009.

<sup>175</sup> *Ibid.*

<sup>176</sup> *Ibid.*

<sup>177</sup> *Ibid.*

<sup>178</sup> Letter from Brothers of Charity to the Commission, dated 8 September 2009.

the HSE. However, it is noted that the new arrangement appears to require the service provider to provide more detail in relation to staffing ratios, the quantity or amount of services within each service unit, how funding is drawn down through the organisation and also provides specific requirements in terms of standards of service provision, self-monitoring of same and HSE review.<sup>179</sup> There is no doubt that the new service arrangements are a significant advance on the previous service level agreement in place at the time the Commission was first contacted by the Parent Group. At that time, service level agreements with appendices comprised 25 pages, whereas at the time of writing this report the service agreements, with appendices, comprised 48 pages of detailed documentation.

6.13 However, although the HSE states that the new service arrangement identifies the processes and quality management systems required to ensure the needs of each individual are identified and addressed, it acknowledges that the new service arrangements do not break down or “itemise” the service needs and costs of individuals. Similarly, the Department of Health refers to the “global amounts” contained in service arrangements and acknowledges that individual service needs are not identified in the current system. To this end, the Department of Health informed the Commission that this matter is being examined in the context of a new “Value for Money” Review which will conclude in 2010 (discussed in Chapter 8).<sup>180</sup>

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<sup>179</sup> See [www.hse.ie/eng/Publications/Non\\_Statutory\\_Sector/](http://www.hse.ie/eng/Publications/Non_Statutory_Sector/)

<sup>180</sup> See Chapter 8 for further detail: letter from the Department of Health to the Commission, dated 11 December 2009.



*Rear View of St Clare's & St Kevin's Day Services at the Centre*

## **Identification of Service Needs**

### ***The National Intellectual Disability Database***

6.14 The National Intellectual Disability Database (“NIDD”) would appear to be the principal source of data for service provision and service needs planning on a national basis. Its data derives from information provided by voluntary service providers, the HSE and individuals.<sup>181</sup> The NIDD was established in 1995 and is managed by the Health Research Board on behalf of the Department of Health.<sup>182</sup> The aim of the NIDD database is to inform regional and national planning by providing information on the demographic profile of persons with intellectual

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<sup>181</sup> For example, the NIDD informs the HSE's National Service Plan, which outlines the type and volume of health and personal social services for the financial year to be provided within the allocated HSE Vote.

<sup>182</sup> The Health Research Board is a specialised body funded by the Department of Health. See <http://www.hrb.ie/>

disabilities, and current and future service provision. It is primarily the responsibility of the HSE to administer the NIDD. In 2008, 26,023 individuals with an intellectual disability were registered on the NIDD, 15,287 of whom were assessed as having a moderate<sup>183</sup>, severe and profound disability.<sup>184</sup>

6.15 The NIDD collects information on a standardised database form.<sup>185</sup> The data form gathers statistical information on current and future service needs (day, residential and multidisciplinary) but does not identify the level of service required to provide these services, such as, the hours of service required or the number and type of staff required for a particular individual in the Centre. For example, where an individual requires speech and language therapy, the data form only identifies that he or she has a current service need or requires an enhancement of their existing service or that the service is required in the future.

6.16 In contrast, as referred to in Chapter 5 of this Enquiry, Part 2 of the Disability Act 2005, provides for persons with a disability to be provided with a service statement in relation to their disability.<sup>186</sup> In this regard, the HSE's 2007 report on the *"Implementation of the Disability Act 2005"* in quantifying the level of unmet needs includes information on staffing (type of post and number) and hours required to provide the service.<sup>187</sup>

6.17 The NIDD has in the past been criticised in relation to the effectiveness and reliability of its reporting systems. According to the Comptroller and Auditor General:

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<sup>183</sup> The World Health Organization (WHO) has defined a person with moderate disabilities as holding an approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years). See further Chapter 10.

<sup>184</sup> Of the total numbers registered on the NIDD, 14,727 (56.6%) were male and 11,296 (43.4%) were female. See NIDD Annual Report, 2008 at pp. 22 and 26.

<sup>185</sup> See Appendix VI: NIDD Data Form.

<sup>186</sup> Currently, this only applies to children under 5 years of age. See further Chapter 5.

<sup>187</sup> The service statement yields specific details in relation to the specific service required and numbers of hours of multi disciplinary services required to meet that need. See HSE Report to the Minister for Equality, Disability and Mental Health, as provided under section 13 of the Disability Act 2005, (2008).

While the [NIDD] provide[s] the principal source of data on service provision and projected needs, there are deficiencies in the completeness and reliability of the data collected in that:

- Participation is voluntary so there will always be some element of under reporting;
- ...
- The assessment process to identify needs is not standardised;
- The assessment process is not independent. It has been criticised for the tendency to identify needs from a narrow perspective and in terms of capacity to deliver.<sup>188</sup>

6.18 The HSE has acknowledged that the NIDD does not provide a “complete and accurate” picture of either service delivery or needs, as the information is provided on a voluntary basis.<sup>189</sup> Also, the Department of Health and the HSE have identified the need to review the information and data collection requirements in respect of disability services in the context of the introduction of the Disability Act 2005.<sup>190</sup> Nonetheless the Annual Report of the National Intellectual Database Committee 2008 identifies a significant shortfall in service provision to persons with an intellectual disability:

In 2008 multidisciplinary support services were availed of by 20,971 people [with intellectual disabilities], 16,798 of whom had further requirements for such services. A further 2,714 individuals who did not access such services in 2008 require them. Therefore, there are 19,512 (16,798 plus 2,714) individuals with a need for multidisciplinary support services; those needs involve either an enhancement of a type of service received in 2008 (3,333 individuals), a requirement for a new type of service (7,341 individuals) or both (8,838 persons). Of this 19,512 people with future multidisciplinary support services needs, 158 received no service whatsoever in 2008. Ninety-nine per cent of the demand is immediate.

Despite high levels of service provision in 2008, there was substantial demand for new services and enhanced service relating to all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy. For example, 8,232 individuals received a psychology service in 2008, 4,039 of whom needed an enhancement of their service, and a further 7,337 individuals who did not receive a psychology service in 2008 require one in the period 2009-2013.<sup>191</sup>

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<sup>188</sup> Comptroller and Auditor Report 2005, at pp. 19-20.

<sup>189</sup> HSE National Service Plan, 2009 at p. 34.

<sup>190</sup> *Ibid.*

<sup>191</sup> Health Research Board, National Intellectual Disability Database Annual Report 2008, at p. 75.

6.19 According to the service level agreements, relevant data must be provided to the NIDD by the Brothers of Charity to inform the HSE in respect of service needs of the individuals in the Centre. The Brothers of Charity thus collect the required data, where informed consent has been provided by the individuals in the Centre or in cases where it is considered that an individual cannot provide consent by a parent or next of kin. The information for the NIDD is regularly updated by key workers at the Centre onto NIDD web-enabled software, where a report is then sent to a database coordinator from the Brothers of Charity each day to validate the information. At the end of each year, the Brothers of Charity state that a review takes place and is uploaded onto the NIDD which informs the HSE. Nonetheless the Brothers of Charity drew the attention of the Commission to the fact that although 84 individuals in the Centre were registered on the NIDD, in fact only 77 individuals should have been so registered, and that the error, which has since been corrected, had arisen due to a number of individuals moving within the service.<sup>192</sup> In addition to the NIDD, the Brothers of Charity states that it has “Personal Outcome Plans” which inform the organisation of the service levels and service needs of individuals in the Centre.

### ***Personal Outcome Plans***

6.20 Personal outcome plans were initially introduced at the Centre in 2003. Prior to this, the Centre devised group programmes that were based on a person’s likes, dislikes and interests. The Brothers of Charity advised the Commission that group activity programmes were delivered as far as possible to be compatible to groups of five to six individuals in the Centre, which it stated was due to the fact that the Centre did not then have full formal day programmes for all individuals.<sup>193</sup>

6.21 In 2003, the Brothers of Charity engaged a United States based private not for profit company the Council for Quality Leadership, which is stated to

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<sup>192</sup> Letter from the Brothers of Charity to the Commission, dated 25 September 2009.

<sup>193</sup> Letter from Brothers of Charity to the Commission, dated 14 July 2009.

provide a quality of life assessment service for persons with disabilities through personal outcome plans (further discussed in Chapter 7). In theory, personal outcome plans are based on a system which establishes from each individual in the Centre the services they require in a range of areas in their life, for example: living situation, support needs (such as independent living skills, home activities; etc) respect, health; and so on.

**Extract from Council for Quality Leadership document – Measuring Personal Quality of Life Personal Outcomes Measures, 2005 Edition**

People define outcomes themselves. The outcomes are non-prescriptive; they have no norms. Each person is a sample of one. We all define friendship, health or respect uniquely. Thus, the meaning and definition of Personal Outcome items will vary from person to person. An organisation can only design and provide the needed supports after it figures out how the person defines his or her outcomes

Personal outcomes are important because they put listening to and learning from the person at the center (sic) of organizational life Personal Outcomes Measures enable us to learn about people in a new and different ways. They provide a guide to person-directed planning. Personal Outcomes Measures enable organizations to identify people's priorities. Knowing about people's priority outcomes directs planning efforts.<sup>194</sup>

6.22 As of 1 January 2009, the Brothers of Charity advised the Commission that all individuals in the Centre (both residential and day) had a personal outcome plan.<sup>195</sup> Although the Brothers of Charity commenced implementing this system in 2003 it was not fully implemented until 2008.<sup>196</sup> The Brothers of Charity advised the Commission that the personal outcome plans informed middle and senior management in relation to its budgetary review and budgetary allocation meetings with the HSE.<sup>197</sup> Therefore, in theory the residential, day and multidisciplinary service needs of individuals in the Centre should be identifiable from personal outcome plans.

6.23 The Brothers of Charity informed the Commission that each individual in the Centre has a key worker who is specifically dedicated to them under the

<sup>194</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>195</sup> Meeting between the Commission and the Brothers of Charity, 20 May 2009.

<sup>196</sup> Letter from Brothers of Charity to the Commission, dated 15 July 2009.

<sup>197</sup> Letter from Brothers of Charity to the Commission, dated 17 October 2008.

programme. Each personal outcome plan is drawn up on an annual basis and reviewed every three months.<sup>198</sup> In addition, the Brothers of Charity informed the Commission that the multidisciplinary team (see further below) inputs into the preparation and review of the plan, which is also reviewed at the end of the year to determine whether the individual's personal objectives were met. The Commission was also informed that both the individuals in the Centre and their families are usually engaged in the preparation of the plan. In terms of the direct input of individuals in the Centre, the Brothers of Charity advised that staff are trained in alternative communication systems in order to identify as best as possible the wishes of individuals in the Centre.<sup>199</sup>

**Letter from the Brothers of Charity to the Commission – 17 September 2009**

Family involvement in the Individual Plans is very personal to each family. All families are invited to be part of the Individual Planning process, which includes the gathering of information to highlight priorities for the plan, attending the meeting and being part of the review system for each plan.

The keyworker or other relevant people gather information and document this information in the Personal Outcomes Workbook, the family are asked to contribute to this information gathering – the key worker sometimes arranges to have a meeting with the family or may gather by telephone. The keyworker with service user/family/staff involvement decide on the priorities for the coming year and then the relevant people attend the Individual Planning meeting (family, multidisciplinary staff and other staff working with the individual may attend the meeting but this is very dependent on the priorities and the individual)

....

The family, manager, and keyworker approve the final plan and sign off on same on the Individual Planning Form.

Reviews are held quarterly and how the reviews are carried out is very individual to each service area, family involvement in reviews is from a formal meeting in some case, by telephone call in other cases.

A Barrier Form is completed after six months if the individual's goals cannot be achieved at local level. The form is completed by the keyworker and the service user, and signed off by the manager, who categorises the barrier, and it is then sent to the Sector Manager and the information is entered onto a database.<sup>200</sup>

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<sup>198</sup> Meeting between the Commission and the Brothers of Charity, 20 May 2009.

<sup>199</sup> *Ibid.*

<sup>200</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

6.24 The Brothers of Charity has put in place personal outcome plans for 75 out of 77 individuals in the Centre.<sup>201</sup> The HSE has stated that the introduction of personal outcome plans which attempts to identify and implement responses to identified needs, represents a proactive approach by the Brothers of Charity which has resulted in an acknowledged improvement in services.<sup>202</sup> However, it is unclear whether all personal outcome plans are being fully implemented. In this regard, the Brothers of Charity has stated that the personal outcome plans also identify barriers where a planned outcome cannot be readily achieved. The Commission reviewed a number of personal outcome plans and it is clear that inadequate funding was identified as a barrier to fulfilling certain objectives. The Brothers of Charity states;

From 2004 up to 2007, we continued to implement Personal Outcomes to all other services in the John Paul Centre. However, some areas were faced with difficulties, such as Radharc Na Mara which provides a service for individuals who have challenging behaviour which has to take priority if any individual is going through a difficult period. Recruitment and retention of staff was an issue that had to be addressed, and in some instances, families were unsure of what the benefits for their family member would be causing a delay in the implementation of outcomes.<sup>203</sup>

6.25 A number of the parents raised concerns with the Commission in respect of the extent to which the plans had been or could be implemented. Some parents questioned whether the personal outcome plans had been fully pursued and questioned their relevance to developing life skills:

**Parent: Telephone interview with Commission - 18 June 2009**

If I am asked if personal outcomes plans are useful I would say yes and no. There is a welcome emphasis on social outings, but personal outcome plans should be more relevant on a daily basis. Personal outcomes plans should be a personal thing for each service user. The Service should be built around the person, rather than the person fitting into the service, but that isn't happening so far.<sup>204</sup>

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<sup>201</sup> The Brothers of Charity advised the Commission that two individuals at the Centre have no personal outcomes plan as their parents have not agreed to their son/daughter being part of this process.

<sup>202</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>203</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

<sup>204</sup> Parent 3, telephone interview with the Commission, 2 July 2009.

6.26 However, other parents have indicated a positive experience from the implementation of personal outcome plans:

**Parent: Letter to the Commission - 25 March 2008**

Jim's day in the John Paul Centre seems to be much busier now. He enjoys short periods in the sensory room on the vibrating bean bag and with others toys which vibrate in his hands. He also enjoys massage, the foot spa, aromatherapy and of course plenty of walks, and meals out. He spent a weekend in Limerick last year with his key worker, B, with whom he has a good relationship and she is extremely good to him and with him. They are planning another weekend away this year; all these outings are part of his social training.<sup>205</sup>

6.27 In June 2009, the Council for Quality Leadership carried out an audit of the implementation of personal outcome plans within the Centre. The audit found that the Brothers of Charity were implementing personal outcome plans to a satisfactory level.

6.28 The Commission requested and received nine personal outcome plans of individuals in the Centre from the Brothers of Charity. An analysis of the plans found that a number of plans are being effectively implemented. However, it is also noted that other plans do not appear to be implemented at the same level. For instance, one plan has identified the need for the individual concerned to move to a smaller group since 2006, and this was still not implemented in 2009.<sup>206</sup> The implementation of all personal outcome plans submitted to the Commission are limited to a varying extent<sup>207</sup> by recurring barriers, such as inadequate staffing and resources.

## **Residential and Respite Services**

6.29 As of 1 January 2009, 37 individuals in the Centre were provided with a campus based residential service at the Centre.<sup>207</sup> The age of the residents

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<sup>205</sup> Parent 5, letter to the Commission 25 March 2008. Jim is not the individual's real name.

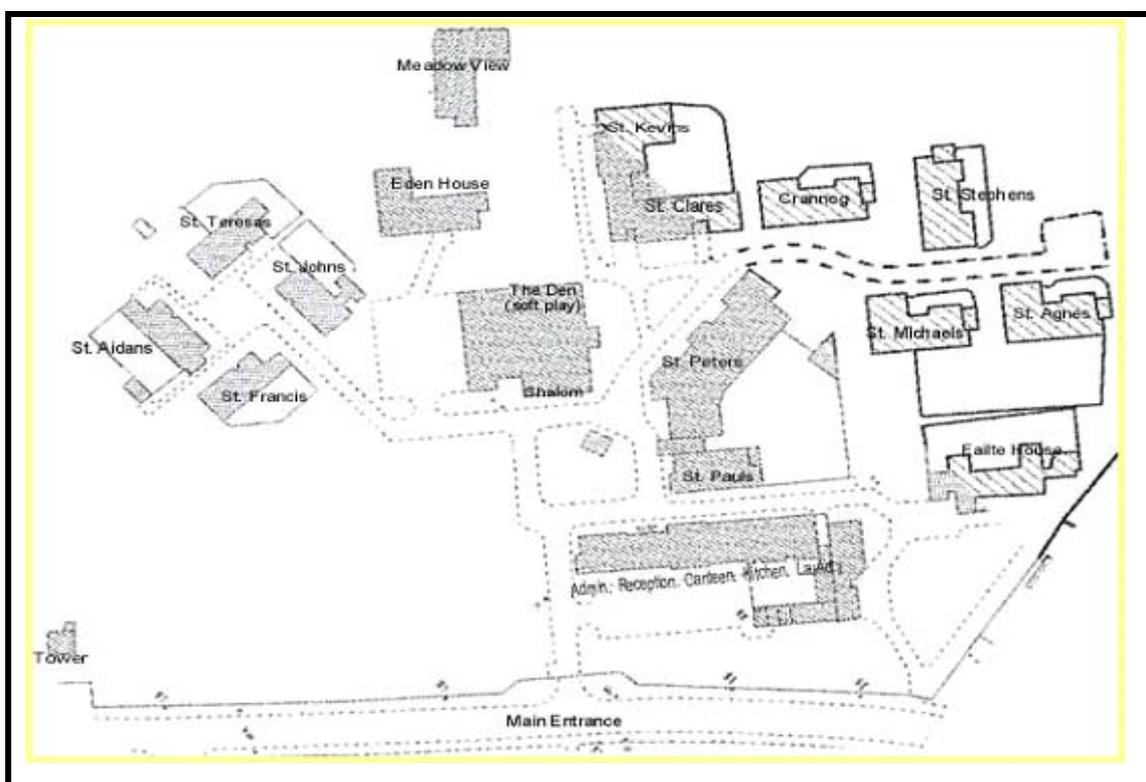
<sup>206</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

<sup>207</sup> The 37 individuals are occupying 35.5 bed places at the Centre, as some individuals in the Centre are sharing places on a scheduled basis (see below). There are twenty two male service users and fifteen female residents in the Centre.

ranges from those aged in their twenties to one individual aged in his early fifties, with 12 individuals residing in the Centre for over 25 years. In recent years, the Brothers of Charity has been moving individuals off the campus to group homes in the community, although some parents have anxieties concerning the perceived isolation of living off-campus. As of 1 January 2009, 21 individuals in the Centre were living in off-site community group homes.

### Campus-based residential service

6.30 As noted in Chapter 4, the campus is situated in an urban residential area on the eastern suburbs of Galway City, approximately two kilometres from the city centre. Individuals who live on campus at the Centre are provided with accommodation in bungalows, 24 hour support from care assistants and nursing staff, catering facilities, and clothing.<sup>208</sup> Other medical services are available as required (see further below).



*The layout of the Centre*

<sup>208</sup> Some parents state that they provide clothing for their children at the Centre; letter from the Parent Group to the Commission, dated 1 December 2009.

6.31 The on campus residential services are divided into three communities namely: St. Stephen's, the Maples, and Radharc Na Mara. All the bungalows were built in 1979 to accommodate children with intellectual disabilities.<sup>209</sup>

6.32 Although originally built for children, adults now reside in these bungalows. In 2002, the Brothers of Charity established a project team made up of both staff and parents of individuals in the Centre, to develop a proposal on the future development of the Centre.<sup>210</sup> One of the key issues and challenges identified by the project team was that buildings were unsuitable. The report of the project team stated:

...many of the facilities were originally designed for children and as such are unsuitable for the needs of the individuals now using them. This has led to a number of safety concerns in buildings where there are a high number of individuals who are non-ambulant and the bedrooms are too small to fit a hoist. The buildings are not adequately geared for wheelchair users and the bathroom facilities are grossly inadequate for the individuals using the bungalow.

...

Some work has gone into adapting and extending some facilities. However other facilities are clearly not suited for their present purpose and should be replaced. In particular the Radharc Na Mara bungalows provided home for individuals with complex needs and who have challenging behaviour. Many of the individuals are in the autistic spectrum. The bungalows are smaller than the others on the campus. For these individuals, having inadequate space is a critical element for a successful programme and the present facilities rather than lessening the individuals challenging behaviour have in many respects exacerbated it.<sup>211</sup>

6.33 Up until 2009, the Brothers of Charity advised the Commission that the bungalows were overcrowded and too confined to meet the needs of the individuals in the Centre. In its communications with the HSE in recent years with

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<sup>209</sup> St. Stephen's and the Maples (which is comprised of two bungalows - St Michael's and St. Agnes) are located close to each other on one side of the campus, while Radharc Na Mara makes up a cluster of four small bungalows on the opposite side of the campus. In 2009, the bungalows of St Michael's, St Agnes' and St. Stephen's accommodate between six to nine adults. The individuals living in these bungalows not only have severe to profound intellectual disabilities, with a high dependency needs, but a number of the individuals are also non-ambulant. The three bungalows have a similar layout and comprise of six to eight small bedrooms, a kitchen and dining area, bathroom and toilets, storage areas for equipment and small staff areas. St. Stephen's has a small visitors area for families.

<sup>210</sup> The Future Development of John Paul Services – Report of the John Paul Services Project, July 2004, provided with the Brothers of Charity's letter to the Commission dated 27 January 2006.

<sup>211</sup> *Ibid.*

regard to service levels and funding, the Brothers of Charity indicated that inadequate staffing levels combined with overcrowding had been major causative factors in the incidents of challenging behaviour which took place in the bungalows by a number of individuals. In particular, the Brothers of Charity stated that its aim was to reduce persons per bungalow to a maximum of five.<sup>212</sup> These general concerns about overcrowding were echoed by the Parent Group and also by the HSE in its 2008 Review of the Centre.

6.34 In 2009, the Brothers of Charity advised the Commission that the on-campus residential service and staffing levels had improved. This was deemed to be partly due to a reduction in the number of residents per bungalow. In this regard, the Brothers of Charity advised the Commission that in 1999, in an attempt to tackle overcrowding at the Centre, the HSE agreed that any places vacated at the Centre as a result of the death of an individual in the Centre, would not be filled.<sup>213</sup> Since 1999, 13 individuals have passed away and one individual was moved to another centre.<sup>214</sup> The Brothers of Charity state that with the exception of one “crisis” admission, all other spaces have been left vacant. In addition, the Brothers of Charity informed the Commission that in recent years they have improved the on-campus living conditions by renovating a number of the bungalows and are currently engaged in a programme of moving residents off-site. However, members of the Parent Group continue to raise their concerns about overcrowding and inadequate staffing ratios in respect of the on-campus residential services, while also expressing their anxieties concerning perceived isolation by moving their adult children “off-site”.<sup>215</sup>

6.35 The Brothers of Charity accept that not all overcrowding issues have been resolved. In May 2009, the Brothers of Charity indicated that overcrowding remained a problem at times when all residents are indoors. In November 2009, the Brothers of Charity indicated that there are nine individuals living in nine

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<sup>212</sup> Letter from the Brothers of Charity to the Commission, dated 24 September 2008.

<sup>213</sup> Meeting between the Brothers of Charity and the Commission, 20 May 2009.

<sup>214</sup> *Ibid.*

<sup>215</sup> Meeting between the Parent Group and the Commission, 3 July 2009.

bedrooms in St. Stephen's bungalow.<sup>216</sup> Further, the 2008 HSE Review Report recommended that there should be a maximum of four individuals per bungalow.<sup>217</sup>

6.36 It would appear that the living conditions at the Centre have improved, particularly since the HSE review took place in 2008. However, many of the bungalows still have a high number of residents - up to nine in one bungalow.<sup>218</sup>

### **Community Group Homes**

6.37 As already noted, in 2002, the Brothers of Charity set up a Project Team to consider the future of the Centre. In 2004, the project team published a report recommending that an Implementation Group be established to develop a five year plan including plans to move the individuals currently residing on the campus to a community setting.<sup>219</sup>

6.38 The Brothers of Charity advised the Commission that its rationale for moving individuals in the Centre to community-based homes is predicated on the personal outcomes measures model and on the "social model" of disability.<sup>220</sup> The Brothers of Charity explained that:

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<sup>216</sup> See Appendix VII: Residential Services at the Centre. Up until late 2009, two individuals in the bungalow shared a place.

<sup>217</sup> The review was initiated in response to the Commission's decision to conduct the current enquiry: see further Chapter 7.

<sup>218</sup> See Appendix VII: Residential Services at the Centre.

<sup>219</sup> For its part, the HSE advised the Commission that it has had an extensive engagement with the Brothers of Charity in respect of the future development of the Centre since 2002, and that local HSE officials were aware of the Project Group set up to review accommodation at the Centre: letter from the HSE to the Commission, dated 11 December 2009.

<sup>220</sup> In the Brothers of Charity's letter to the Commission dated 17 October 2008, it stated that in the early 1980s there was a paradigm shift in organisational models of service from institutional campus services to community integrated services for people with an intellectual disability. The Brothers of Charity advised the Commission that in 2006 it conducted a total organisational review. In 2007, a five year Strategic Plan (From Vision to Action) was developed based on the learning from the organisation review, and from a consultation with all its stakeholders including parents. This was then launched at its General Meeting with families and all stakeholders. It states that Goal Three of this plan specifically addressed the development and implementation of a strategic objective to support individuals living in campus facilities to living in the community; see also Chapter 10.

Personal Outcomes Measures (POM) is a powerful tool for evaluating personal quality of life and the degree to which organisations individualise supports to facilitate the person's desired outcomes. POM heralded the model of service delivery promoting change from a model of residential care in an institution, to one of community living with a person-centred focus. This "social model" of disability increasingly challenged the segregated nature of the delivery of services for people with Intellectual Disabilities. It also implied that services should be directed at the removal of societal barriers to empower full and equal participation of people with a disability in society, rather than seeing disability as a medical issue (A strategy for Equality, 1996).

....

The transformational model adopted by the BOC Services will oversee the institutional model transferring to the development of a community model supporting and empowering people with intellectual disability to be active citizens, and to live and participate in ordinary life experiences i[n] so far a[s] they wish and are able.<sup>221</sup>

6.39 A number of members of the Parent Group are negative about the decision to move their children to community group homes and felt it was a model being imposed by the Brothers of Charity without regard to the benefits of the Centre itself.<sup>222</sup> The parents felt that the Centre offered a better quality of life if the bungalows were improved and overcrowding dealt with.<sup>223</sup>

**Parent: Telephone interview with the Commission - 26 August 2009**

There is no point in sending children with severe to profound disabilities into community group homes in Galway. They are not capable of getting a bus, or crossing a road. All they get is a house with no staff, no stimulation and no movement. Where they are they have recreation, walks etc...They cannot get that in a housing estate. It is alright for able bodied people, but not our children.<sup>224</sup>

**Parent: Telephone interview with the Commission - 1 July 2009**

Personally, I would not like community group homes. Tom has all the services in the Centre, the swimming pool, the Jacuzzi and restaurant. I understand there is a choice about community group homes, you don't have to agree.<sup>225</sup>

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<sup>221</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>222</sup> Meetings between the Parent Group and the Commission 20 May 2009 and 3 July 2009.

<sup>223</sup> *Ibid.*

<sup>224</sup> Parent 9, telephone interview with the Commission, 26 August 2009.

<sup>225</sup> Parent 1, telephone interview with the Commission, 1 July 2009.

6.40 At the time of writing this report the Centre comprised the campus and four community group homes. The community group homes are located between one and six miles away from the city centre within residential housing estates and similar distances from the Centre. The Brothers of Charity recently bought two additional houses that are between five to six miles from the City Centre.<sup>226</sup> Both houses are being restructured, with an intended opening date set for the end of 2009. The two future homes aim to provide a service for up to five individuals from the Centre per home. The Brothers of Charity state that the houses are located in towns and villages with vibrant communities, close to all amenities – shops, cafes and restaurants, churches and that each house has its own form of transport.<sup>227</sup>

6.41 Currently, 21 individuals have been moved to community group homes from the Centre. In contrast to the on-campus bungalows, the community group homes are stated to be more modern, with greater space and are more appropriately adapted to meet the needs of individuals. The Brothers of Charity have stated that they consult with individuals, family members and staff in respect of moving individuals to community group homes. The community group homes are owned by a housing association established by the Brothers of Charity, and most residents have a tenancy agreement and pay rent.<sup>228</sup> The Brothers of Charity informed the Commission that the issue of tenancy agreements was being reviewed, and that the Brothers of Charity had received advice to the effect that those with high dependency who require 24 hour support should have a license agreement rather than a tenancy agreement.<sup>229</sup> Some individuals living in the community group homes commute to campus each day for their day and multidisciplinary services.

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<sup>226</sup> One house was purchased by the John Paul Parents and Friends Housing Association, a group of parents involved in fundraising for the Centre. The Brothers of Charity advised the Commission that this group has purchased a number of houses in the community for residents of the Centre; letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>227</sup> *Ibid.*

<sup>228</sup> See further Chapter 8.

<sup>229</sup> Letter from the Brothers of Charity to the Commission, dated 2 October 2009.

6.42 As noted, a number of members of the Parent Group raised concerns in relation to individuals moving to the community group homes stating that there may have been a lack of consultation with family members and that certain homes are more isolated than the campus based residences. One parent while acknowledging that her daughter was very well cared for by staff and has excellent and spacious facilities within the community group home, feels that there was a lack of consultation in respect of the decision to move her daughter to this group home. In addition, this parent felt that the group home, in a housing estate, was not close to family members.

6.43 In November 2009, the Brothers of Charity indicated that its current view is to facilitate people to live in ordinary communities in the same way as the general population and in accordance with best practice standards, but that it also recognises that this may not be the desire of all and that on that basis it does not maintain that all individuals need to move from the Centre to community homes.

6.44 In December 2009, the Brothers of Charity further indicated that a number of modern purpose built facilities have been developed on the campus in recent times including Eden House, Shalom House and Meadow View.<sup>230</sup> It stated that it is envisaged that these services will continue to function in their present location, and that other facilities such as the hydrotherapy swimming pool and the activity/sensory area will be retained as a resource. It advised that the Implementation Group (established on foot of the Project Team Report 2004) also believes that it may be feasible to rebuild some buildings on the present site to replace existing unsuitable accommodation with more appropriately designed buildings. However in the interim, the Brothers of Charity advised that it has extensively renovated some existing buildings to address health and safety and privacy issues as funding was secured. It stated that the plan of “any future redevelopment of the Centre” will be to promote an “integrated community

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<sup>230</sup> Letter from the Brothers of Charity to the Commission, dated 23 December 2009.

setting” to support some individuals who may wish to continue living in their present local community of Ballybane.

6.45 The Brothers of Charity do not accept that there was no consultation in relation to moving persons to community group homes and it states that the location of the homes are in “*vibrant and growing communities*” and close to all amenities. It acknowledged that some families have expressed wishes on behalf of their adult son/daughter to continue to live in the Ballybane community where they have lived and have integrated within this community for many years and as noted it does not maintain that all individuals need to move from the Centre to community homes. In December 2009, the HSE advised the Commission that while it noted the fact that international evidence points towards the benefits of people with disabilities living in community settings, it also recognised the need to identify and respond to the needs of each individual in the Centre and the requirement for effective communication and consultation prior to any planned moves to alternative locations.<sup>231</sup>

6.46 As will be seen in more detail in Chapter 7, the HSE’s 2008 Review Report questioned whether the current campus accommodation, which was originally built to accommodate children could meet current service needs, namely, accommodation and services for adults with severe to profound intellectual disabilities. The HSE Review Report recommended that consideration be given to the re-development of the Centre on the existing site by engaging with some of the social housing agencies which specialise in such developments.<sup>232</sup>

6.47 There is a clear division of opinion whether moving individuals off campus to community group homes is beneficial to their participation in their local community or detrimental to it. At the national level, the HSE has carried out an interagency review of congregated settings on this very issue and expects the group to report in early 2010. The report will address residential centres where

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<sup>231</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>232</sup> See Chapter 7.

people with disabilities are accommodated in campus style accommodation and any other residential arrangements where more than ten persons with a disability are accommodated in one setting. Thus the Centre will be included in the scope of the report. According to the HSE, the intention of the group “is to explore the use of a Community Integration Model of Service Provision”.<sup>233</sup> The HSE advised the Commission that this model will “substantially alter the nature and context of how people with intellectual disabilities experience services and where they experience them”.<sup>234</sup> The HSE advised that indicative provision for €1.5 million over 2010 and the early part of 2011 to create five demonstration sites to explore the model in practice.<sup>235</sup>

## Respite Services

6.48 The Centre also provides a respite service at Eden House. The respite service offers support to full-time carers of persons with intellectual disabilities, by providing scheduled periods where persons with an intellectual disability, who live with their family, can receive on-campus residential services.

6.49 Eden House is a relatively new building on campus, and was built in 1999. As of 1 January 2009, there were five to six individuals staying in Eden House at any one time, and a total of 16 individuals were receiving respite on a planned schedule. In addition, in January 2009, 12 individuals receiving the respite services were in need of a full-time residential place, some of whom had been on a waiting list for up to twelve years. The Brothers of Charity has been raising this problem with the HSE over a number of years, and it would seem that lack of funding is linked to the length of time individuals have been required to spend on the residential waiting lists.<sup>236</sup>

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<sup>233</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>234</sup> Letter from the HSE to the Commission, dated 11 December 2009. The HSE advised the Commission that the Report will include residential centres where people with disabilities are accommodated in campus style accommodation and any other residential arrangements where more than ten persons with a disability are accommodated in one setting and that accordingly, centres such as the John Paul Centre will be addressed in the Report.

<sup>235</sup> *Ibid.*

<sup>236</sup> See Chapter 8.

## **“Wraparound” staffing**

6.50 Between 2003-2004, the Brothers of Charity set up “wraparound” staffing for two individuals (one male and one female) who were living on campus in the Centre. A wraparound service is a “one-on-one, or, two on-one” staffing ratio provided for an individual exclusively in their own accommodation, including waking night staff. The Brothers of Charity advised the Commission that this service was introduced due to the high level of incidents/ assaults against staff and individuals in the Centre by two individuals and was on a risk-funded basis.<sup>237</sup> Two separate apartments were created to cater for the two individuals. While it is referred to as a service, it does not appear to be part of the standard services provided by the Centre, but rather a temporary response to incidents of challenging behaviour caused to some degree by a lack of adequate staffing and overcrowding.

6.51 The HSE Review Report raised concerns in relation to the lack of interaction these two individuals have with the community and other individuals in the Centre and was concerned by the increased isolation caused by the wraparound service.<sup>238</sup>

6.52 In June 2009, the Brothers of Charity advised the Commission that only one individual remained within the wraparound service and that the other individual had been moved to a bungalow in St. Aidan’s and no longer receives one to one care during the night, although she still receives one on one care during the day. In 2009, the Brothers of Charity also advised the Commission that it was considering scaling back the wraparound service of the other individual to move the person to more suitable accommodation; i.e. to an apartment attached to a bungalow on the campus (where a second night staff would be required).

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<sup>237</sup> See Chapter 7 for further information.

<sup>238</sup> *Ibid.*

## Day Services

6.53 The Centre provides a day service not only to individuals availing themselves of residential and respite service, but also to individuals who reside at home and commute to the campus. Day services are provided in six on-campus bungalows (St Kevin's, St Claire's, St Peter's, St. Paul's, Meadow View Centre and Shalom House). The Brothers of Charity informed the Commission that its day programme offers individuals in the Centre a range of occupational and therapeutic activities, including self-help skills, fine-motor skills, cognitive skills, language and communication skills, play skills, gross motor skills, personal development skills, community skills, spirituality and social outings. On the basis of a number of personal outcome plans reviewed by the Commission, it was clear that some day activities are cancelled on occasion. The Brothers of Charity indicated that last minute changes to daily planned activities may occur due to an individual's increased behavioral support needs or when an individual is unwell. The individual's day programme will then be reviewed according to the individual's wishes and will also depend on the resources and staffing available.<sup>239</sup>



*Rear view of St. Michael's Residential House*

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<sup>239</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

6.54 The day centre's facilities include a swimming pool and hydrotherapy area; physiotherapy; a music therapy room; art therapy rooms; multi-sensory rooms; soft play area; a cinema (projector) room and a "chill out" area. At the time of writing this report, the Brothers of Charity advised the Commission that it had received funding for transport, and that following the 2008 HSE Review Report, each day centre now has a bus and driver, which greatly assists with social outings. Some of the day centres, such as St Claire's and St. Kevin's, were originally built as residential homes for children and are therefore not equipped to provide the same level of service as the more modern purpose built centres such as the Shalom House or Meadow View Centre.<sup>240</sup>

6.55 The day service at the Centre is provided Monday to Friday, from 10am to 4pm. Individuals are allocated to a designated day centre for their day services, depending on their service needs. Day programmes are structured from and implement personal outcome plans. These plans are reviewed every three months. The Brothers of Charity advised the Commission that individuals in the Centre and their families are consulted in relation to their day programmes in a similar manner to consultation on their personal outcome programmes. For individuals using residential services (whether living on campus or in a community home), their personal outcome plans also outline their activities outside the core day service hours (i.e. on evenings and weekends).<sup>241</sup> However, the Brothers of Charity advised the Commission that staffing levels decrease during the evenings and at weekends. Members of the Parent Group had concerns in respect of staffing levels during evening and weekend periods, feeling staffing levels had a knock-on effect on the involvement of individuals in activities at those times.<sup>242</sup>

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<sup>240</sup> The Brothers of Charity informed the Commission by letter dated 15 July 2009, that Meadow View Centre and Shalom were both built in 2001. However, the other buildings were originally built in 1979.

<sup>241</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>242</sup> Meetings between Parent Group and the Commission, 20 May 2009 and 3 June 2009.

**Letter from the Brothers of Charity to the Commission – 17 September 2009**

The consultation process involved is linked with Personal Outcomes where goals for the individual are discussed. The linked worker in the day programme will review the programme for the individual and will adapt the programme depending on the wishes and likes of the individual along with the resources and staffing levels available.

Planned changes to day programmes or suggested new activities can be forwarded from a variety of sources, such as through the individual's Personal Outcomes meeting, which attended by the individual (as appropriate), their family, their key worker, the local manager, and/or relevant Multi-Disciplinary members, or through regular team meetings where staff who know the individual can make suggestions.<sup>243</sup>

6.56 As stated, the Brothers of Charity advised the Commission that, as of 1 January 2009, 67 individuals in the Centre received a day service and that no individual who required such a service failed to receive it. However, between 2003 and 2006, the Centre did not provide a full day programme to all individuals in the Centre. This was due to inadequate staffing and space for individuals at the day centres. Table 1 below provides an overview of the number of individuals in the Centres with no formal day service provision on 1 January 2003, 2006 and 2009.

**Figure 1: Overview of individuals in the Centres with no formal Day Service**

	1 Jan 03	1 Jan 06	1 Jan 09
Number	16	7	0

6.57 Since 2004, members of the Parent Group have raised their on-going concerns in relation to the lack of what they describe as “full” day services to individuals within the Centre. This remained an issue at the time of writing this

<sup>243</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

report. Some parents' perception of day services differed from those of the Brothers of Charity.

6.58 The parents of one individual at the Centre stated that they have sought a daily structured programme for their daughter for over 10 years. They stated that in 2008 a personal outcome plan was put in place for her and that they now attend personal outcomes meetings on an annual basis. They stated that, although their daughter is brought shopping, to the cinema or for coffee from time to time, they remain dissatisfied with the implementation of the personal outcome plan. The Commission reviewed a number of the personal outcome plans in the Centre including the plan of this individual. Although it is clear that a day programme is in place for the individual in question, the plan notes that one barrier to the implementation of certain activities is that of staffing levels.<sup>244</sup>

6.59 The Brothers of Charity has noted that due to high medical needs and health issues, some individuals cannot cope with a full continuous day programme and that in such cases a structured, time-tabled programme designed to meet the individual's needs, abilities and current medical condition will be put in place, with access to appropriate therapies, care and attendance at specialist clinics, where required.<sup>245</sup> While stating that all personal outcome plans have been implemented, the Brothers of Charity acknowledge that funding difficulties have an appreciable impact on individuals' day programmes.

### ***National Review of Day Services***

6.60 In December 2009, the HSE advised the Commission that it is completing a National Review of Day Services. It stated that both this review and that of congregated settings (discussed above) are detailed processes under the National Steering Committee for Disability Services within the HSE and that it is

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<sup>244</sup> Parent 9 Letter to the Commission, dated 25 March 2008; Parent 9 telephone interview with the Commission, August 2009; Parent 9 daughter's personal outcome plan.

<sup>245</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

hoped to advance both at policy and operational level new structures for services for people with disabilities.<sup>246</sup>

## **Medical Services**

6.61 The Brothers of Charity advised the Commission that individuals in the Centre are provided with accessible medical services and that their medical requirements are recorded in their personal outcome plans. The medical services provided at the Centre refer to both physical and mental health services, including access to a General Practitioner, annual dental visits and referrals to consultants, including Consultant Psychiatrists, where appropriate.

6.62 In relation to physical health, the Brothers of Charity state that all individuals in the Centre have access to a General Practitioner (“GP”). This takes place on a referral basis by an on-duty nurse or as a result of a case conference by the multidisciplinary team. A team of three GPs, two male and one female visit the Centre on a Monday, Wednesday and Friday to see any referrals. The GPs are also available for emergency call outs between 9am and 5pm. Outside these hours, the individuals in the Centre can avail themselves of “Westdoc”, a private service. Where a GP considers that an individual requires specialised medical treatment, a referral to a specialist will be made. In addition, where there are long waiting lists, a private referral may also be made.<sup>247</sup>

6.63 It is noted that the HSE review recommended that individuals be offered a choice with regard to their GP service and that women in the Centre should have access to a female GP. In the Brothers of Charity’s response to the HSE review, it advised that as part of the personal outcome plans, individuals in the Centre are given a choice of GP, and where an individual or family member expresses a wish to change their GP, this is followed up. However, the Brothers of Charity also

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<sup>246</sup> Letter from the HSE to the Commission, dated 11 December 2009. The letter advises that this will be strengthened by a new appointment of a dedicated Assistant National Director for Disability Services to ensure policy and operational advances ensue.

<sup>247</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

advised that it has found it difficult to find GPs willing to take on new clients with the kind of complex needs of individuals in the Centre. It stated that it has carried out a review of GP medical services with individuals, families and frontline staff and that the review concluded that all groups are very satisfied with the current GP medical service. Although different GPs may attend the Centre, the Brothers of Charity pointed out that they come from the same practice and have access to GP notes to ensure there is no inconsistency in care.<sup>248</sup>

### **Dental treatment**

6.64 The Brothers of Charity advised the Commission that all individuals in the Centre receive an annual dental check up and that a dental appointment can be made at any other time where a dentist will either visit the individual at the Centre or where the individual will visit the dentist surgery, if the dentist is unable to attend the Centre.<sup>249</sup>

### **Mental Health Services**

6.65 In respect of mental health needs, a Consultant Psychiatrist runs a mental health clinic at the Centre and is assisted by a Registrar, a Psychologist, and a Nurse. The clinic is organised on a half day (three hours) basis in the Centre once per month. The Consultant Psychiatrist is also on call for any urgent matters that might arise and endeavors to be in the Centre twice per week, meeting individuals either in the clinic or in bungalows. In May 2009, the Commission was informed by the Consultant Psychiatrist that 30 out of 65 individuals in the Centre are receiving mental health care, which also includes treatment for the management of epilepsy, which is a common condition among individuals in the Centre.<sup>250</sup> Furthermore, a Psychiatric Registrar is based on campus and does two

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<sup>248</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>249</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>250</sup> Meeting between the Brothers of Charity and the Commission, 20 May 2009.

“rounds” weekly. The Brothers of Charity state that the Registrar is available for urgent reviews and crisis situations.<sup>251</sup>

## **Consent to Medical Treatment and Medication**

6.66 The Brothers of Charity advised the Commission that the “*service users’ cognitive ability does not permit service users to understand why decisions are made in relation to their medical treatment. Their cognitive ability status would have been decided through psychological assessments*”.<sup>252</sup> The Commission was informed that all individuals in the Centre undergo a psychological assessment when they are admitted to the Centre to determine their level of intellectual disability. Although there have been no recent admissions to the Centre, the Brothers of Charity advised that all individuals in the Centre received a psychological assessment between November 2008 and August 2009. The Brothers of Charity also advised that the level of functioning of each individual was consistent with the outcome of their most recent previous assessment.<sup>253</sup>

6.67 As noted in Chapter 5, there is no formal procedure in place to determine the capacity to consent to medical treatment for individuals in the Centre, partly because there is no legislation underpinning the determination of capacity in Irish Law. The Consultant Psychiatrist who attends the Centre noted her concern that consent for people lacking capacity is not valid and welcomed the advice of the Commission on this issue.<sup>254</sup> The Brothers of Charity has constantly stated that it would welcome clear and unequivocal guidelines in relation to consent as it is its understanding that consent by parents for medical treatment of persons aged 16 years of age and over has no legal validity. It states that it accepts this consent in

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<sup>251</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009. In addition to her monthly clinics (see below), the Consultant Psychiatrist endeavours to be in the Centre twice weekly and visits or reviews clients on request outside of clinic times.

<sup>252</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>253</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>254</sup> *Ibid.*

the absence of any legal framework for valid consent for people who lack capacity.<sup>255</sup>

6.68 Where difficult procedures such as dental extractions or CT scans requiring anaesthetics are needed, multidisciplinary protocols are drawn up. Ultimately, the Brothers of Charity advised the Commission that the guiding principle for all medical interventions is that there is an onus on all medical practitioners to act at all times in their patient's best interest and to cause the minimal amount of distress and the least restriction to freedom and dignity. The Brothers of Charity also stated that where possible, especially at health clinics, families are invited to attend.<sup>256</sup>

6.69 Due to the severity of their disabilities many individuals in the Centre are prescribed some form of medication. The Brothers of Charity has set out a policy for the administration of drugs to individuals in the Centre. Prior to an individual being admitted to the Centre, his or her parents, guardians, or next of kin will be required to sign a consent form relating to the administration of medication.<sup>257</sup> The Commission was informed that the consent forms for individuals in the Centre were updated in 2005 and again in 2008 and 2009, and that by November 2009, the Centre had written consents signed by a parent or a family member for all the service users on file except one.<sup>258</sup> Although no written protocols exist for contacting family members where an individual in the Centre becomes ill and needs treatment, the Commission was informed that the culture of the organisation was to communicate with, and seek the consent of, the parents as a matter of good practice, for example, where medication is involved.<sup>259</sup> The Brothers of Charity advised that it continuously updates its consent forms, such as in the case of the H1N1 virus vaccination where it states

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<sup>255</sup> *Ibid.*, insofar as it states the age of consent for medical treatment was reduced to 16 years under the provisions of the Non Fatal Offences against the Persons Act 1997.

<sup>256</sup> *Ibid.*

<sup>257</sup> Meeting between the Brothers of Charity and the Commission, 20 May 2009.

<sup>258</sup> Letter from the Brothers of Charity to the Commission, dated 23 December 2009. The Brothers of Charity advised that the parents of this individual are very active in their son's life and are fully consulted before the prescribing and administration of any medication or other interventions.

<sup>259</sup> *Ibid.*

consent for the vaccination of the individuals in the Centre was sought from all families. It advised that while a person is in its care, the Brothers of Charity seeks additional consent for the annual “Flu Vaccine”, obtaining bloods, and any other invasive procedures an individual in the Centre may require.<sup>260</sup>

6.70 The drugs policy sets out a procedure for the administration, self administration, recording, storage, and transportation of medication. The policy states that drugs shall always be administered by a qualified Nurse and in some circumstances certain drugs may be administered by a nominated trained member of staff.<sup>261</sup> At the time of writing this report, the Brothers of Charity was carrying out a review of its drugs policy.<sup>262</sup>

6.71 A number of parents were happy about the level of information provided by the Centre in relation to the medication of their children; however, others raised concerns in respect of the adequacy of information and the level of consultation on this issue.

**Parent: letter to the Commission - 25 March 2008**

Recently I received a CONSENT FORM from one of the psychologists on campus. It, asked me to agree to psychological interventions and others things, which I cannot recall now I was totally taken by this form and its implications and it struck me as being ‘carte blanche’ for anything. I immediately decided that I wouldn’t sign it...<sup>263</sup>

6.72 Whereas some parents raised concerns about the use of medication in crisis or other situations and the availability of second opinions, the Brothers of Charity provided the Commission with detailed feedback on these issues. It

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<sup>260</sup> *Ibid.*

<sup>261</sup> The policy lists tasks that must always be undertaken by a trained Nurse, including: administration of rectal drugs, when the drugs must be mixed or prepared; the administration of subcutaneous and intramuscular drugs; the administration of insulin to a diabetic, where the insulin dose varies from day to day; the placing of nasogastric tubes and the administration of nutrients and drugs through a nasogastric tube; and the insertion of gastric buttons.

<sup>262</sup> See Chapter 7.

<sup>263</sup> Letter from Parent 10 to the Commission, dated 28 March 2008.

advised that parents are always welcome to attend the Consultant Psychiatrist's monthly mental health clinic when their family member is reviewed and that additionally family members can make telephone contact with the Consultant Psychiatrist or Registrar which is always facilitated.<sup>264</sup>

6.73 Regarding second opinions, the Brothers of Charity advised that the individuals in their services have the same right to request a second opinion as any citizen in relation to their health needs. It states that second opinions are available and are facilitated if requested by the family or on a clinical needs basis, for example, clarity of diagnosis. While there was a funding issue, the Commission was informed that a second opinion request had never been refused and is occasionally initiated by the psychiatry service, instancing occasions where the Consultant Psychiatrist requests second opinions from colleagues in other agencies.<sup>265</sup>

6.74 In terms of reviewing medication prescriptions, the Brothers of Charity pointed out that all such prescriptions are used for treatment purposes and that all prescriptions for psychotropic medications are regularly reviewed at clinics and prescribed at the lowest effective dose. In addition, it pointed out that its medication policy clearly states that all psychotropic medication prescribed is reviewed three monthly.<sup>266</sup>

6.75 Although on balance it appears the medical services available to individuals in the Centre are adequate to their needs, both the Brothers of Charity and the Parent Group have raised separate concerns in relation to clarity around capacity to consent to medical treatment and the adequacy of the structures in place to inform and consult with individuals in the Centre and family members with regards to the prescription and administration of medication.

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<sup>264</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009. The Consultant Psychiatrist holds Multidisciplinary Mental Health Clinics on a monthly basis assisted by the Psychiatric Registrar, a Psychologist, a Clinical Nurse Specialist and a social worker.

<sup>265</sup> *Ibid.*

<sup>266</sup> *Ibid.*

## Multidisciplinary services

6.76 Personal outcome plans identify the level of multidisciplinary support needed and the level received by each individual. This is essential given the divergent nature of the needs of the individuals in the Centre. The Brothers of Charity advised the Commission that all multidisciplinary assessments of individuals in the Centre occur on an in-house basis by members of the multidisciplinary team.<sup>267</sup> Figure 2 sets out details of the multidisciplinary service available at the Centre in 2003 and again in 2009.

**Figure 2: Overview of multidisciplinary services at the Centre - 2003 and 2009**

Multidisciplinary Staff	2003 - wte <sup>268</sup>	2009 - wte
Speech and Language Therapist	0	0.2 (1 day/ wk)
Psychologist	1	1
Social Worker	0.9	0.9
Teacher	0.77	0.77
Educator	0	0
Occupational Therapist	0.7	0.5
Physiotherapist	1.4	1.4
Psychiatric Registrar	0.3	0.3
Special needs assistants	1.77	1.77

Additional Multidisciplinary Staff required - Brothers of Charity	wte
Speech and Language Therapist	+1
Psychologist	+0.5 psychologist and +0.5 assistant psychologist
Social Worker	+0.8
Occupational Therapist	+1
Physiotherapist	+0.6

*Figures supplied by the Brothers of Charity as of 17 September 2009*

<sup>267</sup> See Chapter 5 for further detail.

<sup>268</sup> The term "wte" refers to "whole time equivalent".

## *Speech and Language Therapy*

6.77 The Brothers of Charity advise that the speech and language therapy service provided at the Centre is a “*therapy to assist with communication, eating and drinking difficulties*”.<sup>269</sup> The Brothers of Charity advised the Commission that in 2000 it contracted a speech and language therapist in private practice to carry out a needs assessment in relation to the individuals in the Centre who would benefit from speech and language therapy intervention and also to advise on the most appropriate model of speech and language service. Between November 2000 and February 2001, a screening assessment with 72 individuals took place, however the Brothers of Charity state it was unable to follow up on interventions following the assessment reports as it could not achieve the funding for the post.<sup>270</sup>

6.78 Since 2008, a part-time speech and language therapist now attends the Centre one day per week. In November 2009, the Brothers of Charity informed the Commission that 41 individuals in the Centre have been assessed for speech and language therapy needs.<sup>271</sup> The Brothers of Charity Services Galway employ one part-time speech and language therapist for all adults using services provided by the Brothers of Charity in the West Galway area, while 6.9 whole time equivalent speech and language therapists were allocated to children (preschool and school going age). The Brothers of Charity explained this prioritisation process as follows;

To ensure the most effective use of scarce resources a system of prioritisation is required. Children are prioritized for speech and language therapy input because of the importance of developing communication skills in the early years of the child's life. The focus in the school age services is on the development of the child's language skills to support him/her to access the curriculum at school and to develop social relationships.<sup>272</sup>

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<sup>269</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>270</sup> Letters from the Brothers of Charity to the Commission, dated 30 November and 23 December 2009.

<sup>271</sup> *Ibid.*

<sup>272</sup> *Ibid.*

6.79 The Brothers of Charity informed the Commission that it has had ongoing funding difficulties concerning the provision of speech and language therapy. In 2007, the funding for a part-time senior speech and language therapist post was secured by diverting some of the salary of a staff member who had retired. This post was established in January 2008 and although the Brothers of Charity state that the filling of this position has made a very significant contribution to the development of a speech and language programme in the West Galway service area, including the Centre, it notes that a part-time post is obviously inadequate to meet the needs of persons who require speech and language therapy. The Brothers of Charity has highlighted this problem to the HSE. In its response to the 2008 HSE Review Report it stated:

Throughout Service Level Agreement meetings, the Brothers of Charity Services have continually highlighted to the HSE that several individual outcomes of service users are not being achieved as there is no speech and language therapy for adults, and insufficient service from other disciplines...However the Brothers of Charity would like to clarify that there is not the capacity within the Brothers of Charity multidisciplinary services to allocate additional time to the John Paul Services, as per the recommendation of the report.<sup>273</sup>

6.80 In December 2009, the Department of Health advised the Commission that it had granted delegated sanction to the HSE to fill key posts, including Therapy posts and this point was reiterated by the HSE.<sup>274</sup> In its response to the draft enquiry report, the HSE advised the Commission that “in the overall reorganisation of resources, the HSE would be supportive of the Brothers of Charity in converting some level of existing grades to enhance Therapy services”.<sup>275</sup> However, it is noted that previous obstacles to sourcing a Speech and Language Therapist included the need to locate monies to fund the position and the need to obtain permission from the HSE to recruit a therapist (see discussion on staff employment in Chapter 8). It is further noted that currently the Speech and Language Therapist only works one day per week in the Centre.

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<sup>273</sup> Letter from the Brothers of Charity to the Commission, dated 25 September 2008. See also Chapter 7.

<sup>274</sup> Letter from the Department of Health to the Commission, dated 14 December 2009 and letter from the HSE to the Commission, dated 11 December 2009, respectively.

<sup>275</sup> Letter from the HSE to the Commission, dated 11 December 2009.

## Social Work Service

6.81 The Brothers of Charity Services Galway provides social work services to engage with parents and family members, to provide advocacy for individuals in the Centre and to highlight the unmet needs of individuals.<sup>276</sup> Social work assessments are only required if there is a new referral to the Centre. Given the freeze on new admissions to the Centre, the Brothers of Charity advised the Commission that the need for social work assessments is not relevant where there have been no new referrals, but that the social work service is available to families and individuals on an on going basis. In general, the Parent Group expressed satisfaction with the social work service, and use it as a point of contact in relation to any concerns or to seek information.<sup>277</sup>

## Occupational Therapy

6.82 The Brothers of Charity advised the Commission that occupational therapy is provided at the Centre and is the *“on-going assessment in postural management, equipment, assistive technology accessibility and sensory integration”*.<sup>278</sup> The Centre has a part-time occupational therapist and referrals are made on a needs basis where services are delivered accordingly. At present there is a case load of approximately 47 individuals in the Centre; and a further five individuals in the Centre are on the waiting list for this service. The Brothers of Charity state that further funding is required for this service.

## Physiotherapy

6.83 The Brothers of Charity state that the physiotherapy service provided at the Centre is a combination of direct intervention, staff liaison, and assessment of individuals in the Centre for equipment and orthotics. The Physiotherapist has a

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<sup>276</sup> Letter from the Brothers of Charity to the Commission, dated 15 July 2009.

<sup>277</sup> Parents 1-10 - Telephone interviews with parents/relatives of individuals in the Centre, June to August 2009.

<sup>278</sup> Letter from the Brothers of Charity to the Commission dated 15 July 2009.

caseload of 22 individuals in the Centre on an on going basis. The Brothers of Charity also state that further funding is required for this service.<sup>279</sup>

### **Adequacy of multidisciplinary services**

6.84 Between 2005 and 2009, the Brothers of Charity raised its concerns in respect of the inadequate level of multidisciplinary staff for the needs of individuals in the Centre. In July 2009, the Brothers of Charity informed the Commission that multidisciplinary services:

...would be greatly enhanced if there was full and appropriate allocation of multidisciplinary staff to the John Paul Services as it is often quite difficult to work with individuals who present with complex needs. Thus the appropriate allocation of other disciplines will greatly enhance the ability of each discipline to provide the optimum and most useful input for each individual using our services and their families.<sup>280</sup>

6.85 Many members of the Parent Group consider multidisciplinary services to be totally inadequate in certain areas stating that many of their children have never received any speech and language therapy.

**Parent: Letter to the Commission – 25 March 2008**

Up to age 18 David had a basic programme to suit his ability but since then only receives a minding service basically. While he gets out for social training regularly I would like if he also had a programme teaching him basic skills to help him be more independent. David has no speech and has never received speech therapy over the years.<sup>281</sup>

6.86 In interviews with the Commission all parents were unclear as to what multidisciplinary assessments had been carried out in relation to their children. Most parents felt they had to pursue this matter with the Brothers of Charity on behalf of their children, rather than being satisfied it would happen automatically.

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<sup>279</sup> *Ibid.*

<sup>280</sup> *Ibid.*

<sup>281</sup> Parent 11 – Letter from a member of the Parent Group to the Commission, dated 25 March 2008. David is not the individual's real name.

Parents were concerned about the lack of multidisciplinary and expert input into the care of their children, including basic social skills training. This was particularly so in relation to speech and language therapy and after that occupational therapy was a key concern.<sup>282</sup>

6.87 Provision for multidisciplinary supports appear to have improved at a national level in recent years. The Department of Health advised that a particular priority in recent years has been the expansion of the supply of therapy graduates and that the Government has also invested heavily in the education and training of such personnel in order to secure a good supply of graduates to provide for the care needs of the population.<sup>283</sup> In this regard, it advised that since 1997 the number of training places for speech and language therapy has increased from 25 to 125, while the number of training places for occupational therapy has increased from 29 to 110.<sup>284</sup> The HSE also stressed that, since its establishment (in 2005), the number of therapists employed has increased, noting, however, that the focus had been on children with disabilities.<sup>285</sup> Both the Department and the HSE stressed an expansion in the development of Primary Care Teams and cited that the importance attached to therapy services was reflected in the fact that Therapy Grades are not included in the current moratorium on recruitment of personnel (discussed further in Chapter 8). As noted above, while the HSE indicates it is supportive of the Brothers of Charity converting some level of existing grades to enhance Therapy services, this does not appear to have occurred to date to an adequate level despite Brothers of Charity efforts.

6.88 There have been some improvements in terms of multidisciplinary supports at the Centre, with speech and language and psychological assessments now

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<sup>282</sup> Telephone interviews with parents/relatives of individuals in the Centre, June to August 2009.

<sup>283</sup> Letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>284</sup> The Department of Health has also advised that the Government has invested funding of €20 million in 2009 for health and education services for children with special education needs, which it states will provide for a total of 125 additional therapy posts in the HSE, with 90 of these posts directed to children's disability services, including speech and language therapists, occupational therapists and physiotherapists: letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>285</sup> Letter from the HSE to the Commission, dated 11 December 2009.

more regular. However, the Brothers of Charity and the Parent Group both express the view that multidisciplinary supports remain wholly inadequate, in particular in relation to the provision of speech and language therapy. This raises major concerns in relation to individuals in the Centre who rely on therapies in order to undertake basic tasks such as swallowing food properly to avoid choking and developing basic communication skills. In addition, a number of parents have highlighted that their children did not receive the same level of interventions in early childhood as may be available for children today, thus impacting on their baseline assessment and on their life skills. It is noted that the HSE advised the Commission that it is committed to the ongoing enhanced and development of services to persons with disabilities, including multidisciplinary supports such as speech and language therapy. It stated that normally multidisciplinary services are funded on the basis of all the individuals in the Centre rather than the needs of any one individual.<sup>286</sup>

6.89 Significantly, the HSE has stated that access to multidisciplinary services in the Centre needs to be seen in the context of the relative underdevelopment of multidisciplinary services in health provision in Ireland compared to international norms.

### **Educational Services**

6.90 There is no formal mechanism for the delivery of educational services to adults with intellectual disabilities at the Centre.<sup>287</sup> However, the Brothers of Charity receives funding from the Department of Education on an annual basis.<sup>288</sup> The Brothers of Charity states that the education service provided to young adults in the Centre *“is delivered in a holistic manner based on the individual needs of each young adult, designed to ensure that each person’s potential is*

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<sup>286</sup> Letter from the HSE to the Commission, dated 15 September 2009.

<sup>287</sup> See Chapter 5 for further detail.

<sup>288</sup> See Chapter 8 for further detail.

*fully developed: mentally, physically, socially, educationally emotionally and spiritually.*<sup>289</sup>

6.91 Prior to the Education Act 1998, children with intellectual disabilities had no clear statutory entitlement to an education; rather their rights to an education were determined by reference to the Constitution.<sup>290</sup> This has had a direct effect on the majority of individuals in the Centre who did not receive adequate educational services before they turned eighteen years of age. Furthermore, at the time of writing this report there was no requirement to provide educational services to persons over 18 years of age.<sup>291</sup>

6.92 In 2003, the Department of Education agreed to provide €70,000 for the provision of educational services for all young adults at the Centre, who are over 18 years of age. The Department of Education has granted this amount on an annual basis since 2003, and it was provided again in 2009. In the last two years, the Department of Education has indicated to the Brothers of Charity that there is a cut-off point for funding of 25 years of age. Both the Department and the Brothers of Charity also advised that an additional funding sum of €122,823 from the Department allows the Brothers of Charity to increase the staffing level by employing two special needs (or care) assistants at the Centre for two individuals. Both also advised the Commission that 1,200 teaching hours have also been allocated to the Centre by the Vocational Educational Committees under its “*Co-operation With Other Institutes*” scheme for the 2006/07 and 2007/08 school years and similarly for the 2008/09 and 2009/10 school years (discussed further in Chapter 8).

6.93 Programmes under the educational service contain the following components, largely the same as under the day care programme: communication, daily life skills, self-help skills, use of the “snoozelen rooms”, relaxation therapies, horticulture programmes, computer and adaptive technology, social skills and

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<sup>289</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

<sup>290</sup> See Chapter 5.

<sup>291</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

engagement with the local community, arts, crafts, drama, gross motor and fine motor, physiotherapy and swimming.<sup>292</sup>

6.94 However, as noted, only two individuals in the Centre are specifically funded by the Department of Education under the second stream of funding. Total funding provides for one teacher and two special needs assistants and is based on the special circumstances in each case.<sup>293</sup> It is not the policy of the Department of Education to provide similar services to all individuals in the Centre.<sup>294</sup> The Brothers of Charity advised that funding for educational services, provided on an annual basis, could not be guaranteed from year to year and that this has in the past created considerable difficulty in recruiting suitably qualified staff and caused unnecessary stress to parents.

6.95 The Brothers of Charity has advised the Commission that it has submitted to the Department of Education that the education for individuals in the Centre should continue past the age of 25 years on the basis that the Department had not provided the statutory educational component for many of these individuals when they were children.<sup>295</sup>

6.96 The Brothers of Charity has indicated that the fact that funding is applied for on an annual basis presents difficulties for the organisation in retaining staff and particularly with regard to recruiting a teacher, the continuity of service delivery, the “unnecessary stress to parents” and the concern for the Brothers of Charity as regards individual supports should services be withdrawn.<sup>296</sup>

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<sup>292</sup> In one case funding occurred on foot of litigation in the High Court.

<sup>293</sup> In the case of one of these individuals, the provision of a fully qualified teacher and special needs assistant appears to have been put in place as a result of a settlement reached between the individual’s parents and the State on foot of legal proceedings initiated before he turned 18 years of age. In relation to the second individual, a special needs assistant was provided as the person had not yet reached 18 years of age when he left formal education classes.

<sup>294</sup> *Ibid.*

<sup>295</sup> *Ibid.*

<sup>296</sup> *Ibid.*

## General Issues

### *Personal Finance*

6.97 The individuals in the Centre all receive Disability Allowance and most are also liable for in-patient charges.<sup>297</sup> The Brothers of Charity maintains an account for each individual into which their Disability Allowance is paid and from which the in-patient charges are deducted.<sup>298</sup> With some exceptions, the balance between the two is the net amount that each individual is left with as their personal income. The Brothers of Charity has a system for authorising expenditure from each individual's account to ensure appropriate records are maintained and authority is provided for any monies removed, with the primary responsibility for managing each individual's money being that of their key worker.<sup>299</sup> The Brothers of Charity also advised the Commission that an assessment of each individual's ability to manage their own monies is carried out.<sup>300</sup> The Brothers of Charity's "Policy on service users money" states:

For individuals who are in residence it is policy that the person's money is managed through a local account record that is linked to bank account(s) in the person's own name. In circumstances where the individual doesn't have a bank account or a similar financial institution account, the Service's finance office maintain a central ledger account in the person's own name. Generally service users who reside in community settings have opened bank accounts with reputable "main street" financial institutions. Service users residing in John Paul Centre and Kilcornan Centre are currently under the central ledger accounts system. Like bank accounts with financial institutions, the centre ledger accounts system provides regular statement of account to account holders. In

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<sup>297</sup> See also Chapters 5 and 8.

<sup>298</sup> In November 2009, the Brothers of Charity informed the Commission that a discussion was initiated with the Department of Social and Family Affairs in June 2009 to have weekly benefits, including Disability Allowance payment of people who use the Brothers of Charity Service paid directly into their personal bank account. The Brothers of Charity understood that the Department of Social and Family Affairs had no difficulty with this, and the Brothers of Charity state that they wish to facilitate this in order to empower individuals. However, it states that opening and maintaining a large number of bank accounts, ensuring the security of accessibility to funds, and all the administrative underlining controls and oversights necessary would place an enormous burden of their financial department which it could not support given its current staffing levels; letter from Brothers of Charity to the Commission, 30 November 2009. *Also* See Chapter 8 for further detail.

<sup>299</sup> Letter from the Brothers of Charity to the Commission dated 17 September 2009.

<sup>300</sup> *Ibid.*

addition to these money holding systems a small number of service users have accounts opened under the HSE Patients Property Accounts.<sup>301</sup>

6.98 As will be set out in Chapter 8, in-patient charges are levied at two rates. The higher rate applies to those in the campus accommodation, with the lower rate being payable by those in community type residences. The net effect of the interaction between the charges and the Disability Allowance payments is that most individuals residing on campus are left with an amount of approximately €50 per week from their Disability Allowance for personal expenditure, but do not pay any rent. On the other hand, most individuals residing in community group homes are left with a minimum €90 for personal expenditure. If individuals residing in community group homes are tenants who pay rent to a landlord, their rents cost (net of rent allowance if granted) reduces their in-patient charge rate accordingly (see Chapter 8). The assessment for the purpose of in-patient charges is carried out in accordance with relevant guidelines by the Brothers of Charity rather than by the HSE.<sup>302</sup> The individuals in community group homes may also benefit from a reduction in the amount of in-patient charges for what are termed ‘socialisation/ care plan expenses’, which are stated to refer to “additional expenses incurred as a result of greater independence and integration into the community.”<sup>303</sup>

### *Staffing*

6.99 In relation to the provision of day, residential and multidisciplinary support the Brothers of Charity and the Parent Group have both highlighted their concerns about inadequate staffing levels at the Centre, in particular at evenings, weekends and during the night.

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<sup>301</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>302</sup> Letter from the Brothers of Charity to the Commission, dated 9 October 2009.

<sup>303</sup> See *Charges for In-Patient Services, National Guidelines*, HSE, January 2009. The HSE has discretion to reduce or waive in-patient charges in light of financial hardship; specified allowable expenses and also other expenses which may be allowed on an individual basis. In addition in respect of community group homes or hostels where persons live independently, they may meet part of their in-patient charges by deducting an amount to reflect their contribution to the running costs of the premises (such as food and utility bills). Although the net financial position is the same this is stated to: “ensure that the independence of the clients is not compromised”, and reflects what was previously referred to as the house hold kitty system which operated before in-patient charges were introduced.

6.100 Staffing levels are decided between the HSE West and the Brothers of Charity West annually and are dependant on the level of funding allocated to the Centre and on national employment controls established by the HSE.<sup>304</sup> It is the responsibility of the senior management of the Brothers of Charity to allocate staff within its services in line with the employment ceiling. Further, it is noted that there are no national requirements or guidelines in relation to staffing ratios for adults with severe to profound intellectual disabilities.<sup>305</sup>

6.101 Although it is the responsibility of the Brothers of Charity to allocate and manage staff within its service units, it has informed the Commission that limited staffing levels has been a result of inadequate funding:

[M]any individuals in the John Paul Service required 1:1 or 2:1 support to access their local community and to participate in recreation activities. We facilitate this as much as possible and are successful during the day but evenings and weekends remain a challenge, due to limited staff resources, to support people to participate as much as they desire.<sup>306</sup>

6.102 There was a general consensus among the Parent Group that staffing had improved over the last few years; however, there were still concerns about the limited amount of staff at night and weekends, particularly in community group homes. Members of the Parent Group also raised concerns about the lack of temporary staff cover in the event of staff members being absent and the knock on effect this had on the implementation of an individual's day programme. Parents were also concerned about the high level of staff turn-over at the Centre, a difficulty which was also acknowledged by the Brothers of Charity.<sup>307</sup> One parent explained:

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<sup>304</sup> See Chapter 8 for further detail.

<sup>305</sup> Letter from the Department of Health to the Commission, dated 8 February 2006.

<sup>306</sup> Letter from the Brothers of Charity to the Commission, dated 15 July 2009.

<sup>307</sup> The HSE review also referred to staff training; see Chapter 7.

**Parent: Telephone interview with the Commission - 29 June 2009**

If a staff member is sick they don't have locum staff to cover, so they pool resources between the bungalows and that's simply not adequate. Paul needs one to one care, but he never gets it because there are other service users to care for. When there are new staff Paul can react badly, he needs to get to know staff, but it is unreal how high the turnover of staff has been.<sup>308</sup>

6.103 Although the Commission has been informed of improvements in staffing levels it would appear that it remains short of what the Brothers of Charity state is required for many of the individuals in the Centre.

*Communications systems at the Centre*

6.104 Another issue raised by a majority of the Parent Group was their concerns about the lack of communication and consultation in decisions affecting their children. In particular, they referred to the lack of information about personal outcome plans and a lack of consultation in relation to the decision taken to move individuals in the Centre to community group homes.<sup>309</sup> In addition, many parents stated they were unaware of any multi disciplinary assessments carried out in relation to their children, although as noted above the Brothers of Charity indicated that for example, 41 individuals had been assessed by the speech and language therapist by November 2009.

6.105 It should be noted, that the Parent Group informed the Commission that the majority of parents and individuals in the Centre have very good relationships with frontline staff who are caring for their children on a daily basis. Moreover, a number of parents believe that relationships with senior staff have improved in recent years. Further, parents stated that where key-workers were known to

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<sup>308</sup> Parent 6, telephone interview with the Commission, 29 June 2009. Paul is not the individual's real name.

<sup>309</sup> Meetings between the Parent Group and the Commission, dated 20 May 2009 and 3 July 2009 and telephone interviews with parents, June to August 2009.

parents, they were generally well liked and they were generally pleased with the feedback and relationships they had with these staff.<sup>310</sup>

6.106 However, some parents informed the Commission that they had a sense of disconnect with senior management. The Parent Group felt that beyond immediate care staff there was little structured communication between them, their children and management.<sup>311</sup>

6.107 In relation to a regional communications framework for parents, the HSE West set up a Consultative Committee which is made up of senior management of non-statutory service providers, HSE West representatives and parent representatives. However, the terms of reference of this Committee is advisory in nature and although it is informative to parents, and it does not necessarily include them in decision making processes.<sup>312</sup> Further, the majority of the Parent Group do not appear to view this mechanism as a point of communication in terms of service provision for their children.

6.108 At a local level, the Brothers of Charity advised the Commission that there is communication on a day to day basis with families, individuals in the Centre, frontline staff, management and social workers. It stresses that the philosophy of its management system is to bring decision-making as close to the individuals in the Centre as possible. In particular, it states that there has been involvement since 2003 from families through the personal outcome plans in relation to the personal goals and wishes of individuals in the Centre.<sup>313</sup> It pointed not only to a range of communication mechanisms in place, but also cited the fact that frontline staff are empowered by the management teams to communicate directly with parents as further evidence of their focus on this area.<sup>314</sup>

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<sup>310</sup> *Ibid.*

<sup>311</sup> *Ibid.*

<sup>312</sup> Enhancing the Partnership Report, pp. 30-31 and also letter from the HSE to the Commission, dated 6 November 2008.

<sup>313</sup> Letter from the Brothers of Charity to the Commission, dated 15 July 2009.

<sup>314</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

6.109 Also the John Paul Project team, which was discussed earlier in this Chapter, included in its membership two parent representatives nominated by parents. Further, the project team carried out an independent survey with families as part of the process. The Brothers of Charity also refer to a number of committees and local groups that were set up to roll out the recommendations of the project group, which also included parents of individuals in the Centre.<sup>315</sup>

6.110 The Brothers of Charity, and to a limited extent the HSE, would appear to have put in place communications frameworks to allow for individuals in the Centre and their families to engage with the service provided. However, it is unclear how effective these mechanisms are in practice as a majority of the Parent Group feel that they and their children are not included or informed in respect of decisions that affect the provision of services in the Centre. Whereas the Brothers of Charity clearly felt that communication with parents was good, it also indicated that insofar as matters could be improved, it was fully committed to developing in partnership with families a more effective communication and consultation system.<sup>316</sup>

## Summary

6.111 The service provision at the Centre appears to have improved in recent years, with personal outcome programmes now being rolled out for all individuals, speech and language and psychological assessments more regular. However, the Parent Group remain concerned about the adequacy of the services, in particular with regard to multidisciplinary supports, the implementation of personal outcome plans and the decision to move individuals in the Centre to community group homes. Further an underlying concern of Parent Group is the

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<sup>315</sup> *Ibid.* The Brothers of Charity cite as an example one family member who is a parent of an individual at the Centre and who is on the Quality Enhancement Forum, which the Brothers of Charity states is a group that monitors the personal outcomes and quality initiatives and development systems throughout the Sector including the Centre. The Brothers of Charity also refer to the fact that there are parents of individuals using Brothers of Charity Services on the Board of Directors of the Brothers of Charity Services Galway: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>316</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

apparent lack of effective communication mechanisms between individuals in the Centre, their families and senior management staff. In this respect, the Brothers of Charity has pointed to a range of communication mechanisms in place but has also indicated that it is fully committed to developing in partnership with families a more effective communication and consultation system. Critically, both the Brothers of Charity and the Parent Group believe that inadequate funding and staffing levels are a source of some of the difficulties facing the Centre.

6.112 The HSE has stressed the advances that will be made under the new service arrangements which will commence in 2010. However, it also stated that access to multidisciplinary services in the Centre needs to be seen in the context of the relative underdevelopment of multidisciplinary services in health provision in Ireland compared to international norms. Further, while the HSE indicates it is supportive of the Brothers of Charity converting some level of existing grades to enhance Therapy services, this may not have occurred to date despite Brothers of Charity efforts. The framework for the provision of funding to the Centre is considered separately in Chapter 8.

## Chapter 7 HSE Review Report

7.1 In April 2007, the Commission notified the HSE and the other parties of its decision to conduct an enquiry into, *inter alia*, whether the State had fully respected the human rights of the individuals in the Centre, including through reference to whether the State had provided adequate facilities and/ or services for the individuals concerned. The HSE decided to conduct a review of services in the Centre following the Commission's decision.<sup>317</sup> This HSE review was finalised in October 2007. In April 2008, the HSE provided the Commission with a copy of the resulting report which was entitled '*Review of Brother of Charity Services, John Paul Centre, Ballybane, Galway*' (HSE Review Report).

7.2 The internal HSE request commissioning the review was made in July 2007 by the Assistant National Director (Primary, Community and Continuing Care), HSE West.<sup>318</sup> Work in respect of the review process commenced in September 2007 and was conducted by a Review Group comprising two HSE personnel and an independent psychologist.<sup>319</sup> The HSE Review Report was completed in February 2008.

7.3 The HSE Review Report states that at the time the review was being conducted, there were 63 individuals accessing services at the Centre; 37 individuals residing at the campus and 26 persons living in four community houses. Thirty nine (39) individuals were deemed to be attending Day Services at the Centre from their family home/ community group home on a daily basis, returning each evening on transport provided by the Centre. The Review Group observed that many of the individuals attending the Centre on a daily basis also availed themselves of respite and shared residential services. Thirty four (34) residential individuals at the Centre were noted as receiving day services on site.

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<sup>317</sup> HSE, *Review of Brothers of Charity Services, John Paul Centre, Ballybane, Galway* (February 2008), p. 2.

<sup>318</sup> *Ibid.*

<sup>319</sup> The independent psychologist was involved in the Review on a limited participation basis only.

## Terms of Reference of the Review

7.4 Under its *Terms of Reference*, the Review Group was tasked with conducting a review of the following areas:

### HSE Review - Terms of Reference

1. Review of incidents as reported to the Irish Human Rights Commission, the incidents in the following years 2003/ 2004/ 2005/ 2006/ 2007 and the process and procedures put in place by the management and staff at the John Paul Centre to manage and reduce the level of incidents and the issues relating to those incidents.
2. Review the client profile/ groupings having regard to the need of each client.
3. Review the staffing resources and support available and utilised.
4. Review the daily living activities for service users.
5. Review the management and provision of medical services to service users.
6. Review the availability and usage of equipment, aids and appliances appropriate to the needs of the service users.
7. Review the effectiveness of information systems in place.
8. Review the funding available to the service and the efficiency and effectiveness of its application.
9. Review the crisis management intervention techniques in place to manage those with behavioural problems.
10. Review training and support provided to staff particularly training in crisis management techniques.<sup>320</sup>

7.5 The Review Group stated in its report that its work was conducted within a very short timeframe and with limited resources available to it.<sup>321</sup> Due to the tight timeframe involved, the priority given to the immediate safety and needs of the individuals at the Centre and the professional scope of the Review Group, it appears that HSE West management agreed that Term of Reference 8 (regarding funding) would be undertaken at a later date in conjunction with a nominated HSE accountant. At the time of compiling this report, it does not appear that a corresponding review by the HSE of the funding available to the

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<sup>320</sup> *Supra* nt. 1 at p. 5.

<sup>321</sup> *Ibid.*, p. 6.

Centre has been conducted. Chapter 8 of this report, however, addresses issues relative to the framework for funding to the Centre.

7.6 Overall, the Review Group observed in the HSE Review Report that:

[S]ervice users were well cared for and it was evident that there was good interaction between staff and service users. The Review Group has found that while there are many positive aspects to the work being carried out in the John Paul Centre, not least the commitment and enthusiasm of staff, there are areas that require to be addressed. These areas relate to current and future accommodation needs; identification of the needs of service users and appropriate allocation of resources to meet these needs; management of the recording of incidents and accidents; procedural and training matters relating to the management of challenging behaviour and the HSE's contractual arrangements with service providers regarding the standardisation of working conditions. The areas identified, individually and cumulatively constrain and hinder service users from living more independent and empowered lives.<sup>322</sup>

7.7 More specifically, the Review Group made 18 formal recommendations across four categories: (1) '*organisational systems*' in operation at the Centre; (2) the '*physical structure*' of the accommodation at the Centre; (3) the sufficiency of '*resources*' and; (4) the means of addressing the needs of '*individual service users*'. The recommendations of the Review Group are set out and discussed below under these four headings.

7.8 On request, the Brothers of Charity provided the Commission, in September 2008, with a copy of a detailed letter of response it had sent to the HSE regarding the HSE Review Report. In this letter, the report of the Review Group was welcomed for reiterating and supporting issues which the Brothers of Charity stated that it had been highlighting for more than 10 years; such as accommodation at the Centre not being suitable for the individuals in the Centre and the inappropriate location of children's respite services (Crannóg) on the campus.

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<sup>322</sup> *Ibid.*, at p. 4.

7.9 The Brothers of Charity indicated that it was “surprised and concerned”, however, at what it regarded as inadequate consultation by the Review Group with individuals in the Centre, their families and with staff during the course of the Review. The Brothers of Charity indicated that the Review Group did not meet with the parents/ relatives of individuals in the Centre. The Brothers of Charity stated that it felt strongly that the HSE Review Report did not reflect the improvements made regarding health and safety and to the quality of life of individuals and their families. In addition, it was the firm view of the Brothers of Charity that significant developments and improvements had taken place subsequent to the time period considered by the Review Group. The Brothers of Charity has since reiterated this view to the Commission.

7.10 Specific issues in the HSE Review Report on which the Brothers of Charity commented are set out below in conjunction with the relevant HSE Review Report Recommendation. In addition, the degree of implementation by the Brothers of Charity of each of the 18 HSE Review Report Recommendations, as of November 2009, is discussed below. Also discussed below is the HSE's response to the Commission, in December 2009, on the implementation of the Recommendations. In that response, the HSE informed the Commission that it was:

*...satisfied that all the recommendations of the HSE Review have been taken on board and are being implemented to the greatest extent possible.<sup>323</sup>*

**1) Organisational Systems in Operation at the Centre**

**a) Reporting and recording incidents and accidents at the Centre**

7.11 The Review Group found that the system for reporting and recording all incidents and accidents at the Centre was flawed. The Centre was using one type of incident form for reporting all incidents and accidents involving individuals at the Centre, staff and the public. This approach, according to the Review

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<sup>323</sup> Letter from the HSE to the Commission, dated 11 December 2009.

Group, distorted the number of incidents at the Centre, potentially causing the data to be misinterpreted.

7.12 Regarding the actual contents of the incident reports, the Review Group found that inappropriate language was being used in the reports and observed micro-reporting of what it considered to be personal and daily living activities. The Review Group viewed this latter factor as infringing on the civil liberties of individuals at the Centre. The Review Group also found that the process for following up on incident/ accident reports was not robust.

7.13 The inappropriateness of the incidents and accidents recording practice by staff at the Centre was held by the Review Group to have profound implications for the management and governance of the Centre. It was also held to have governance implications for the HSE, given its responsibility for providing services to persons with intellectual disabilities. A lack of appropriate training for staff in compiling reports was noted by the Review Group and the introduction in 2004 by the Brothers of Charity of a recording/ grading system for aggressive assaultive behaviour – the Challenging Behaviour Scoring System (“CB System”) – was found not to have made any change to the inappropriate pattern of recording.<sup>324</sup>

***b) The quantum of recorded incidents and accidents at the Centre***

7.14 Regarding the number of recorded incidents and accidents at the Centre, the Review Group found that the statistics previously reported to the Commission by the Brothers of Charity for the period 2003 and 2004 (i.e. 4,571) had been significantly distorted due to widespread multiple recording by staff and through considerable inappropriate recording of incidents, such as slips and falls and property damage, as assaults.

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<sup>324</sup> *Ibid.*, at pp. 15 and 16.

7.15 The Review Group established that there had in fact been 2,060 forms regarding incidents and accidents submitted by staff at the Centre in the period in question. In analysing the 2,060 reports forms, the Review Group found that a total of 6,560 incidents/ accidents had been recorded. Forms were identified as recording up to 20 to 30 “assaults” by an individual on a particular day without details being provided on each individual incident.

7.16 In the absence of such detail, the Review Group was unable to review the 6,560 incidents and could only consider the 2,060 report forms. The Review Group found that while 1,458 (71%) of the report forms could be classified as recording “assaults of varying degree”,<sup>325</sup> the remaining 602 (29%) reports were in relation to “non-assault” related incidents/ accidents. The Review Group noted the high number of accident/ incidents carried out by two individuals, i.e. 633 (31%), and that ‘wrap-around’ services had been established to minimise the scope for further assaults by these individuals, as discussed in Chapter 6 and further below.

7.17 Based on these findings, the Review Group made the following recommendations:

**HSE Review Report – Recommendations 1 to 3**

- i) It is recommended that there should be two separate processes of recording incidents and accidents, one relating to staff only and one for service users, members of the public etc. It is recommended that consideration be given to using the national HSE system of recording incidents and accidents, the Starsweb system.
- ii) It is recommended that a training needs analysis of staff training needs is undertaken to identify core competencies that staff should possess by grade and job role and that a Training Plan is developed to enable staff to achieve and practice to the required competencies.
- iii) It is recommended that control systems are put in place and that responsibility for the monitoring and evaluation of incident/ assault reports are devolved to team leaders to promote a proactive approach in the intervention and appropriate action of same.

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<sup>325</sup> *Ibid.*, at p. 14.

### ***Brothers of Charity Response to Recommendation 1***

7.18 While the Brothers of Charity accepted that there were anomalies around the recording of incidents and accidents, it disputed the finding of the HSE Review Report that staff at the Centre had been over zealous in reporting such events. In its view, non-reporting of certain behaviour, such as self-injurious behaviour, would amount to negligence and would not enable the analysis of such behaviour for the purpose of taking steps to reduce reoccurrence.

7.19 The Brothers of Charity indicated that there has always been separate processes at the Centre for reporting incidents and accidents relating to individuals in the Centre and staff. In July 2009, the Brothers of Charity advised the Commission that it had further modified its system for reporting incidents and accidents to make it more robust. The Brothers of Charity indicated that this new system – Accident and Incident Reporting System (“AIRS”) - is being piloted in 2009 with staff training being rolled out across all areas. In addition, the Brothers of Charity also advised the Commission that it continues to liaise with the HSE about expanding the STARS Web/ CIS system to incorporate a field to facilitate the recording of challenging behaviour.

### ***Brothers of Charity Response to Recommendation 2***

7.20 The Brothers of Charity advised the Commission that its practice for many years has been to undertake a training needs analysis of staff annually, with training needs being identified, prioritised and a training plan then rolled out. It further advised that its recruitment strategy identifies core competencies that staff should possess by grade and job role. Although it is stated to be a strategic goal of the Brothers of Charity to develop an individualised personal development training plan for all staff members, the Brothers of Charity indicated that due to financial constraints this remains a challenge.

### ***Brothers of Charity Response to Recommendation 3***

7.21 The Brothers of Charity also indicated that staff training in how to correctly complete the relevant AIRS forms has been rolled out following the development by its IT Department of an AIRS database system. A system of supervision and screening has been put in place to limit errors on forms. In November 2009, the Brothers of Charity confirmed that the AIRS system now allows local team leaders to enter data on accident and incidents on site. According to the Brothers of Charity, the AIRS system facilitates monitoring and analysis of all accidents and incidents both by local and senior management, which promotes the type of proactive approach to intervention and action recommended in the HSE Review Report. In December 2009, the HSE confirmed to the Commission that this new system for reporting incidents has been piloted by the Brothers of Charity in all its Galway services in 2009 and that staff have been trained in the new system.

#### ***c) Crisis management and intervention procedures***

7.22 Given the high number of individuals displaying challenging behaviour, the Review Group noted that a crisis management intervention technique (Studio 3) had been put in place at the Centre to minimise incidents occurring. According to the Review Group, Studio 3 is a recognised model for the prevention of challenging behaviour, including intervention procedures. The Review Group observed that no formal evaluation of the effectiveness of the Studio 3 technique had been carried out. The Review Group also observed that although a personal alarm system was in use at the Centre, not all staff were supplied with an individual personal alarm on their person.

7.23 Based on these findings, the Review Group made the following recommendations:

### HSE Review Report – Recommendations 4 and 5

iv) Given the high number of service users displaying challenging behaviour it is recommended that an overall review of crisis management and intervention take place urgently at the John Paul Centre.

v) In accordance with best practice, it is recommended that each staff member be supplied with a personal alarm and that a debriefing be conducted and recorded following each critical incident.

#### *Brothers of Charity Response to Recommendation 4*

7.24 The Brothers of Charity indicated that the number of incidents and accidents at the Centre decreased dramatically as a result of the decision to establish two wraparound services. The Brothers of Charity also indicated that all staff are trained in the Studio 3 crisis management technique as part of their orientation into the service and that this is a mandatory requirement.

7.25 In November 2009, the Brothers of Charity informed the Commission that it had completed a full review of its policies and procedures in relation to challenging behaviours and positive behaviour support strategies.<sup>326</sup> As a consequence of this review, the Brothers of Charity stated that it has re-organised its model of crisis management and intervention, including the Studio 3 crisis management approach and further development of targeted multi-disciplinary interventions.<sup>327</sup>

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<sup>326</sup> The relevant document is Brothers of Charity; Challenging Behaviour: A Unified Approach – Policy for Providing Services and Supports; Procedural Guidelines for Assessment and Intervention Approaches when Working with Services Users who present with Behaviours that Challenge.

<sup>327</sup> See Chapter 6. In particular, the Brothers of Charity informed the Commission that this intervention is provided in a team approach “involving psychologists, speech and language therapist, social workers, occupational therapist, relevant frontline staff and social workers. In the case of service users who have co-existing mental health disorders the psychiatrist is also involved. There is also a full time Clinical Nurse Specialist in challenging behaviour who intervenes directly with staff to support the implementation of multi-element intervention plans and who co-ordinates the debriefing process for staff”; letter from the Brothers of Charity to the Commission, dated 30 November 2009.

## ***Brothers of Charity Response to Recommendation 5***

7.26 The Brothers of Charity do not accept the recommendation that all staff should be supplied with personal alarms, stating that *“this would send out a very negative message about the type of people we work with and would give the impression that all our service users are violent”*. The Brothers of Charity, however, indicated that while it agreed that all staff working in “at risk of assault” situations should (and in fact do) have a personal alarm, staff working with persons who do not present with challenging behaviour do not need personal alarms. Regarding the debriefing of staff after critical incidents, the Brothers of Charity indicated that training and debriefing programmes have been developed for staff regarding challenging behaviour among individuals in the Centre. Specifically in this regard, it stated that in March 2008 the allocation of funds made available through Pobal enabled the Centre to hire a Clinical Nurse Specialist for a two year period to provide both specialist support to individuals in the Centre and a debriefing programme for staff.<sup>328</sup>

### ***d) Drug administration procedures***

7.27 Regarding the strengthening of drug administration procedures at the Centre, the Review Group made the following recommendation:

#### **HSE Review Report – Recommendation 6**

vi) All medicine cabinets should have An Bord Altranais guidelines clearly displayed and nurse management should ensure that staff are regularly appraised of their professional accountability in this regard. Nurse management should ensure that the drug administration procedures are being adhered to and that regular stock takes are carried out.

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<sup>328</sup> Pobal is a not-for-profit company with charitable status that manages programmes on behalf of the Irish Government and the EU. The relevant funding from Pobal appears to have been allocated through the Dormant Accounts (Amendment) Act (2005) which allows for the disbursement of Dormant Accounts to fund projects relating to the alleviation of economic and social disadvantage, educational disadvantage or the provision of supports for people with disabilities.

## ***Brothers of Charity Response to Recommendation 6***

7.28 The Brothers of Charity indicated that it has no difficulty having An Bord Altranais guidelines clearly displayed on medicine cabinets and that its Nurse managers carry out stock takes on a regular basis and ensure that the Drug Administration Procedures are adhered to. In addition, the Brothers of Charity stated that its Medical Director carries out unannounced audits of drug administration and storage procedures. The Brothers of Charity also advised the Commission that its Drugs Policy was in the process of being reviewed by a group chaired by the Medical Director at the Centre.

### **(2) The Physical Structure of the Accommodation at the Centre**

7.29 The Review Group noted that when the Centre was originally built it had been regarded as a model of excellence in the State for intellectual disability services for children. The Review Group also noted that the Centre is based in a very good location with access to local amenities and public transport.

#### ***a) Accommodation at the Centre 'unfit for purpose'***

7.30 In being designed to meet the needs of children, the Review Group found the bungalows/ houses at the Centre to be 'unfit for purpose' and not suitable for meeting the needs of the current adult individuals. The Review Group also found the number of adults living together in bungalows designed for children to be inappropriate, causing major overcrowding and safety issues. Some of the bungalows were found to be poorly lit, poorly ventilated, with narrow corridors and poor bathroom, toilet, bedroom, living and storage facilities. These factors were deemed by the Review Group to be potential contributors to incidents of challenging behaviour among individuals at the Centre.

7.31 Although the Review Group did note that the houses were kept homely and clean, it was of the overall impression that the buildings were in a state of

poor decorative repair, with furniture in need of replacement and upgrading. The entire facility was deemed to require a considered review so as to meet the changing needs of the individuals at the Centre and to create an appropriate care setting.

***b) Accommodation of 23 individuals with high dependence needs***

7.32 The Review Group observed 23 individuals with high dependence needs living in three bungalows at the Centre; namely St. Stephen's (10 persons), St Michael's (6 persons) and St Agnes' (7 persons). While the three bungalows were found to be homely and clean, in the opinion of the Review Group the buildings are not suitable for the particular client group. Specifically, the Review Group found that the houses lacked space, ventilation and lighting. Bedrooms were observed to be too confined for persons in need of lifting and handling equipment and beds were deemed to be in need of replacement. Toilet and bathroom facilities were similarly found to be inadequate for the needs of the individuals in these bungalows.

7.33 In the opinion of the Review Group, given the high dependency needs of the individuals in the bungalows, there should be no more than four persons residing in any one of the bungalows. A review was also sought to determine the most appropriate peer groupings in the bungalows using a multi-disciplinary person-centred approach. The Review Group stated that individuals should be central to all aspects of decision making.

***c) Accommodation of 12 individuals who display challenging behaviour***

7.34 The Review Group observed 12 individuals who display challenging behaviour living in another three bungalows; namely St Aidan's (4 persons), St Teresa's (4 persons) and St John's (4 persons). The Review Group was of the opinion that these bungalows are totally unsuitable to meet the needs of this particular group of persons. The houses were found to be too small and dark,

with a lack of toilet facilities, poor ventilation and lighting and inadequate circulation space. The impact of the restrictive nature of this environment on persons who might be overactive and boisterous at times was cited as potentially leading to residents exhibiting challenging behaviour.

7.35 The Review Group found the furniture, fixtures and fittings in some of the bungalows to be sparse and in a poor state of repair. St John's bungalow was specifically singled out as being in a very poor state of repair and the refurbishment of this building was recommended as a matter of urgency.

7.36 As with the accommodation of individuals with high dependence needs, the Review Group recommended that a review be conducted to determine the most appropriate peer groupings in the bungalows for individuals who display challenging behaviour. A multi-disciplinary person-centred approach was advocated for this purpose and emphasis was placed on individuals being central to all aspects of decision making.

**d) “Restrictive practices”**

7.37 The Review Group employed the term “restrictive practices” to refer to restraints on the personal freedoms of the individuals in the Centre. The term employed thus encompasses physical restraints and other forms of behavioural control such as seclusion.<sup>329</sup> The Review Group observed that some of the bedrooms had “spyholes” or “observational lenses” restricting the privacy of individuals and offending their dignity.<sup>330</sup> Many of the toilet facilities were noted as having no doors and bedroom doors were recorded as being left open. In one house it was observed that toilet doors were locked so that individuals were

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<sup>329</sup> In its recent Code of Practice, the Mental Health Commission defines “restrictive practices” thus: “Restrictive practices may include, but are not limited to, the use of mechanical restraint, physical restraint, psychotropic medication as restraint and seclusion”: *Mental Health Commission Code of Practice Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities*; October 2009. See also Chapter 10.

<sup>330</sup> HSE Review Report, p.7. While the term ‘spyhole’ was employed in the HSE Review Report, the term ‘observational lens’ is used by the Brothers of Charity as a more appropriate term. This term is in fact used later in the HSE Review Report in connection with the Brothers of Charity’s response to the report.

unable to go to the toilet by themselves. The Review Group noted that although the Mission Statement of the Centre indicated an 'unlocked door policy', "restrictive practices" were evident throughout the services. In another house, for instance, taps had been removed from the sink and staff indicated that they had been removed to stop an individual from drinking water from the taps. According to the Review Group, this directly affected the rights of the individuals in the house who were unable to wash their hands whenever necessary.

7.38 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 7**

vii) The Review Group recommends that a review of the accommodation for the John Paul Centre be conducted which would involve an option appraisal of identified options available to the service so that the needs of the service users can be best met. The grouping of individuals should be reviewed using a multidisciplinary person-centred approach to determine the most appropriate peer grouping for the future development of the services being provided for the service users at the John Paul Centre. Consideration should be given to a more appropriate location off site for the Children's respite services provided at Crannóg.

***Brothers of Charity Response to Recommendation 7***

7.39 The Brothers of Charity indicated that it was very pleased that the HSE Review Report confirmed that the accommodation for individuals in the Centre does not meet the needs of an adult population. As stated above, the Brothers of Charity indicated that it had been highlighting this issue to the relevant State authorities for over 10 years.

7.40 Regarding the "restrictive practices" discussed in the HSE Review Report, such as locked doors and removed taps, the Brothers of Charity stated that such restrictions are for the purpose of protecting the health of individuals with obsessional behaviours who abscond or drink excessive amounts of water or tea and are only considered as a last resort. The impact of such restrictions on other

individuals was recognised by the Brothers of Charity in its response to the HSE Review Report and it agreed that “restrictive practices” should only be used as a last resort, for instance in a situation due to a medical condition or in a situation of risk to one’s health.

7.41 Regarding locked bedroom doors specifically, the Brothers of Charity referred to its Unlocked Door Policy and the overview of same by a multi-disciplinary team. It was acknowledged by the Brothers of Charity that some doors had been locked to protect personal items from breakages and damage. According to the Brothers of Charity, missing toilet doors in one bungalow have since been replaced.

7.42 On the issue of ‘observational lenses’ in bedroom doors, the Brothers of Charity indicated that due to a lack of appropriate space, bedrooms were being used in connection with ‘low arousal technique’ or ‘time out’ behaviour management strategies, as agreed by the multi-disciplinary team. Observational lenses were regarded as the least intrusive means of ensuring the safety of individuals during such strategies. The Brothers of Charity states that only a very small number of observational lenses are in bedroom doors due to the need to monitor some individuals for levels of self-injurious behaviour and for whom opening and closing the door would be disruptive.

7.43 The Brothers of Charity indicated that it plans to address concerns regarding “restrictive practices” by establishing more suitable accommodation in the community and considering the compatibility of individuals in residential buildings and day services. It was stated that such initiatives are, however, dependent on the availability of funds.

7.44 In a further substantial response to the Commission on “restrictive practices”, the Brothers of Charity indicated that it had either amended its

existing policies or adopted new policies in respect of such practices.<sup>331</sup> The Brothers of Charity also indicated that it had established procedures whereby restrictions on the personal freedom of individuals in the Centre would be regularly audited. It advised that both management and multidisciplinary professionals providing services in the Centre are involved in the examination of restrictions and in reviewing same on a three or six month basis. It further advised that “restrictive practices” can be referred for review to a committee entitled the ‘Human Rights Committee’, which was established by the Brothers of Charity in 2007.

7.45 Regarding the review of “restrictive practices” by its Human Rights Committee, the Brothers of Charity stated that:

In the case of 6 service users, a restrictive element was part of a reactive strategy in the case of a severe incident of challenging behaviour. It was one component of a positive programming and interdisciplinary approach highlighting a holistic approach to each individual. In one specific circumstance, the restrictive practice that was invoked involved the use of a walk around physical restraint to assist in transitioning a service user from a highly stimulating environment to a low arousal environment. Only a technique that is approved by Studio 3 (low arousal approach to challenging behaviour training system and the British Institute of Learning Disability) is permitted as it ensures that the service user does not experience pain or discomfort. In the past, seclusion (5 minutes) was part of a reactive strategy for one individual in extreme situations.

The above restrictive practices were all submitted to the Service's Human Rights Committee which includes external members (e.g., a consultant paediatrician; a barrister; a parent; a principal social worker; an advocate; and a service user) for examination. The Human Rights Committee reviewed in detail the 6 individuals where a restrictive element was part of a reactive strategy (in most cases the restrictive element was rarely used). Due to further development of intervention plans as well as environmental changes made by the staff teams working with the service users, it was possible to eliminate five of the restrictive practices. At the present time, there is one service user with a restrictive element to his

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<sup>331</sup> Letter of 17 September 2009 from the Brothers of Charity to the Commission. In this letter, the Brothers of Charity lists examples of restrictive practices regularly reviewed at the Centre including (1) 'locked doors', (2) 'linking individuals on main roads', (3) 'harnesses on buses', (4) 'wheelchair belts', (5) 'all in one vests', (5) 'hand and arm splits', (6) 'hip orthiosis and spinal jackets' and (6) 'commode straps'. The policies in operation at the Centre in connection with the use of restriction practices include (1) *Policy on Using Locked Doors* (May 2003) and (2) *Challenging Behaviour: A United Approach Policy for Providing Positive Services and Supports* (July 2008).

comprehensive multi-element intervention plan and it is planned for this to be removed due to active plans which will address environmental considerations.<sup>332</sup>

7.46 In November 2009, the Brothers of Charity confirmed that all “restrictive practices” which had been place in the Centre have been reviewed, with the vast majority eliminated and it reiterated that the development of appropriate accommodation will facilitate the elimination of the small remaining number of restrictions.

7.47 In July 2009, the Brothers of Charity advised the Commission that recommendations in the HSE Review Report around the need to improve the standard of accommodation at the Centre have been substantially implemented. The Brothers of Charity indicated that in 2008, capital funding was made available to the Centre by the HSE in the order of €677,678. This was confirmed to the Commission by the HSE. Of this allocation, €518,478 was for the purpose of improving the accommodation at the Centre, while the remaining funds were for the purchase of three new buses (€154,000) and health and safety equipment (€5,200). This was confirmed to the Commission by the HSE in December 2009, with the HSE also indicating that it had engaged extensively with the Brothers of Charity in respect of future development of the Centre since 2002.

7.48 The capital investment allocation by the HSE towards improving the standard of the accommodation at the Centre appears to have gone some way towards ameliorating some of the urgent concerns identified in the HSE Review Report.<sup>333</sup> It is noted that these capital building/ renovation projects were the subject of a submission by the Brothers of Charity to the HSE for the 2008 period. The building/ renovation works targeted by the capital funding allocation and the status of the projects are set out in Figure 3 below.

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<sup>332</sup> *Ibid.*, p. 11.

<sup>333</sup> The Brothers of Charity advised the Commission that prior to the HSE Review Report and the current enquiry, the Brothers of Charity had secured POBAL funding of €300,000 to improve two residential bungalows at the Centre: Brothers of Charity letter to the Commission, dated 17 September 2009.

7.49 The Brothers of Charity emphasised to the Commission the role that its 'Project Team' of families, management and staff established in 2002 played in reviewing both residential and day services at the Centre.<sup>334</sup> The Brothers of Charity also welcomed the HSE's recommendation to relocate the Crannóg Children's Respite Service off-site. It informed the Commission that it had recognised this need for several years but have not been able to effect any relocation for budgetary reasons.

**Figure 3: Building/ renovation works targeted by HSE capital funding allocation**

Location	Type of work	Cost	Status
St Aidan & St Francis' bungalows	Refurbishment	€10,000	Completed
St John's bungalow	Redecoration	€15,000	Completed
St John's, St Teresa's & St Claire's bungalows	Repairs to roofs	€68,478	Completed
St Michael's & St Agnes' bungalows	Adaptations and redecoration	€75,000 (plus €300,000 received from Pobal grant)	Planning permission received. Work to be completed by late 2009.
Arduan House	Extension, adaptation and redecoration	€350,000	Planning permission received. Tender sought. Work to commence in September 2009.
<b>Total</b>		<b>€518,478</b>	

<sup>334</sup> As noted in Chapter 6, the Brothers of Charity advised that the Project Team, established in 2002, comprises family representatives, management members, frontline staff and multidisciplinary staff and that it has carried out person-centred consultations with persons at the Centre and their families to determine the most appropriate peer groupings for the future development of services: letter from the Brothers of Charity to the Commission dated 30 November 2009.

**e) *The nature of the care provided to individuals by staff***

7.50 The Review Group noted that individuals in the Centre appeared to be well cared for and that efforts were made to keep the accommodation homely and clean. Throughout the service, the Review Group observed that staff were courteous and helpful and appeared motivated and committed to those in their care. The Review Group was impressed with the variety and quality of the food available to individuals through the central catering facility at the Centre, which could be consumed in the central dining area or transported to individual bungalows. The integration of individuals in the Centre and staff at meals times in the central dining area also drew positive comment from the Review Group.

7.51 It was considered, however, that individuals were “cared for” rather than enabled and empowered by staff to be as independent as possible. In the course of the site visits by the Review Group, it was observed that staff, as opposed to individuals in the Centre, opened doors in most homes and that frequently individuals in the Centre were not asked whether the Review Group could enter their homes. In the opinion of the Review Group, staff at the Centre should be made aware, possibly through a specific educational programme, of the rights of individuals in respect of daily living activities and how to implement best practice to affect these rights.

7.52 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 8**

viii) It is recommended that greater emphasis be placed on enabling service users to be more independent and empowered in all aspects of their daily living to their full potential. This should be evident in each service user’s individual plan. Consideration should be given towards a specific educational programme for staff to equip them with the skills in the empowerment of service users.

### ***Brothers of Charity Response to Recommendation 8***

7.53 While recognising that the HSE Review Report praised the commitment and enthusiasm of staff at the Centre, the Brothers of Charity expressed its view that comments in the Report - to the effect that individuals were being 'cared for' rather than 'empowered' by staff - seriously undermined the efforts of all concerned. The Brothers of Charity reiterated its view that the Review Group would have benefited from spending more time at the Centre in order to gain a greater understanding of the service provided.

7.54 According to the Brothers of Charity, its training programmes emphasise the importance of building autonomy and independence for persons with a severe to profound level of disability, including through itemising practical steps to achieve this in individual plans. In addition, the Brothers of Charity indicated that psychologists at the Centre have developed a personal development programme to empower service users around their sense of their own body and their self-identity. This, according to the Brothers of Charity, has been warmly welcomed by staff and families.

7.55 Also, the Brothers of Charity stated that since the appointment of a (part-time) speech and language therapist (see Chapter 6), it has been able to further support persons at the Centre in the development of their communication skills and to work with staff to develop positive communication environments. A physiotherapist and an occupational therapist are also said to work with individuals and staff on 'mobility' and 'activities of daily living' in order to put in place the necessary aids and appliances.

7.56 The view of the Brothers of Charity on the question of enabling individuals in the Centre to be more independent appears to differ significantly from that expressed in the HSE Review Report. In December 2009, the HSE confirmed, in respect of "enabling and empowering" individuals in the Centre, that a personal development programme had been developed by the Brothers of Charity for the

individuals in the Centre and that five training events had been completed, with all individuals expected to have received training by summer 2010.

**f) “Wraparound” services**

7.57 The Review Group commented on the “wraparound” services introduced in the Centre, stating that the standard of accommodation for two particular individuals (Individual A and Individual B) in apartments in separate buildings was adequate. It was noted that the accommodation of these two individuals had contributed to a significant reduction in the levels of assaults on individuals in the Centre and on staff. While recognising this positive development, the Review Group expressed its reservations that the two individuals concerned did not have the opportunity to integrate with the community due to restrictions on their environment.

7.58 The Review Group noted that it was encouraging to learn from management at the Centre that consideration was being given to moving one of these individuals to a community house. It was recommended that a more appropriate environment and facilities be put in place for the individual who would remain at the Centre. The Review Group also expressed its general view that all individuals in the Centre should have the choice to live in, participate in and contribute to the community and that this would enhance a sense of belonging and connection to others.

7.59 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 9**

ix) The Review Group recommends that the programme for these individuals be re-evaluated and it is recommended that an external assessment by a Consultant Psychiatrist Specialist in Learning Disability be conducted as a matter of priority. This assessment should incorporate a multi-disciplinary team approach and action plan for these service users' future needs.

### ***Brothers of Charity Response to Recommendation 9***

7.60 The Brothers of Charity regarded as “unfounded” the statement in the HSE Review Report that two individuals receiving ‘wraparound’ care do not have the opportunity to integrate into the local community. In the view of the Brothers of Charity, the two persons at issue are in fact well orientated and known in their local community, take daily exercise locally and make frequent trips into Galway City and local amenities.

7.61 The Brothers of Charity emphasised that the two wraparound services had been developed in consultation with family members, the multi-disciplinary team providing services at the Centre and a specialist in challenging behaviour. According to the Brothers of Charity, the creation at the Centre of the two wraparound services was a temporary arrangement with a long-term plan to move the individuals at issue to apartments attached to a bungalow or to a house in the community.

7.62 The Brothers of Charity stated that one individual has now moved to an apartment attached to a bungalow on the campus and no longer requires an awake night staff but continues to require one to one staffing care throughout the day. There appear to be plans to move the other individual to an apartment attached to a bungalow also on the campus.

7.63 The Brothers of Charity stated that it was unclear why the HSE Review Report had recommended an external psychiatric assessment of these two persons as the individuals concerned are regularly reviewed by the multi-disciplinary team and have been assessed by a consultant psychiatrist specialist in learning disability.

**g) Future model for the service**

7.64 Again, the Review Group stated its view that the buildings at the Centre, in being designed to meet the needs of children, are not suitable for meeting the needs of the adult individuals currently in the Centre. The Review Group emphasised that the buildings are inadequately equipped for wheelchair users and that inadequate toilet, bathroom and bedroom facilities do not empower the development of skills in daily living activities among individuals in the Centre. The Review Group recommended a future model for the service which meets the needs of individuals incorporating social inclusion, integration, recreation and training opportunities. It also recommended that such a model be developed by a Project Team incorporating an architect, finance person, staff and management representatives and user and family representatives. In the opinion of the Review Group, this model should be based on best practice and on a needs assessment of each individual.

7.65 Significantly, the Review Report recommended that consideration be given to the re-development of the service on the existing site by engaging with some of the social housing agencies which specialise in such developments and exploring fully the public funding options, revenue and capital, currently available for such developments.<sup>335</sup> The benefits of redeveloping the existing site were stated to include the stability inherent in providing homes for life to persons who, in most cases, have lived at the Centre for the majority of their lives. Also, these homes could be designed to accommodate the changing needs of the individuals throughout their lifetime and would promote further integration into the existing and somewhat familiar community.

7.66 The redevelopment of the Centre could, in the view of the Review Group, provide a holistic strategy for meeting the service needs of the residents and promote choices for individuals. In the view of the Review Group, individuals could achieve enhanced status in society by having a tenancy agreement with the

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<sup>335</sup> *Ibid.*, Appendix IV of HSE Review Report.

housing association. Also, the Review Group stated that such an approach would enable the Brothers of Charity to focus on primary goals such as service delivery.

7.67 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 10**

x) The Review Group recommends a possible future model for the service which meets the needs of individuals incorporating social inclusion, integration, recreation and training opportunities. It is recommended that a model be developed by a Project Team incorporating an architect, finance person, staff and management representative and [service] user and family representatives. The model should be based on best practice and in accordance with the established needs of the service users, based on a needs assessment of each service user.

***Brothers of Charity Response to Recommendation 10***

7.68 The Brothers of Charity stated that it has engaged in reviewing possible future models for the service since 2002. During the enquiry, the Brothers of Charity informed the Commission that the future plan for the Centre was to facilitate a number of individuals residing on the campus to move to a community home setting and that improvements to the standard of existing accommodation would be made in the interim, as funds allow. Issues such as safety, privacy and dignity of individuals in the Centre would also be addressed in the context of both the relocation of some individuals to community housing and improvements being made on campus.

7.69 In November 2009, the Brothers of Charity clarified that its emphasis is to facilitate individuals in the Centre living in ordinary communities in the same way as the general population and in accordance with best practice standards. The Brothers of Charity stated that it also recognises that this may not be the desire of all individuals and their families. On that basis, the Brothers of Charity does not maintain that all individuals need to move from the campus to community houses. Facilitating individuals to move from the campus into community houses is,

according to the Brothers of Charity, subject to the wishes of the individuals in the Centre.<sup>336</sup>

7.70 In December 2009, the HSE informed the Commission that it noted the concerns of some parents in relation to the relocation of their adult children to community settings and emphasised the importance of effective communication and consultation with individuals at the Centre and their families prior to any planned move to alternative locations. As noted previously, the HSE also referred to the benefits of community living for persons with disabilities as identified in a domestic interagency review of 'congregated settings'. The HSE indicated that this review is expected to recommend further development of the 'Community Integration Model of Service Provision' in the State "which will *substantially alter the nature and context of how people with intellectual disabilities experience services and where they experience them.*"

### **3) The Sufficiency of Resources**

#### **a) Staff resources**

7.71 The Review Group found sufficient staff resources available at the Centre. Problems were found to exist, however, regarding the deployment of these resources, with individuals with high behavioural needs being deemed to benefit more than persons with high nursing needs. The Review Group found evidence that supervisory grades were somewhat removed from front-line activity at the Centre and that the allocation of duties was disproportionate throughout the Centre. In some areas visited by the Review Group they observed an inappropriate skills mix, with certain categories of staff carrying out duties inappropriate to their role. An example was given concerning a member of the nursing staff carrying out tasks that could more appropriately be allocated to a non-nursing staff member.

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<sup>336</sup> See discussion in Chapter 6.

7.72 The Review Group noted the advice it had received from management at the Centre regarding the high turnover of staff. Following induction and intensive training, it stated that a high number of staff leave after only a short time. The Review Group directed a specific recommendation to the HSE in this regard (i.e. Recommendation 12).

7.73 Based on these findings, the Review Group made the following recommendations:

**HSE Review Report – Recommendations 11 and 12**

xi) It is recommended that a review of the allocation of staff and distribution of resources be conducted by the John Paul Centre with a view to improving the equitable utilisation of resources. It is recommended that a review of the Team Leaders responsibilities takes place by management with a view to maximising resources at a local level.

xii) The Review Group also recommends that the HSE review its contractual arrangements with service providers so that equal working conditions prevail in each contracted service.

***Brothers of Charity Response to Recommendation 11***

7.74 The Brothers of Charity indicated that it accepts Recommendation 11 and that prior to the HSE Review it had been actively engaged in reviewing the management structures in the Centre. The Brothers of Charity disagreed, however, with the HSE Review Report finding that supervisory grades of staff are somewhat removed from frontline activity. According to the Brothers of Charity, the offices of all managers are based in the day service buildings, located in “the heart of the local services”. Managers, it stated, regularly work frontline to cover staff shortages and are involved in all aspects of service delivery.

7.75 In relation to individuals with high behavioural needs being deemed, in the HSE Review Report, to benefit more than persons with high nursing needs, the Brothers of Charity stated that, given limited staff resources, it prioritised safety needs first as there were a high number of challenging behaviour incidents by

some individuals in the Centre on other individuals. The Brothers of Charity agreed that people with high 'nursing' needs do require high staffing levels to realise their outcomes, improve their quality of life and realise their core potential.

7.76 In December 2009, the HSE indicated to the Commission that it fully supports the issue of realigning management resources and restructuring of staff as part of the overall transformation of public services to address modern day needs.

### ***Brothers of Charity Response to Recommendation 12***

7.77 Regarding the issue of staff retention at the Centre, the Brothers of Charity acknowledged that, while some of its staff had, in the past, been recruited as care assistants by another service provider, this was no longer an issue as the same rate of pay and qualification criteria for staffing grades was common to similar organisations in the Galway region. Although this recommendation was directed to the HSE specifically, the Brothers of Charity indicated that the conditions underlying the recommendation have not existed since 2004.

#### ***b) Storage for aids and appliances***

7.78 The Review Group found that aids and appliances, such as appropriate chairs, were available at the Centre to individuals with high physical needs. It was observed, however, that there was no storage facility for this equipment and that sitting areas were being used as storage areas for these items. This reduced the living space for individuals in the Centre.

7.79 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 13**

xiii) The Review Group recommends that the storage of equipment be reviewed in order to maximise the available space for service users and staff and that alternative storage areas are sourced.

***Brothers of Charity Response to Recommendation 13***

7.80 The Brothers of Charity acknowledged that the lack of physical space in which to store equipment at the Centre was causing a problem. The Brothers of Charity referred to the particular storage problem caused by wheelchairs, as individuals in the Centre require a minimum of two such chairs which must be personalised to meet their individual requirements. It appears that the Brothers of Charity plans to address this recommendation through its policy of moving some individuals residing at the Centre to community homes over time.<sup>337</sup> Again, it appears that this is dependent on the availability of resources and subject to the wishes of the individuals in the Centre.

***c) Recreational facilities***

7.81 The Review Group listed a number of very good recreational facilities available at the Centre, including a swimming pool, sensory garden and jacuzzi. It was noted that staff had advised the Review Group that these recreational facilities were well used and that individuals in the Centre enjoyed using them. The Review Group, however, observed little evidence of usage of any of these facilities during their short site visits.

7.82 Based on these findings, the Review Group made the following recommendation:

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<sup>337</sup> This policy is discussed further in Chapter 10 in the context of a future model for residential services for persons with intellectual disabilities.

#### **HSE Review Report – Recommendation 14**

xiv) The Review Group recommends that the usage of the existing facilities be reviewed to maximise usage and to give consideration to allowing other service providers to use the facilities. The facilities usage should be incorporated into the service users' individual plans.

#### ***Brothers of Charity Response to Recommendation 14***

7.83 The Brothers of Charity stated that the HSE Review Report was inaccurate in stating that certain recreational facilities (pool/ jacuzzi) are under-utilised. Attendance records were furnished by the Brothers of Charity to the Commission illustrating that these facilities have been utilised fully and it was indicated that such activities are incorporated into individuals' plans.

#### **4) The Means of Addressing the Needs of Individuals in the Centre**

##### ***a) Individuals with no programmatic day care service***

7.84 The Review Group noted that many of the individuals in the Centre received formal day programmes at the Centre in designated day care areas. However, a number of individuals were found not to have access to those services. These individuals would remain in the bungalows and there was little evidence apparent to the Review Group of planned daily activity programmes for these persons. Other individuals were noted as embarking on bus trips and social outings accompanied by staff. It was recommended that more planned and varied activity programmes be available for all individuals who do not receive a formal day service. In the view of the Review Group, such activities should be incorporated into the overall individual plan for each individual which should detail measurable outcomes and be reviewed regularly.

**b) *The maintenance of records on individuals***

7.85 Regarding the maintenance of records at the Centre on each individual in the Centre, the Review Group observed that records were retained in the form of (1) Daily Life Skills Plans, (2) Daily Report Books and (3) Personal Outcome Plans. While records of the type (1) and (2) were in place, up to date and easy to read, the Review Group observed that type (3) records - Personal Outcome Plans – were not kept updated. Details in relation to each individual were also observed not to be available in one centrally kept complete file. The Review Group recommended that an individual plan, informed by a needs assessment, be carried out for each individual and that this plan, along with all other relevant details, should be retained in one comprehensive file for each individual.

**c) *Personal Outcome Plans***

7.86 Regarding personal outcome plans specifically, the Review Group recognised these as an established system for measuring the quality of services provided to individuals. Based on an agreement with individuals in the Centre as to what they require in a range of areas of their life (such as friendships, living situations, community involvement, work, respect, health etc), the personal outcome system was described as facilitating supports to be put in place to enable the person to achieve each personal outcome within a given timeframe.

7.87 The Review Group received advice from Management at the Centre that many positive outcomes had been delivered though the personal outcomes system. It was also advised that a comprehensive staff training programme in relation to personal outcomes was in place. However, the Review Group observed during its site visits that the personal outcomes programme was not being implemented on a managed and planned basis.

7.88 Based on these findings, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 15**

xv) It is recommended that the Personal Outcome system be reviewed, accredited and updated on a regular basis as required.

***Brothers of Charity Response to Recommendation 15***

7.89 Difficulties in managing the personal outcome plans of individuals in the Centre were acknowledged by the Brothers of Charity. It indicated, however, that the Review Group had been informed that the Centre had experienced a very difficult period of absenteeism of managers due to sick leave and that this had impacted on the management and monitoring of the personal outcomes system. The Brothers of Charity stated that this was not acknowledged by the Review Group in its report. It was further stated that since the implementation of the personal outcomes system in 2003, the development of this system and of individual plans for each individual has been a major focus for the Brothers of Charity, forming an integral part of day to day service provision.

7.90 In July 2009, the Brothers of Charity indicated that, as of 1 January 2009, all individuals in the Centre (both residential and day) have a personal outcome plan and that these are prepared on an annual basis and reviewed regularly during the year.<sup>338</sup> The Brothers of Charity also indicated at that time that it had just received accreditation for its personal outcomes system from the Council on Quality and Leadership, an American based not-for-profit organisation.<sup>339</sup> Accreditation by this provider of personal outcomes systems runs for a four-year term and involves three on-site visits by the provider over this period. According to the Brothers of Charity, the accreditation process was rigorous with the

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<sup>338</sup> Meeting between the Commission and the Brothers of Charity, 20 May 2009.

<sup>339</sup> The Council on Quality and Leadership (CQL). According to its website, CQL is an international not-for-profit organization that brings together providers, professionals, advocates and other leaders in the disability field whose vision is community inclusion, dignity and quality of life for people with intellectual and developmental disabilities and people with mental illness.

preparation for the accreditation review in 2009 being preceded by a detailed self-assessment which was sent to the system provider for information. Following that, in June 2009, a team of five people from the system provider visited the services and conducted a review over the course of a full week. This involved random sampling of personal outcome interviews, focus group meetings with individuals in the Centre, their families, local community members and staff of the Centre.<sup>340</sup> The team from the system provider also reviewed, *inter alia*, individual files, policies and procedures, available health and safety data and practices and meetings with management.<sup>341</sup>

**d) *Systematic care planning and multi-disciplinary services***

7.91 The Review Group noted that the majority of individuals in the Centre have high support needs. Little evidence was found, however, in the care records of systematic care planning for each individual. The Review Group referred to advice it had received from Management of the Centre that multi-disciplinary services were provided to individuals consisting of physiotherapy, psychiatry and social work. It was noted in this regard that no speech and language therapist was in place at the Centre. It was further noted that the multi-disciplinary professionals providing services at the Centre operated on a sessional basis only.

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<sup>340</sup> According to the Brothers of Charity, the system provider, CQL, carried out a random sample of Personal Outcomes Interviews with people using services and their families (both from the children and adult services); held 2 separate Focus Groups of families; held 2 separate Focus groups of individuals using services; held a Focus Group of members of the local community; held 2 Focus Groups of staff; met and interviewed the person who had made the most recent complaint about their service; met and interviewed a person who had been involved in a client protection allegation and met and interviewed a person with complex medical: letter from the Brothers of Charity to the Commission, dated 30 November 2009. See also discussion in Chapter 6.

<sup>341</sup> According to the Brothers of Charity, the system provider, in addition to the interactions with people using services; Reviewed organisational policies and procedures; Reviewed health and safety data and practices; Reviewed individual files; Examined the work of the Human Rights Committee and interviewed the members; Had detailed discussions with the Services Management Team; Visited a number of service areas – day and residential services, as well as visiting and meeting with people living in community houses: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

7.92 Based on these findings the Review Group made the following recommendations:

**HSE Review Report – Recommendations 16 and 17**

xvi) It is recommended that a holistic, person-centred needs assessment is completed on each service user as a matter of urgency to facilitate future planning. This should be incorporated into an individual plan for each service user which should be subject to regular review and appropriate revision. The contents of the individual plan should inform the future service provision for the individual and their future accommodation needs. A Risk Assessment and Management Plan should be incorporated as part of this Person-Centred Plan.

xvii) The Review Group recommend that all services be provided to the service users in keeping with their individual plans as informed by their needs assessment. The provision of certain service to the service users which are currently unavailable (e.g. Speech and Language Therapy) should be addressed and consideration should be given to providing such services from within the overall Brothers of Charity Service and from other voluntary agencies in the Galway region.

***Brothers of Charity Response to Recommendation 16***

7.93 As stated above, the Brothers of Charity informed the Commission in July 2009 that as of 1 January 2009, all individuals in the Centre (both residential and day) have a personal outcome plan and a tailored daily programme to suit their needs and wishes. According to the Brothers of Charity, individuals are able to input into their daily timetables and, in its view, this serves to maximise their independence. The extent to which personal outcome plans rely on funding availability will be explored in Chapter 8.

***Brothers of Charity Response to Recommendation 17***

7.94 The Brothers of Charity confirmed that it had continually highlighted to the HSE, through the forum of Service Level Agreement meetings, that personal outcomes of individuals in the Centre are not being achieved due to the lack of speech and language therapy and insufficient services from other disciplines. Whilst it was acknowledged that the HSE Review Report recognised this unmet

need, the Brothers of Charity clarified its view that it could not allocate additional multi-disciplinary services to the Centre from its own resources, as suggested in the Report, due to a lack of available funds.

7.95 In November 2009, as noted, the Brothers of Charity advised the Commission that 41 individuals at the Centre have received a speech and language assessment. The Brothers of Charity had also indicated, in July 2009, that occupational therapy services at the Centre have a caseload of 47 individuals and that five persons are on the waiting list for assessment. Regarding psychological services, the Brothers of Charity indicated, in November 2009, that the most recent assessment of individuals in the Centre occurred between November 2008 and August 2009, at which time all individuals were reassessed.

7.96 The HSE, in December 2009, suggested that access to multi-disciplinary services in the Centre should be seen in the context of the relative underdevelopment of multi-disciplinary service provision in the State generally. While referring to a 'significant increase' in the number of therapists employed by it, the HSE acknowledged that the focus of this increase had been on services for children with disabilities.

**e) *Medical services and the prescription of medicines for individuals in the Centre***

7.97 The Review Group expressed the view that adequate medical services are available to the individuals in the Centre from GPs at a local health centre and that all individuals were registered with a local GP. As also noted elsewhere in the Review Report, individuals were observed to be in good health and well cared for. It was recommended that individuals be offered choice in relation to their GP, particularly women, whom the Review Group stated should be provided with access to a female GP.

7.98 Although the Review Group did not consider that it was within its professional remit to comment on the appropriateness of medication prescribed to individuals, it noted that it would be good practice to incorporate a review of same as part of each individual's needs assessment.

7.99 In this context, the Review Group made the following recommendation:

**HSE Review Report – Recommendation 18**

xviii) It is recommended that a review of all medication prescribing and usage be carried out in respect of each service user in line with best practice at least once a year.

***Brothers of Charity Response to Recommendation 18***

7.100 In November 2009, the Brothers of Charity advised the Commission that a Consultant Psychiatrist holds a monthly multidisciplinary Mental Health Clinic in the Centre, involving the Centre's Medical Director, a Psychiatric Registrar, a Psychologist, a Clinical Nurse Specialist and a Social Worker. Ten (10) individuals can attend the clinic each month and part of the clinic is dedicated to a review of medication. The Brothers of Charity indicated that, if necessary, additional reviews could be established, outside the arranged clinics.

7.101 The Brothers of Charity indicated that any ill person in the Centre is seen by their GP, just like any other citizen. According to the Brothers of Charity, any medication that has been prescribed for the person is reviewed at this time by the GP. It advises that independent of episodes of illness, every individual gets an annual health check with their GP which includes a review of prescribed medication. Further, individuals who have been prescribed psychotropic medication have their medication reviewed on a three monthly basis and the monthly Mental Health Clinics ensure monitoring and follow up on individuals who have been prescribed such medication.

7.102 The Brothers of Charity stated that this recommendation is being followed and that the medication of individuals in the Centre is, in fact, reviewed more frequently than the HSE Review Report recommends.

### **The Response of the HSE to the HSE Review Report and its Recommendations**

7.103 The HSE indicated to the Commission in November 2008 that it had engaged with the Brothers of Charity regarding the priority areas identified in the HSE Review Report and that many of the recommendations of the HSE Review were already the subject of regular meetings between it and the Brothers of Charity in the context of Service Level Agreements. As noted earlier, the HSE further informed the Commission in December 2009 that it was satisfied that all the recommendations of the HSE Review Report had been taken on board and were being implemented to the greatest extent possible and it identified five relevant areas by way of illustration:

#### **Letter from the HSE to the Commission - 11 December 2009**

**Reporting of Incidents:** New system for reporting incidents is piloted by the Brothers of Charity in all Galway services in 2009. Staff have been trained in the new system.

**Reallocation of Staff Resources:** The issue of realigning management resources and restructuring staff is one that the HSE fully supports as part of the overall transformation of public services to address modern day needs. The HSE is aware that the Brothers of Charity are progressing this issue.

**Accommodation:** In 2008 Capital funding in the amount of €677,678 was allocated to enable the priority works to be carried out. These capital projects continued the programme of improvements which were financed through capital monies in recent years, including improved access to buildings, extension/renovation of buildings and garden areas, as well as the purchase of motor vehicles and specialist aids and appliances. Notwithstanding this, issue remain with accommodation within the centre, which will be addressed in a later paragraph.

**Enabling and empowering service users:** a personal development programme has been development for service users and five training events for service users have been completed with all service users to have received training by summer 2010.

**An individual plan for each service user:** each individual in the Centre has a Personal Outcome Plan in place, which incorporates all the areas outlined in the recommendation.

7.104 The HSE informed the Commission in November 2008 that as a direct consequence of the recommendations of the HSE Review Report, it had made available capital funding in the order of €677,678 for projects at the Centre.<sup>342</sup> This funding, as outlined above at Figure 3, was directed towards improving substandard accommodation at the Centre (€168,478), making alterations to a community house (€350,000) and for purchasing three new buses (€154,000) and health and safety equipment (€5,200). The HSE indicated that this capital funding allocation was a continuation of a programme of improvements at the Centre financed through capital monies in recent years, such as improved access to buildings, extension/ renovation of buildings and garden areas. The HSE acknowledged that, notwithstanding this allocation of funds, issues remain with the accommodation at the Centre.

7.105 Regarding the issue of accommodation, the HSE confirmed in December 2009 that all individuals now have their own bedrooms (i.e. no bedrooms are now shared). The HSE also indicated its understanding that in 2010 the Brothers of Charity intend pursuing the relocation of a further four individuals in the Centre to community housing. In addition, the HSE referred to its involvement, on a national level, in progressing accommodation issues for persons with disabilities through an interagency review of congregated settings. As noted in Chapter 6, according to the HSE, the report of this group may recommend the use of a 'community integration model of service provision'.

### ***Term of Reference No 8 of the Review***

7.106 It will be recalled that the HSE Review Report was unable to address the issue of funding to the Centre and the efficiency and effectiveness of its

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<sup>342</sup> Letter from the HSE to the Commission, dated 6 November 2008.

application. This originally had been set out as Term of Reference No 8 of the Review. As previously stated, the Review Group did not consider itself to be appropriately qualified to address this matter and an agreement was made with HSE West management that a review of this issue would be undertaken at a later date in conjunction with a nominated HSE accountant.

7.107 Regarding the arrangement to undertake this further review, the HSE has indicated that other initiatives had been developed subsequent to the completion of the HSE Review Report which have addressed this requirement.<sup>343</sup> The HSE referred specifically, in this regard, to (1) the implementation of the recommendations of the McCoy Report (discussed below),<sup>344</sup> (2) the introduction, on a pilot basis, of a guidance document on residential services for people with disabilities, (3) an ongoing audit on the incidence of abuse in all intellectual disability services and (4) the extension of the requirements of Part 9 of the Health Act 2004 to all agencies providing services under sections 38 and 39 of that Act.

7.108 While points (1) and (2) appear to be relevant to the issue of the funding available to the Centre and are discussed further below, it is unclear how points (3) and (4) are directly relevant to this issue. Point (4) is, however, discussed further in Chapter 9 in relation to the obligations on 'service providers' to operate a complaints process for individuals as required under the Health Act 2004. The HSE later informed the Commission that it had decided to defer the financial review pending the outcome of a separate (interagency) review it was conducting regarding adult services and congregated settings, which includes the Centre.<sup>345</sup>

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<sup>343</sup> Letter from the HSE to the Commission, dated 06 November 2008. The HSE also referred to a report that is being completed on Adult Day Services. At the time of writing that report was in draft form but had not yet been finalised.

<sup>344</sup> HSE, *Report of Dr Kevin McCoy on Western Health Board Inquiry into Brothers of Charity Service in Galway* (November 2007).

<sup>345</sup> Letter from the HSE to the Commission, dated 10 September 2009.

## ***The McCoy Report***

7.109 The McCoy Report, or more correctly the *Report of Dr Kevin McCoy on Western Health Board Inquiry into Brothers of Charity Service in Galway*, was published in December 2007.<sup>346</sup> The issue of 'funding' was not specifically within the terms of reference of the McCoy Inquiry which was concerned with the investigation of allegations of sex abuse in specific care settings in Galway within the charge of the Brothers of Charity. It should be noted that no allegation of sex abuse has ever been made against any persons involved with the provision of services at the Centre.

7.110 The McCoy Inquiry was established in 1999 when the then Western Health Board and An Garda Síochána became aware of allegations of abuse within services for children with intellectual disabilities provided by the Brothers of Charity in Galway. The Inquiry was established at the request of the Brothers of Charity. During the course of the McCoy Inquiry, a further related review was commissioned by the HSE, in December 2005, regarding the adequacy of systems for the protection of individuals within the Brothers of Charity services.<sup>347</sup>

## ***Recommendations of the McCoy Report***

7.111 The McCoy Report made a number of recommendations regarding, *inter alia*, how complaints and allegations should be handled, the future model for the development of services,<sup>348</sup> the contractual arrangements between the HSE and the Brothers of Charity and in respect of safety, standards and quality of service for individuals in the Centre. These include:

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<sup>346</sup> The timeframe for this Inquiry was to examine any allegations of abuse relating to the years 1965-1998.

<sup>347</sup> HSE, *Review of Current Practice for the Protection of Service Users within the Brothers of Charity Services Galway* (the Mulvihill/ Murphy Review) (2006 and 2007). This review was divided into two phases; Phase 1 examined written documentation and reported in June 2006, while Phase 2 examined the standards of safety practice at an operational level and reported in June 2007.

<sup>348</sup> This issue is discussed further in Chapter 10.

### Recommendations of the McCoy Report

- That a comprehensive system of client advocacy be introduced for all service users in the Brothers of Charity Services.<sup>349</sup>
- That specific arrangements for investigation of complaints is included in a new Service Level Agreement between the [HSE] and the Brothers of Charity Services.<sup>350</sup>
- That a fundamental review of campus style residential setting should be undertaken by the [HSE] in partnership with the providers of all such services. Based on that review the stakeholders, which include the Department of Health, the [HSE], the voluntary organisations and the religious congregations, should consider the development of a specific investment programme which would resource the transfer of the vast majority of such persons from campus style setting to community based settings.<sup>351</sup>
- That the contract arrangements between the [HSE] and the Brothers of Charity Services be reviewed on the foot of a new Service Level Agreement which will have a much stronger focus on a multi-dimensional accountability framework with an emphasis on, safety, standards and quality of service for clients.<sup>352</sup>
- That the Annual Service Agreement between the [HSE] and the Brothers of Charity Services includes a monitoring template on complaints and allegations received in the service, assurances that investigation comply with agreed arrangements and an overview of the outcome of such complains/ allegations.<sup>353</sup>
- That the Health Information and Quality Authority, the agency responsible for the development and monitoring of standards in the services for people with a disability, put in place the appropriate processes, best practice standards and associated monitoring/ inspection arrangements as [a] matter of urgency.<sup>354</sup>
- That, the [HSE], as funders/ commissioners of services, develop substantive assurance processes as part of its contractual arrangements with the Brothers of Charity Services. This will be of particular importance in the transition period before the Health Information and Quality Authority becomes fully operational but should continue in an appropriate format into the future.<sup>355</sup>

### ***(2) The introduction, on a pilot basis, of a guidance document on residential services for people with disabilities***

7.112 The Commission was advised by the HSE in November 2008 that it was in the process of introducing, on a pilot basis, a Guidance Document on

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<sup>349</sup> *Ibid.*, at para. 10.5.6.

<sup>350</sup> *Ibid.*, at para. 10.5.7.

<sup>351</sup> *Ibid.*, at para. 10.7.3.

<sup>352</sup> *Ibid.*, at para. 10.10.1.

<sup>353</sup> *Ibid.*, at para. 10.10.2.

<sup>354</sup> *Ibid.*, at para. 10.11.1.

<sup>355</sup> *Ibid.*, at para. 10.11.2.

residential services. In September 2009, the HSE informed the Commission that the Guidance Document had been prepared in the absence of any statutory quality standards for residential services for persons with disabilities. The HSE indicated that the centres involved in the pilot scheme were asked to conduct a self assessment of their residential services against the standards set out in the Guidance Document. The HSE further indicated that the outcome of the pilot scheme was very positive, in that all the centres involved reported that their facilities would be capable of achieving the requirement of the Guidance Document within current resources, within a three year period.

7.113 The HSE stated that it had planned a more comprehensive rollout of the Guidance Document scheme but that it was requested by the Minister for Disability and Mental Health to reorientate its focus towards the implementation of the HIQA 'National Quality Standards: Residential Services for People with Disabilities', which are discussed in Chapters 9 and 10.<sup>356</sup>

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<sup>356</sup> HIQA; National Quality Standards: Residential Services for People with Disabilities, May 2009. See also [www.hiqa.ie](http://www.hiqa.ie).

## **Chapter 8            Framework and Application of Funding to the Centre**

8.1    As noted in Chapter 7, one of the terms of reference of the 2008 HSE Review Report was to undertake a review of the funding available to the Centre and the efficiency and effectiveness of its application. As previously stated this term of reference was not addressed in the report and the HSE has since decided not to carry out any further review of the matter.<sup>357</sup>

8.2    This Chapter sets out the framework for the provision of funding to the Brothers of Charity and how it is drawn down to the Centre. The Chapter is divided into four parts: Part one outlines the funding concerns as raised by the Brothers of Charity and the members of the Parent Group. Part two provides an overview of how funding is transferred from the Exchequer through the HSE to the Brothers of Charity. Part three sets out other funding to the Centre which includes funding from other statutory and non-statutory bodies. Part four then provides an overview of the income generated by the Brothers of Charity, with particular regard to the financial contribution to services made by individuals at the Centre. Finally, reference is made to a planned Government “Value for Money” review of disability services in 2010 and to Budget 2010. Figure 4 below provides an overview of funding to the Centre.

### **Part One:    Funding Concerns at the Centre**

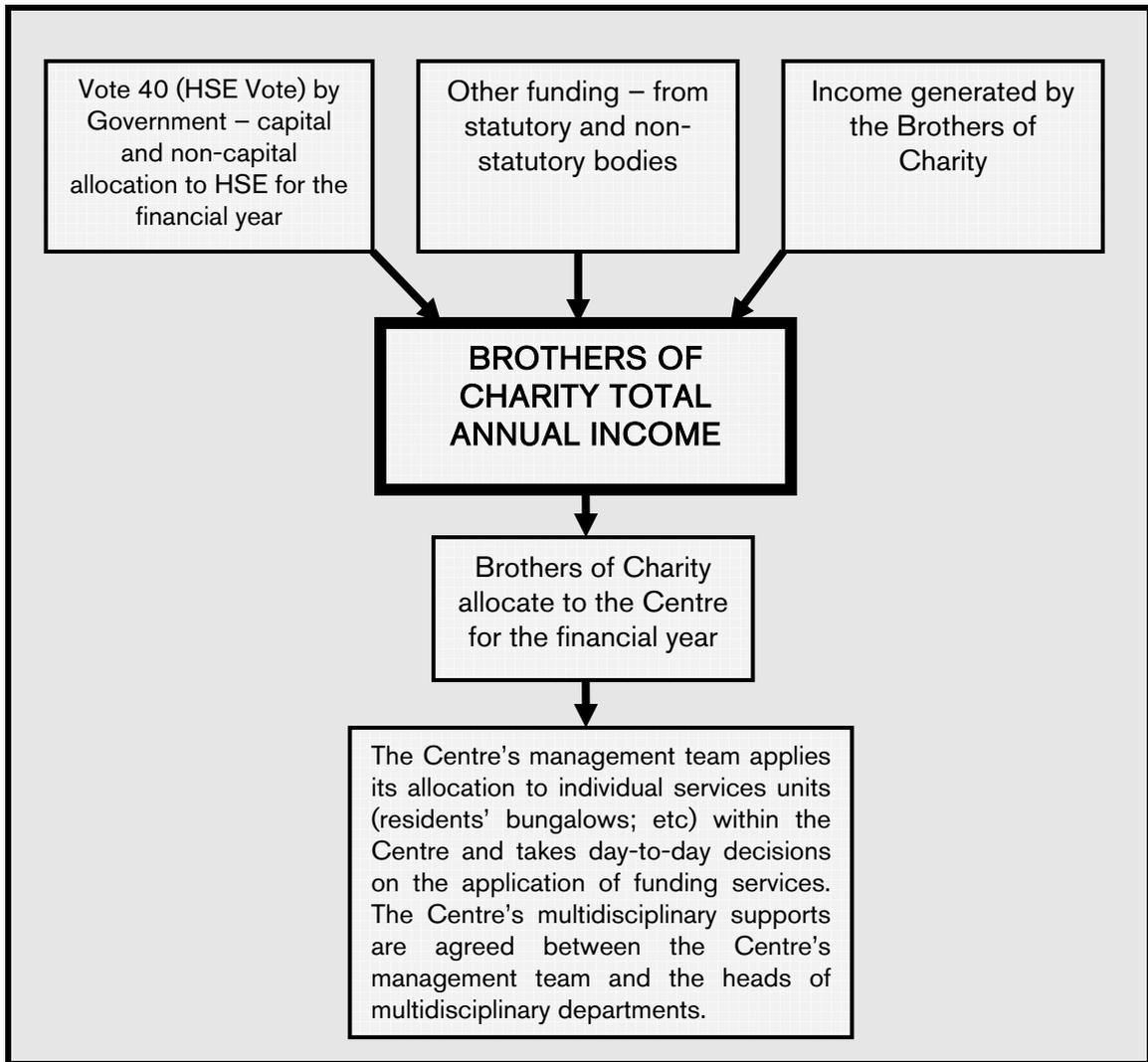
8.3    During the enquiry, the Commission received different accounts of how the costs of residential, day and respite services for persons with a severe to profound intellectual disability are calculated. The Brothers of Charity set out detailed information on how funding is drawn down from the HSE, as set out below. The HSE has similarly indicated the manner in which Service Agreements and separately New Service Development funding operates (see below). The

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<sup>357</sup> See Chapter 7, *supra*.

Department of Health itself refers to an estimated “national average cost of providing a new residential place” as being approximately €80,000.<sup>358</sup>

**Figure 4: Overview of funding to the Centre**



8.4 The Brothers of Charity has repeatedly stated that inadequate funding has been a barrier to providing appropriate services at the Centre. The Brothers of Charity has informed the Commission that since 2003-2004 it has been carrying a core funding deficit as a result of responding to emergency situations that arose, such as the setting up of “wraparound” services at the Centre and other

<sup>358</sup> Letter from the Department of Health to the Commission, dated 14 December 2009.

health and safety concerns noted in this report.<sup>359</sup> In a letter to the Commission the Brothers of Charity summarised the effects of its funding deficit as follows:

Finding funds to support the core funding deficit balance of €689,900 ...for the total Brothers of Charity Galway (€279,500 for the John Paul Centre only) is handled by the Galway Services Senior Management Team. This requires a demoralising regime of continuing a very tight management of spending. It involves, be it planned or opportunistic, the delayed implementation or short-term reduction of service provision – in effect “robbing Peter to pay Paul.”<sup>360</sup>

8.5 The Brothers of Charity later informed the Commission that in light of a subsequent HSE decision, the proportion received was in fact €478,200 rather than €279,500.

8.6 The Brothers of Charity has informed the Commission that the funding deficit is the shortfall between the funding expectations reflected in its service plan and actual funding received. As it is the policy of the Brothers of Charity not to incur a financial deficit (in the form of a financial debt) the funding deficit is dealt with by realigning planned services to income actually received, which has sometimes led to the curtailment of services.<sup>361</sup> In dealing with this deficit in 2009 the Brothers of Charity has advised the HSE that the break-even position for the year is dependent on once off savings of €764,338. It further advises that the strategy of the Brothers of Charity is to maintain existing service levels at appropriate standards and to respond in some way to people in urgent need of services, noting, however, that it is not possible to predict how such emergency

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<sup>359</sup> See Chapter 6.

<sup>360</sup> Letter from the Brothers of Charity to the Commission, dated 28 March 2008. The Brothers of Charity recently advised the Commission that this letter assumed that the Centre would receive proportionally €273,500 from a HSE allocation of €675,000 towards the Brothers of Charity Galway’s total core funding deficit of €1,364,900. It informed the Commission that a HSE decision letter of 1 August 2008 assigned the allocation of €675,000 granted €74,800 to the Centre and the balance of €600,200 to cover core deficits associated with Kilcornan Services. Accordingly, the amount of €279,500 for the Centre only should be corrected to read €478,200 (€279,500 + €273,500 - €74,800: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>361</sup> In this regard, the Brothers of Charity stress that its first approach is always towards Value For Money (VFM) measures and the curtailment of indirect costs: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

needs will impact on the situation, and the likely scarcity of funding for new service developments.<sup>362</sup>

8.7 In response to its on-going funding crisis, the Brothers of Charity has also engaged in a policy of delaying or not filling HSE approved staff posts.<sup>363</sup> Such posts have included psychologists, social workers, speech and language therapists, occupational therapist, and physiotherapists.<sup>364</sup>

8.8 Further, members of the Parent Group have raised their concerns in relation to the funding of the Centre and in particular the negative effect they believe the lack of funding has had on staffing levels and the availability of multidisciplinary supports.

**Parent: Phone Interview with Commission - 1 July 2009**

I am very concerned about the funding cuts to the John Paul Centre. The Centre has never had enough funding, even when the economy was going well, and it seems to me that it is the most vulnerable who should be most protected, are the ones who suffer most.<sup>365</sup>

**Part Two: HSE funding (Capital and Non-Capital)<sup>366</sup>**

***The Funding Framework***

8.9 The HSE provides the main source of funding to the Brothers of Charity, which in turn makes up the core income of the Centre, this funding coming from the budget allocation in any specific year, along with the approved level of staffing. In 2009, overall expenditure at a national level by the HSE on disability

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<sup>362</sup> Brothers of Charity letter to the Commission, dated 7 September 2009.

<sup>363</sup> This is supported in documentation provided by the HSE to the Commission in correspondence dated 17 October 2008.

<sup>364</sup> *Ibid.*

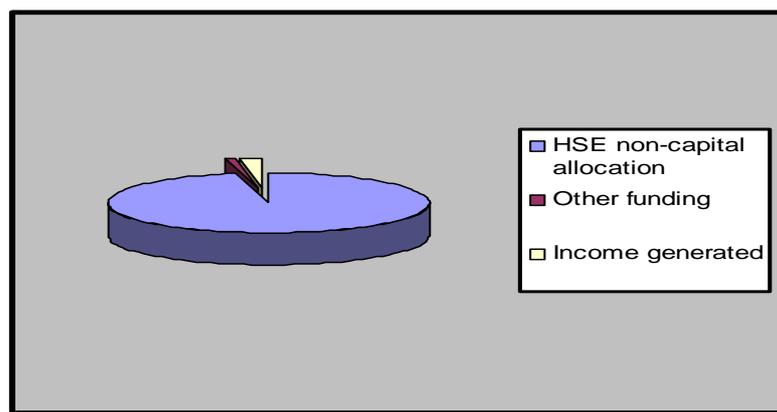
<sup>365</sup> Parent 1, telephone interview with the Commission dated 1 July 2009.

<sup>366</sup> Capital expenditure generally refers to one-off large scale fixed assets. Traditionally capital items mean land, buildings, vehicles, large scale office equipment, and essentially all items that are subject to depreciation in the accounts. Non-capital costs refer to the day to day spending on salaries (pay items), office supplies, light and heat, telephone etc (non-pay items).

services was €1.564 billion, of which €1.18 billion was funded to non statutory agencies. In 2009, €9.2 million was allocated to the Centre under HSE funding.<sup>367</sup> The 1996 Enhancing the Partnership Report provided the framework to govern the allocation of funding from the HSE to voluntary bodies in the State.<sup>368</sup> A Protocol set out in the Enhancing the Partnership report governs the funding relationship between the HSE and the Brothers of Charity.

8.10 In addition to the policy matters set out in the Enhancing the Partnership report, sections 38 and 39 of the Health Act 2004 are the primary legislative provisions under which funding is made to voluntary bodies in the State by the HSE.<sup>369</sup> Section 38 provides that before entering into an agreement for the procurement of services with a voluntary body, the HSE shall determine the maximum amount of funding it proposes to make to the service provider and the level of services it expects to be provided for the funding. Section 39 enables the HSE to give assistance to bodies that provide a service similar or ancillary to a service that the HSE may provide.<sup>370</sup>

**Figure 5: Breakdown of funding sources to Brothers of Charity Galway**



<sup>367</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>368</sup> *Enhancing the partnership : report of the working group on the implementation of the health strategy in relation to persons with a mental handicap*, Department of Health and Children 1997; see Chapter 6. The report was endorsed by the Minister for Health in 1997.

<sup>369</sup> See also Chapter 5.

<sup>370</sup> As set out in Chapter 5, prior to 31 December 2004, the principle legislative provisions under which payments were made to non profit disability providers were section 65 of the Health Act 1953, section 26 of the Health Act 1970 and section 10 of the Health (Eastern Region Health Authority) Act 1999.

## *The HSE Vote*

8.11 As stated above, the main source of funding to the Brothers of Charity comes from Vote 40 of Government Expenditure (“the HSE Vote”).<sup>371</sup> The HSE Vote is divided into a capital and non-capital allocation and is determined on a roll forward of the previous year’s basic allocation with adjustments.<sup>372</sup> The amount to be allocated in the HSE Vote is first arrived at following negotiations between the Minister for Health and the Minister for Finance, before being voted on by Dáil Éireann.<sup>373</sup> It is then the responsibility of the HSE to determine the amount to be allocated to voluntary service providers, including the Brothers of Charity, at a local level.<sup>374</sup>

## *The allocation of funding*

8.12 Under the Health Act 2004 the HSE is required to draw up a National Service Plan (“NSP”) outlining the type and volume of health and personal social services to be provided within the allocated HSE Vote. Once it is adopted by the

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<sup>371</sup> In the State, all money for voted services, such as the HSE Vote are provided through Government Estimates for those services in the course of the year. Where the financial estimates are agreed by Government, they are then given statutory effect in an annual Appropriation Act. Prior to 2005 and the establishment of the HSE, the Health Estimates were directly allocated to the Department of Health, under Vote 39 of Government. However, with the setting up of the HSE in 2005, a separate HSE Vote (Vote 40) was established, as the HSE became directly responsible for the management and delivery of health and personal social services.

<sup>372</sup> Adjustments to the Vote might include agreed new development funding, pay and staff increments and inflation. They may also include cuts to budgets. The Brothers of Charity has advised the Commission that since 2003, with the exception of one year, its allocation from the HSE always suffered “Value for Money” cuts and/or similar cuts in funding: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>373</sup> In response to a Parliamentary Question, the Minister for Health explained the process as follows: “The funding for the HSE is agreed each year by Government as part of the Estimates process which includes negotiations between the Minister for Finance and myself with the support of our respective Departments. The Estimate for the HSE is subsequently put before the Dáil for approval. Operational responsibility for the management and delivery of health and personal social services is a matter for the HSE and funding for the services once approved by Government is provided within its Vote 40”: Dáil Debates, 29 January 2009.

<sup>374</sup> In September 2009, the Department of Health announced the establishment of a Steering Group to oversee a review of the efficacy and effectiveness of Disability Services in Ireland under a Value for Money and Policy Review Initiative 2008–2011. The review is stated to be to for the purpose of assessing how the current services for people with disabilities meet their objectives and facilitate the future planning and development of service. See [www.dohc.ie/press/releases/2009](http://www.dohc.ie/press/releases/2009).

HSE, the NSP is submitted to the Minister for Health for approval.<sup>375</sup> In respect of service requirements and spending on persons with disabilities the NSP is informed by the National Intellectual Disability Database (“NIDD”) and the counterpart National Physical and Sensory Disability Database.<sup>376</sup> Based on this data the HSE will provide the total financial allocation for the relevant year. However, as noted in Chapter 6, the HSE are aware that both databases are not necessarily a true reflection of the current service needs to persons with a disability in the State as the information contained on the databases are supplied on a voluntary basis:

The needs of people with disabilities are identified and planned for through the National Intellectual Disability Database and the National Physical and Sensory Disability Database.

...

Information contained on both databases consist of information supplied on a voluntary basis by people with disabilities or their families, and may not be a complete and accurate picture of either service delivery or needs. The HSE, with the DOHC, have identified the need to review the information and data collection requirements in respect of disability services in the context of the introduction of the Disability Act.<sup>377</sup>

8.13 When the NSP receives Ministerial approval it is the HSE's responsibility to ensure that the national budget and the NSP “cascade” down through the organisation, so that ultimately each service unit has a budget and set of service objectives which are consistent with the budget.<sup>378</sup> However, it is clear this does not always happen. It was noted in the 2007 Annual Report of the Comptroller and Auditor General, that as a result of a net overspend on its budget the HSE

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<sup>375</sup> Section 31 of the Health Act 2004.

<sup>376</sup> The Brothers of Charity informed the Commission that a person with an intellectual disability is recorded only on the NIDD, notwithstanding the fact that he or she may have a physical and or sensory disability. It pointed out that the Physical and Sensory Disability Database is confined to people not classified with an intellectual disability. It also advised of the role of service providers and the HSE in keeping the database up to date, as discussed in Chapter 6: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>377</sup> HSE National Service Plan 2009 at p. 34. It is noted that all service level agreements between the Brothers of Charity and the HSE have required that relevant data must be provided to the NIDD by the Brothers of Charity to inform the HSE in respect of service needs of the individuals in the Centre, and the Brothers of Charity has advised the Commission how this occurs in practice, see Chapter 6, para. 6.16.

<sup>378</sup> Annual Report of the Comptroller and Auditor General 2007 at p. 131.

delayed certain service developments including disability services in the amount of €31 million and mental health services in the sum of €22 million.<sup>379</sup>

8.14 At a local level the service level agreement is the medium through which the HSE West and the Brothers of Charity Galway negotiate the level of funding required for its services within its catchment area. In practice, funding issues are raised during service level agreement review meetings between senior management of the Brothers of Charity Galway and senior management of HSE West which take place on a quarterly basis.

8.15 As part of its communications with HSE West in respect of its non-capital allocation, the Brothers of Charity Galway at the request of the HSE, submit the aggregated estimates of its expected non-capital service needs (i.e. pay and non-pay) for the upcoming financial year, which includes the estimated funding requirements for the Centre. The HSE reviews the estimates and determines the block allocation to the Brothers of Charity Galway. On foot of this, the Brothers of Charity in turn prepares a Service Plan which outlines how it proposes to distribute the block allocation to its service providers including to the Centre. The Plan is then approved if appropriate by the HSE.<sup>380</sup> Where new service developments are to be funded as part of the Service Plan, this requires further HSE scrutiny by the Consultative and Development Committees, as provided under the Enhancing the Partnership report (see below).<sup>381</sup> The Centre's budget is devolved down to house-level (bungalows), but is not individualised after that. The Brothers of Charity has advised the Commission that one of its services in the United Kingdom has adopted a "person centred funding model", where funding is individualised, but it does not operate in Ireland as yet. However, the Brothers of Charity has stated that this is an appropriate model to emulate.<sup>382</sup>

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<sup>379</sup> *Ibid.*

<sup>380</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009; letter from the HSE to the Commission, dated 11 December 2009.

<sup>381</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>382</sup> Meeting between the Commission and the Brothers of Charity 20 May 2009.

## *The Incremental Determination Process*

8.16 Although the Brothers of Charity submits estimates outlining its funding requirements, the HSE non-capital allocation to the Brothers of Charity has been historically established through an incremental determination process, also known as the Existing Level of Service funding. Incremental budgeting is the process by which the previous year's total non-capital allocation forms the current year's baseline determination in order to maintain the same level of services in the current year and to ensure no regression in service provision.<sup>383</sup> The baseline determination is then adjusted down by certain 'once-off' grants that were specific to the previous year.<sup>384</sup> Also additions are made for known and approved 'new service development' funding specific to the current year.<sup>385</sup> The baseline figure is also adjusted up or down by reference to pay awards, increments, non-pay inflation, "value for money" targets, and other current year costs. The final determination of funding is set out in the HSE's Letter of Determination.<sup>386</sup>

8.17 The Brothers of Charity has advised the Commission of its concerns in respect of the incremental system for costing services as it does not necessarily

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<sup>383</sup> Letter from the HSE to the Commission, dated 11 December 2009.

<sup>384</sup> The Centre has been provided with "once off" grants from the HSE in circumstances where crisis or emergency situations arise or in respect to its core funding deficit. In making an application for "once off" funding the Brothers of Charity is required to make a separate submission to the HSE. Where a "once off" grant is provided in a previous year, it will then be deducted from the following year's allocation. In 2006, the Minister for Health invested €10 million to address core under funding and core staffing issues in services for people with disabilities provided by the voluntary sector, and in 2008 a further €5 million was invested. In August 2006 the Brothers of Charity was required to submit "a detailed questionnaire collating financial information for the past three years" to the HSE in respect of this funding programme. In 2006, 2007, and 2008 the HSE supported the Brothers of Charity by providing "once-off" grants of €675,000 per year. The Brothers of Charity advised the Commission that in order for it to be provided with funding in relation to the "core deficit" funding on an on-going basis, it is required to undergo an in-depth audit. It advised that in August 2008, the HSE put the €675,000 portion of the 2006 core funding on an ongoing funding basis. The Brothers of Charity informed the Commission that proportionately, €273,500 is provided to the Centre on an annual basis. In 2009, the Brothers of Charity identified their core funding deficit carried from the previous year at €605,500, but when added to the 3% cut in its funding for 2009 and the non provision for increments and inflation this gave a current funding shortfall of €2,370,176: letters from the Brothers of Charity to the Commission, dated 17 October 2008 and 30 November 2008.

<sup>385</sup> New service development funding is considered further below.

<sup>386</sup> Set out in the Service Level Agreement 2009.

reflect the funding needs of the current individuals within the Centre.<sup>387</sup> The Brothers of Charity advised the Commission that fundamental to the incremental system is the funding which established the first year's budget for a particular service. In terms of the Centre, which was established in 1980, the first year's budget was negotiated on the basis that at the time the Centre was providing day and residential services to children:

It is probable that this funding was then negotiated with the Department of Health on the global cost associated with running a congregated campus based facility for children. No doubt, understandings of service delivery of that time and the Governments funding capacity greatly influenced the first year budget for the John Paul Centre.<sup>388</sup>

8.18 Therefore, the current baseline funding allocated under the incremental determination process for the Centre still has links to the baseline established almost thirty years ago in relation to a service that has changed considerably in the interim. It is noted that other funding has been injected into the service over the years, through for example, new service development funding, Department of Education funding, funds transferred by the Brothers of Charity itself from other services in the early 1990s and the non-filling of some vacancies in the Centre. The HSE current policy/ embargo on filling vacancies has also had a (positive) budgetary consequence.<sup>389</sup> However, the method of allocating the baseline funding does not appear to be directly linked to any individual assessment of needs of the current individuals in the Centre.

8.19 The 1996 Enhancing the Partnership report recommended that a service costing mechanism for persons with differing levels of dependency should replace this incremental system:

The present methodology for arriving at a dependency unit cost is not satisfactory. It has more often than not been based on an average cost of providing a service to a group of persons without taking account of the differing dependency needs at a given point in time. However the dependency needs

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<sup>387</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>388</sup> *Ibid.*

<sup>389</sup> HSE HR Circulars 01/2008 and 001/2009. The moratorium was extended to voluntary bodies in 2009.

within such a group may alter significantly without any revision of the funding base. A mechanism is needed that will enable the services provided to a broad range of persons with differing dependency. The working group recommends that the questions of the establishment of a mechanism to cost accurately the broad range of services required by persons with a mental handicap be examined and resolved at national level at the earliest possible time and that the Department continue to provide management support and direction for the development of service agreements and of new methodologies for costing services.<sup>390</sup>

8.20 In 2005 the Comptroller and Auditor General restated the recommendations in the Enhancing the Partnership report as follows:

The existing incremental funding arrangement, with its weak linkage to levels of identified needs, means that funding may not always be targeted to areas of greatest need. Costing methodologies should model activity-based costs of service delivery.

...

If the health service is to move to a needs based service there will be a need for greater clarity around the costs of services and the services rendered to the clients supported. It is unlikely that simple head counts will supply this need. There is, however, a need to evolve a costing and funding mechanism which is sensitive to the mix and cost of inputs associated with the various levels of care given to persons maintained by public and non-profit organisations.<sup>391</sup>

8.21 At the time of writing this report, the incremental system for the determination of the HSE non-capital funding remains in place, as does the Brothers of Charity's system of providing aggregated estimates (which has to be based on a HSE template). Both the Enhancing the Partnership report and the Report of the Comptroller and Auditor General highlight the need to develop costing methodologies which are sensitive to, and targeted at, the differing needs of individuals. Also at a national level the problem is reinforced as the NIDD continues to inform the allocation of the Health Vote in respect of disability services, a system which the HSE has acknowledged does not adequately reflect the actual service requirements of persons with intellectual disabilities in the State.

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<sup>390</sup> Enhancing the Partnership Report, *ibid.*, at para. 5.15.

<sup>391</sup> Comptroller and Auditor General Report (2005), at p. 24.

### *“Value for money” savings*

8.22 As noted above, the HSE non-capital allocation to the Brothers of Charity also takes into account government policy on “value for money” savings targets (“VFM”) as are set out in the annual Health Estimates. VFM refers to a programme put in place to seek the maximum benefit from spending within available resources. It has been defined by Government as *“the correct balance between economy, efficiency and effectiveness relatively low costs, high productivity and successful outcomes”*.<sup>392</sup> The Health Act 2004 requires the HSE to maximise the return on health investment and *“to use resources available to it in the most beneficial, effective and efficient manner to improve and promote and protect the health and welfare of the public”*.<sup>393</sup> VFM is not exclusive to the HSE but is applied across all government departments in relation to their annual funding allocation.

8.23 VFM savings that relate to the HSE are decided by the Department of Health in line with the Department of Finance guidelines on an annual basis and specific VFM requirements are set out in the NSP in line with the HSE Vote. The Department of Health states that while it sets out overall VFM savings and targets to be achieved, it has instructed the HSE to ensure that VFM efficiencies should not impact negatively on frontline services. It states that it is a matter for the HSE and service providers, where appropriate, to ensure that VFM targets are achieved without impacting on frontline services.<sup>394</sup> The HSE has developed a VFM framework which has set a target of €500 million savings for the period 2007-2010.<sup>395</sup> In 2007 it set up a VFM Unit within the HSE to monitor these targets. In 2009 an overall target of €115 million was set, with a specific one percentage point cut in funding to all voluntary disability providers.<sup>396</sup>

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<sup>392</sup> The HSE National Service Plan 2009, pp. 5-6.

<sup>393</sup> Section 7 of the Health Act 2004.

<sup>394</sup> Letter from Department of Health to the Commission, dated 11 December 2009.

<sup>395</sup> In light of ongoing cuts, these savings may be subject to further budgetary constraints.

<sup>396</sup> The Brothers of Charity advised the Commission that the VFM overall target of €115 million was part of an efficiency/policy savings measures totalling €420 million: letter from the Brothers of Charity to the Commission, dated 30 November 2009, citing a Department of Health document

8.24 The HSE states that VFM savings are delivered through a range of specific plans designed to ensure that frontline services are protected wherever possible from any negative impact of cost management programmes.<sup>397</sup> For example, in the 2009 NSP the HSE referred to the VFM cuts in relation to all non-statutory disability providers and recommended that to avoid a negative impact on frontline service, non-statutory disability providers might achieve savings in the following areas:

- Further significant efficiencies in advertising, PR, consultancy, travel costs not related to clinical service delivery, etc.
- Significant reduction in management and administration costs to cover all areas of management, including clinical management
- Review of transport arrangements, procurement, administration functions, staff training.<sup>398</sup>

8.25 Such guidelines reflect those made across the public service.

8.26 Further, the HSE advised the Commission that in terms of service providers meeting the VFM targets, no service reduction can take place without the approval of the HSE, and that the service provider must demonstrate that *“all other measures have been explored to achieve these savings”*.<sup>399</sup> This guidance was provided to the Brothers of Charity and similar service providers by the HSE.<sup>400</sup>

8.27 However, it is unclear how the HSE ensures these guidelines are achievable so that front-line services are not in fact negatively affected.<sup>401</sup> The Brothers of Charity has raised its concerns with the HSE in respect of the “crude strategy” of VFM, in particular where it states it is already carrying a funding

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entitled *Health Estimates for 2009* 14 October 2008 at [www.dohc.ie/press/releases/2008/20081014b.html](http://www.dohc.ie/press/releases/2008/20081014b.html)

<sup>397</sup> HSE National Service Plan 2009, at p. 6.

<sup>398</sup> *Ibid.*, at p. 77. Opportunities to amalgamate non front line service provision was also cited by the HSE: letter from the HSE to the Commission, dated 11 December 2009.

<sup>399</sup> Letter from the HSE to the Commission, dated 7 September 2009.

<sup>400</sup> Letter from the Brothers of Charity to the Commission, dated 7 September 2009.

<sup>401</sup> In a letter issued by the HSE to the Brothers of Charity dated 9 March 2009, it is stated that the HSE does not intend to take a prescriptive approach to how savings are achieved other than the government requirement that all public funded agencies reduce management/ administration payroll costs by 3% in 2009.

deficit.<sup>402</sup> The Brothers of Charity received a total of a three percentage point (3%) cut in its HSE allocation for 2009, including the one percentage point VFM cut.<sup>403</sup> In a letter to the Commission the Brothers of Charity described how the current budgetary cuts would affect the services to individuals at the Centre:

In the beginning of 2009, a 3% cut was imposed on the Brothers of Charity Service. The Galway service Management team requested that each area would look within their budget and forward a proposal indicating how they could achieve a 3% cut to their budget, if at all possible. This definitely would have a serious and immediate impact in terms of dilution of services, particularly in some areas of the John Paul Services where they are already working in a deficit. The most likely initial target would be our adult respite services. This would have a severe impact on the already stressed families who have been waiting for 10 years for residential services for their adult sons and daughters. To date in 2009 we have not had to implement these cuts but in future years these budgetary restrictions may need to be utilised.<sup>404</sup>

8.28 In December 2009, the HSE advised the Commission that the Brothers of Charity provided ongoing reports to the HSE Galway on how VFM saving were being implemented. According to the HSE, these reports demonstrated that VFM was not impacting “seriously” on service delivery. It is the view of the HSE that while VFM efficiency savings targets challenged service providers to review work practices “frontline services were not significantly impacted”.<sup>405</sup>

8.29 In a synopsis of its service plan 2009 the Brothers of Charity detail cost containment measures to deal with the shortfall in funding and certain measures, such as the reduction in respite services, night cover and swimming pool availability would seem to inevitably impact on front line services. A further measure was not to open a community group home which had already been

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<sup>402</sup> Letter from the Brothers of Charity to the HSE (2003) in respect of VFM cuts.

<sup>403</sup> The 3% cut is made up of the 1% VFM cut in 2009 together with a further 1% cut advised to the Brothers of Charity by the HSE in March 2009 which was applied in light of the worsening financial situation of the HSE at that point, and which was applied for the full year 2009. A further once off contribution back to the HSE Galway Primary Community and Continuing Care section in 2008 was sought from service providers in 2008, but it appears this cut was then made permanent. Letter from the Brothers of Charity to the Commission dated 7 September 2009. In December 2009, the HSE advised the Commission that in 2008 and 2009, the Government and HSE required efficiency savings measures from all disability service providers equal to 3% of their budget: letter from the HSE to the Commission, dated 11 December 2009.

<sup>404</sup> Letter from the Brothers of Charity to the Commission, dated 14 July 2009.

<sup>405</sup> Letter from the HSE to the Commission, dated 11 December 2009.

closed since 2007 and which could cater for five individuals.<sup>406</sup> The Brothers of Charity advised the Commission that a number of these measures, including night cover and swimming pool availability were considered by the Brothers of Charity to be VFM measures notwithstanding the fact that these measures impinged on existing service practice.<sup>407</sup>

8.30 It appears that although the HSE states that it provides guidance to service providers in respect of the implementation of VFM cuts “to ensure” that front-line services are not negatively affected, this may still occur in practice. Indeed the Brothers of Charity has argued that in the context of their past and current funding crisis the imposition of VFM cuts unavoidably affects frontline services to individuals.

### ***New Service Development***

8.31 The Brothers of Charity has also been able to avail of additional funding from the HSE to provide new services or to enhance current services to persons at the Centre. Since 1997 the Government has been investing additional funding in respect of developing and enhancing service provision for persons with an intellectual disability and/or autism under its new service development programme<sup>408</sup>. As noted previously, in 2005, the Government made a commitment to a Multi-Annual Investment Programme (“MAIP”) as part of the National Disability Strategy under which it would develop and enhance certain disability specific services over the period of 2006 - 2009. The commitments included the development of new residential, respite and days places for persons

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<sup>406</sup> Letter from the Brothers of Charity to the Commission, dated 7 September 2007.

<sup>407</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>408</sup> According to the Department of Health, between 1997 and 2005, the Government invested €464 million into services for persons with disabilities and those with autism. The Department of Health has advised that this funding has been used to a) put in place a range of new residential, respite and day services; b) enhance and develop multidisciplinary and specialist support services; c) undertake a programme to transfer persons with intellectual disability and those with autism from psychiatric hospitals and other inappropriate settings to more appropriate care settings; and d) meet identified needs of existing services such as changing needs arising from elderly profile of those in long term residential care, medical conditions or challenging behaviour: letter from the Department of Health to the Commission, dated 14 December 2009.

with intellectual disabilities and autism in each of the years covered by the programme. The HSE has described the “transforming effects” of new service development funding insofar as it augments annual Incremental or Existing Level of Service funding.<sup>409</sup>

8.32 The Department of Health advised the Commission that the cumulative revenue and capital value of the MAIP programme from 2006 until 2009 would be €900 million.<sup>410</sup> The Department states that an extra €75 million was provided in both 2006 and 2007 for the development of services for physical and sensory disability and intellectual disability and that €45 million in capital funding was provided in both years.<sup>411</sup> Both the HSE and the Department advised that by the end of 2008 (at which time the MAIP came to an end), new service development funding had provided 804 new residential places, 307 new respite places and 1,863 new day places for intellectual disability services in the State. In addition, a total of 406 existing residential places, 61 existing respite places and 195 existing day places in the intellectual disability services have been enhanced.<sup>412</sup>

8.33 In the period 2006 to 2008, over €550 million was allocated to the HSE under MAIP, of which over €425 million was for disability services and over €125 million for mental health services.<sup>413</sup> However, the Department of Health has

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<sup>409</sup> Letter from the HSE to the Commission, dated 11 December 2009. The MAIP had been intended to continue until the end of 2009, but came to an end in 2008.

<sup>410</sup> *Ibid.* Letter from the Department of Health to the Commission, dated 7 February 2006.

<sup>411</sup> Letter from the Department of Health to the Commission, dated 14 December 2009. The Department also advised that a further €50 million was allocated for disability services in Budget 2008, of which €17 million was returned to the Exchequer in July 2008 as part of the Department’s budgetary savings contributions.

<sup>412</sup> *Ibid.*; letter from the HSE to the Commission, dated 11 December 2009.

<sup>413</sup> In addition to the services outlined in the main text of this report, new service development funding was used to develop multi-disciplinary and specialist support services both to enhance existing service provision and support the introduction of Part 2 of the Disability Act 2005, which was commenced for children aged under 5 years in June 2007; to continue the programme of transferring persons with intellectual disabilities, and those with autism, from psychiatric hospitals and other appropriate setting to more appropriate care settings; and to meet the identified needs of existing services such as changing needs arising from the increasingly elderly profile of those in long term disability residential care, medical conditions or challenging behaviour: see letter from the Department of Health to the Commission, dated 11 December 2009.

stated that “due to the current economic situation, it has not been possible to provide development funding for additional services in 2009”.<sup>414</sup>

8.34 The HSE informed the Commission that the provision of new service development funding to service providers is made on the basis of a “nationally agreed average cost per place” plus a determination of individual needs regarding the level of support required to provide services for persons who are allocated funding. The HSE stated that the average cost per place is determined by the amount of funding allocated under MAIP and the number of new and enhanced residential, respite and day services which the Department of Finance and Department of Health had agreed to develop.<sup>415</sup> Thus the average cost is dependant on the level of funding provided and does not consider the nature and level of the disability, or the service required for an individual.<sup>416</sup>

8.35 The Department of Health and the HSE created Protocols which govern the implementation of this new service development funding (New Service

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<sup>414</sup>Dáil Debates, 28 April 2009, response of John Moloney T.D., Minister of State, Department of Health. It is noted that in Budget 2009 an additional €20m was allocated for health and education services for children with special educational needs. €10m of this allocation was to the HSE, and €10m to the Department of Education and Science to provide services for children with special educational needs.

<sup>415</sup> Letter from the HSE to the Commission, dated 15 September 2009.

<sup>416</sup> In 2004 and again in 2006, HSE West and its regional Consultative Committee contracted Trutz Haase, Social & Economic Consultants, to identify a formula for allocating new development funding “between counties and services areas” on an “objective and equitable basis”. In 2004, noting that there was no nationally agreed costing unit, Trutz Haase recommended that a joint study be undertaken by the Department of Health, the HSE and service providers to establish an agreed matrix unit cost for residential, day and respite services for persons with intellectual disabilities; letter and enclosures from the HSE to the Commission, dated 6 October 2009. In the HSE letter to the Commission, dated 15 September 2009, it advises that no national costing system for services for persons with intellectual disability have been established, although it states that the new service arrangement introduced in 2009 contains more detailed information on the number of residential, respite and days services which will facilitate the capitation of average cost per place. However, the Brothers of Charity pointed out that the number of residential, respite and day places outlined in Schedule 3 of the Service Arrangements are tied to the current level of funding: letter from the Brothers of Charity to the Commission, dated 30 November 2009. As the funding levels to Centres are arguably understated in these agreements, there is no guarantee that more detailed information will ensure the correct capitation of average cost per place on an individual needs basis. See also National Federation of Voluntary Bodies October 2004 publication entitled “*Analysis of Need for Services & Supports for People with Intellectual Disabilities 2005 – 2008*”.

Development Protocols).<sup>417</sup> The New Service Development Protocols require that seventy percent (70%) of funding provided for any given year from the additional investment funding must be allocated to developing new residential services, while the remaining thirty percent (30%) is to be allocated to enhancing residential services for people *already* within a service. The New Service Development Protocols also state that in respect of day service funding, priority must be given to the provision of day services for school leavers.<sup>418</sup>

8.36 The HSE distributes a percentage of the Government Vote on new development funding to the Regional Offices of the HSE.<sup>419</sup> The Brothers of Charity advised the Commission that this money is distributed on the basis of county population rather than individuals with intellectual disability per county population, or the intellectual disability county needs.<sup>420</sup> The HSE informed the Commission that when the allocation of funding to the large disability service providers in the voluntary sector transferred from the Department of Health to the former Health Boards in the late 1990s, a “partnership framework” was put in place and resulting from that Consultative and Development Committees were established which comprised the Health Board and the intellectual disability service providers. The HSE stated that these committees had significant influence in the Health Boards and subsequently in the HSE’s determination of needs within the different localities and that it allowed service providers directly input into prioritisation and allocation of development funding.<sup>421</sup> At regional level, the HSE West area established a Development Committee, which is made up of the senior management of service providers and senior representatives of the

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<sup>417</sup> Protocols Governing the Implementation of and Reporting on the Proposed Multi-Annual Revenue and Capital Investment Programme for Services for People with Disabilities 2005-2009 (July 2005).

<sup>418</sup> *Ibid.*

<sup>419</sup> Letter with enclosures from the HSE to the Commission, dated 6 November 2008: Minutes of Consultative Committee; Minutes of Development Committee and Submission for Funding. The allocation of funding at a regional level was based on the 2004 and 2006 findings of Trutz Haase Economic and Social Consultants.

<sup>420</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>421</sup> Letter from the HSE to the Commission, dated 11 December 2009.

HSE West functional area to decide on matters including how new service development should be allocated.<sup>422</sup>

8.37 In 2004, the HSE West Development Committee agreed on a prioritisation process in respect of allocating new service development funding to individuals.<sup>423</sup> The prioritisation process refers to a system whereby a service provider lists individuals within their service who it considers require either a new place or an enhanced service. The prioritisation form outlines 6 criteria for prioritising service needs as set out below:

**Tick appropriate Criteria under which the referral is being made to Liaison Group<sup>424</sup>**

- Sudden unavailability of primary carer usually due to illness or death.
- Those whose current service is deemed inappropriate due to risk to their own or others' personal safety or well-being or because of concerns that they are experiencing neglect, emotional, physical or sexual abuse.
- Those whose situation is known to be very difficult and at risk of breaking down within the next 12 months
- Those in service, who have an immediate urgent need for a new element of service, and as adults have been waitlisted for 24 months, or in the case of children have been waitlisted for 12 months, or longer, for this specific service.
- Those who are not in receipt of any service or whose current service is due to cease within the next 12 months.
- Those whose health or wellbeing is seriously compromised in the absence of appropriate supports.

8.38 However the Brothers of Charity informed the Commission that the disability agencies in the County Galway area have been operating from the top

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<sup>422</sup> The terms of reference of this Committee were set out in the Enhancing the Partnership report.  
<sup>423</sup> In 2004 the Western Health Board and the Consultative Committee for Intellectual Disability and Autism identified the need to develop an agreeable formula to divide new development funding between counties and service areas on an objective and equitable basis.  
<sup>424</sup> Set out in Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

two criteria alone for the past number of years, as new development funding was inadequate to address the scale of unmet needs and waiting lists in the region.<sup>425</sup>

8.39 The senior management of the Brothers of Charity will prioritise each individual at the Centre on the basis of their barrier forms as set out in individual personal outcome plans. The prioritisation forms are initially submitted to a Prioritisation Committee, made up of the Operational Managers from service providers within the Galway area, and is chaired by the HSE Galway Disability Manager. It appears that recommendations from the Prioritisation Committee are then submitted to the Galway County local planning team, comprised of Chief Executives Officers of service providers in the Galway area and HSE management, who will then make their final recommendations on priority cases in respect of the Galway area to the HSE. The HSE makes the final determination and allocation of the new development funding based on these proposals.<sup>426</sup> It will be observed that this process is cumbersome and not guaranteed to result in the requested services.

8.40 In practice, the Brothers of Charity have stated that the New Service Development Protocol allocation of funding 70% and 30% has been difficult to draw down, where its main service requirements are to enhance the services of individuals and so there is less funding available than if it were developing new services. Further, the New Service Development Protocols provide that day service allocation must first benefit school leavers again excluding many persons in existing services. Figure 6 below illustrates how New Service Development funding was distributed in the Galway region in 2007.<sup>427</sup>

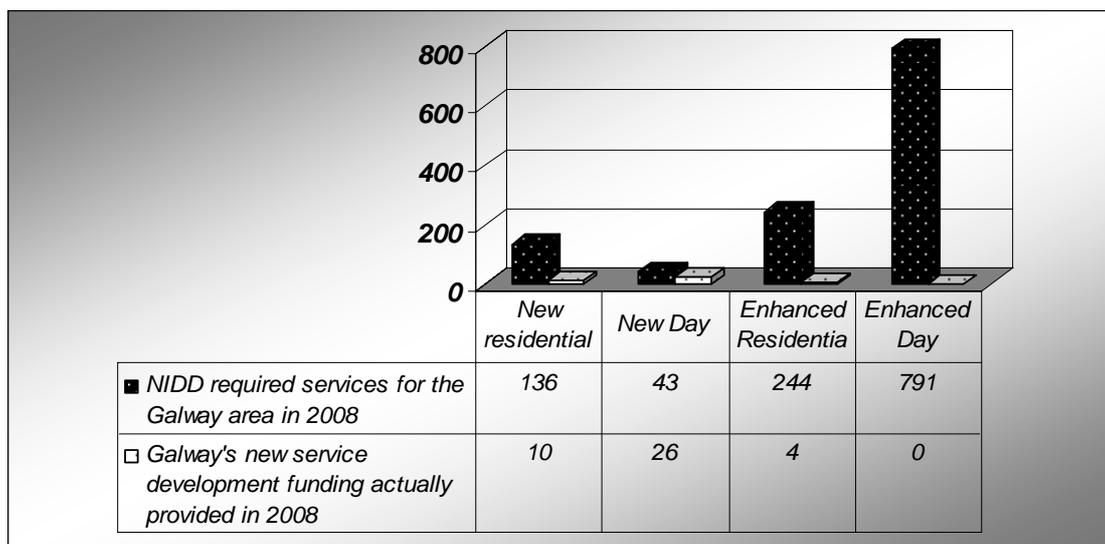
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<sup>425</sup> *Ibid.*

<sup>426</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

<sup>427</sup> Data provided by the Brothers of Charity in their letter to the Commission, dated 28 March 2008.

**Figure 6: New Service Development Funding - Galway Region 2008**



8.41 In 2007 a report commissioned by the HSE (the McCoy report) also noted its concerns about the insufficient distribution of funding to individuals who require an enhanced service, and recommended that a review of the protocol should be undertaken:

It is recognised that there is a concern that, due to the very significant and multi-annual investment programme in the area of disability and the associated concentration on the development of new services for persons who are not in receipt of services to date, the attention would not be focused sufficiently on the needs of the 3000+ people with significant disability who reside in segregated/campus based settings throughout the country.

For this reason a fundamental review should be undertaken by the Health Service Executive in partnership with the providers of all such services. Based on that review the stakeholders, which include the Department of Health and Children, the Health Service Executive, the voluntary organisations and the religious congregations should consider the development of a specific investment programme which would resource the transfer of the vast majority of such persons from campus style settings to community based settings.<sup>428</sup>

<sup>428</sup> HSE, Report of Dr Kevin McCoy on Western Health Board Inquiry into Brothers of Charity Service in Galway (November 2007) at p. 115; see Chapter 7.

8.42 A review of the New Service Development Protocol did not take place, and New Service Development funding to services for adults with intellectual disabilities was not provided within the Budget 2009.

8.43 From a review of the new service development distributed to the Centre between 2003 and 2008, it would appear that the bulk of the funding was allocated to school leavers (€316,000), the remainder of the funding was allocated to enhance one individual's service on health and safety grounds (€70,000) and to provide an emergency residential service due to the sudden death of a family carer (€87,500).<sup>429</sup> Thus, the Brothers of Charity are restricted to reacting to crisis situations as opposed to developing service provision to individuals at the Centre. The allocation of this funding appears to have deteriorated further where no new service development has been provided for adults apart from two cases in late 2009.<sup>430</sup> In 2009 the Commission requested a sample of eight personal outcome plans of individuals in the Centre. From the samples submitted, a 2009 personal outcome plan barrier form, provided by the Brothers of Charity, indicated that one individual who requires a full-time residential place will not receive this service as no new development funding has been allocated in 2009, stating that "*due to the current financial situation, there is no new development funding for 2009 and possibly none for the next year either. This has a serious impact on future service enhancement and development.*"<sup>431</sup>

### **Average Cost of Services**

8.44 It will be recalled that the Department of Health advised the Commission that the national average cost of providing a new residential place for a person

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<sup>429</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>430</sup> The Brothers of Charity advised the Commission in November 2009 that the HSE had recently confirmed that two emergency residential cases in the Centre were to benefit from €59,012 (full year) under Demographic Emergency Funding 2009: letter from the Brothers of Charity to the Commission dated 30 November 2009. The full amount of money applied for by the Brothers of Charity had been €194,000.

<sup>431</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

with an intellectual disability is approximately €80,000.<sup>432</sup> However, the HSE advised that no national costing system for services for persons with intellectual disability has been established.<sup>433</sup> The Brothers of Charity stated that its experience with the HSE was that while efforts are made to fund new services on the basis of costing individualised dependency needs, nevertheless, these attempts may be thwarted both by (i) the corporate administrative requirements of implementing a pre-set number of places for given amount of money (for example 4 residential places at an average of €80,000 each), and by (ii) the dearth of new service development funding (see above).<sup>434</sup>

8.45 In terms of the cost of the services in the Centre, in December 2009, the HSE advised that its 2009 allocation to the Centre was €9.2M, which provided (i) 54 residential places, (ii) 8 additional day places, (iii) 7 respite places and (iv) staffing complement to 170 WTE.<sup>435</sup> Also regarding service costs, the Brothers of Charity stated that an analysis of the data contained in Schedule 3 of the Service Level Agreement 2009 shows that average direct residential unit costs of the Brothers of Charity are equivalent to the Department of Health's national average cost per place of €80,000.<sup>436</sup> It stated that the direct full time residential unit costs of the Brothers of Charity range in value from a low of €23,600 to a high of €365,100 depending on the requirements of the individual. Figure 7 sets out the average direct service unit costs for services at the Centre, as provided by the Brothers of Charity.

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<sup>432</sup> Letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>433</sup> Letter from the HSE to the Commission, dated 15 September 2009.

<sup>434</sup> Letter from the Brothers of Charity to the Commission, dated 23 December 2009.

<sup>435</sup> "Whole time equivalent": letter from the HSE to the Commission, dated 11 December 2009. According to the Brothers of Charity, a separate audit report carried out by the HSE into the Kilcornan Centre found no resources that could be redirected within the Brothers of Charity Services: letter from the Brothers of Charity to the Commission dated 17 September 2009.

<sup>436</sup> Letter from the Brothers of Charity to the Commission, dated 23 December 2009. In its letter to the Commission dated 14 December 2009, the Department of Health indicated that the estimated figure for the national average cost of providing a new residential place for a person with an intellectual disability is approximately €80,000. On this basis, and with regard to the relevant expenditure figures provided to the Commission by the Brothers of Charity (see para. 4.14 above), the Department of Health questioned whether the average cost being paid by the HSE to the Brothers of Charity was not in excess of the national average figure for the number of persons with disabilities benefiting from the service. According to the Department of Health, "*in the absence of a robust financial analysis of the Centre's funding...the inferences in the analysis about underfunding of the service are at best, questionable*"; letter from the Department of Health to the Commission, dated 14 December 2009.

**Figure 7: Brothers of Charity estimation of service costs at the Centre**

Type of Service	Cost/ yr
Residential – integrated residential & day (John Paul Centre)	€158,613
Residential only - (Community Group Homes)	€83,449
Day only - (John Paul Centre)	€29,863

8.46 The Brothers of Charity advised that the service unit cost of multidisciplinary services to the Centre is more difficult to ascertain on the basis that while the cost per discipline is readily obtainable, the determination of an average individual (unit) costs would require the collection of data on the case load of each discipline, noting that this data varies from month to month. The difficulties in identifying average costings for residential, day and respite services and then accessing adequate funding based on individual needs for those services is thus apparent. These difficulties would appear to contrast with the incremental determination system which uses the previous year’s total non-capital allocation as the current year’s baseline determination, which may then be adjusted down.

***Funding of Staff and Employment Controls***

8.47 The HSE Vote also takes into account the national pay (i.e. staffing) costs for the HSE for the relevant year. The Minister for Health will approve the HSE national employment ceiling (the total staff to be employed by the HSE) and will set out specific employment controls in the annual Health Estimates. The employment controls are then given effect to through HSE circulars.<sup>437</sup> In 2006, the HSE introduced an employment control framework to ensure that staffing costs remained within the HSE Vote. A national monitoring body was set up, the National Employment Monitoring Unit (“NEMU”), to monitor and control these

<sup>437</sup> The Brothers of Charity advised that it always operated to employment ceiling since the time it was directly funded by the Department of Health and Children: letter to the Commission, dated 30 November 2009.

targets.<sup>438</sup> The Department of Health informed the Commission that employment increased in the provision of health services from 68,000 in 1997 to over 111,000 in 2008. It states that this increase is largely due to the significant funding provided in line with Government objectives, including the implementation of the Disability Act, commencement of the EPSEN Act, the roll-out of primary care teams and services for older persons. The relevant tables are set out in Appendix V.<sup>439</sup>

8.48 At the local level, HSE West and the Brothers of Charity agree the employment ceiling for its services on an annual basis which will take into account the HSE employment ceiling and any specific employment controls that have been set at the national level, such as job freezes or reductions.<sup>440</sup> In this regard, it is noted that since March 2009, the HSE extended a moratorium on the filling of most HSE posts to voluntary bodies.<sup>441</sup> However, the Department of Health provides for exemptions to the current employment moratorium that may be created within the overall staff ceilings.<sup>442</sup> Exempted positions include therapists, psychologists, social workers and emergency medical technicians, including delegated sanction for filling these posts.<sup>443</sup> The Department of Health has advised the Commission that up to 1,000 posts of therapists, psychologists, social workers and emergency medical technicians may be created between 2009 and 2010 “within the overall employment ceiling”. It also advised that redeployment and reassignment of existing staff in the HSE will also support the “reorientation” of care from hospitals to the community and to facilitate the development of integrated care.<sup>444</sup>

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<sup>438</sup> HSE HR Circular 01/2006.

<sup>439</sup> See Appendix V for further information on employment trends in the health sector. This data was provided by the Department of Health in its letter to the Commission, dated 14 December 2009. The Department also advised that an Employment Control Framework was agreed between the Departments of Health and Finance, in conjunction with the HSE, in December 2006.

<sup>440</sup> The employee ceiling for the year commencing 1 January 2009 for the Brothers of Charity Services Galway was 851.37, Service Plan 2009.

<sup>441</sup> HSE HR Circulars 01/2008 and 001/2009.

<sup>442</sup> According to the Department of Health, this is to maintain insofar as possible key services in respect of children at risk, older people and persons with a disability: letter to the Commission from the Department of Health, dated 14 December 2009.

<sup>443</sup> *Ibid.*

<sup>444</sup> Letter to the Commission from the Department of Health, dated 14 December 2009.

8.49 The Brothers of Charity outlines its staffing requirements during service level review meetings, in its funding applications to the HSE and in its annual service plan. The Brothers of Charity Galway's annual service plan will estimate the staffing needs for each service unit (i.e. residents' bungalow). It also provides the global pay costs for each multidisciplinary department for the Brothers of Charity Galway. As required under Schedule 3 of the new Service Arrangement, general staffing is devolved down to individual service units. However, neither the general staffing nor the multidisciplinary staff needs are broken down to the individual needs of persons at the Centre.<sup>445</sup>

8.50 However, in separate funding applications such as for emergency "once off" grants, or new service development funding, the Brothers of Charity is required to apply separately and identify the number and type of posts required to provide services to an identified individual or individuals. This must be approved by the HSE National Directorate and forwarded to NEMU.

### ***The Allocation of HSE Capital Funds***

8.51 The HSE has provided capital funding to the Brothers of Charity through the HSE Capital programme which does not form part of the service level agreement.<sup>446</sup> However, the service level agreement states that the Brothers of Charity cannot undertake any capital project without the prior consent of the HSE. Thus, the Brothers of Charity is required to make separate capital funding applications to the HSE in terms of its capital requirements.

8.52 Unlike the non-capital allocation from the HSE, capital funding would appear to be provided on an *ad hoc* basis and not annually. In Brothers of Charity's capital funding applications to date it was required to identify each

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<sup>445</sup> This remained the position under the Service Level Arrangement in 2009 which at Schedule 3 now requires the details of staffing by each service providing unit. The Brothers of Charity also make an annual census return to the HSE of various categories employed. It also files staff monthly returns: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>446</sup> The HSE capital programme will list intended capital expenditure projects for the relevant year, and must be approved by the Minister of Health. The approved capital projects are also identified within the National Service Plan.

capital project and provide a brief description of the project along with its cost. Where a capital project is approved, the Brothers of Charity is required to invoice the HSE with the paid invoices of each individual project within a set deadline.

8.53 Between 2004 and 2008 the Centre received a number of capital grants from the HSE, in relation to its on-campus facilities (see Chapters 6 and 7).<sup>447</sup> In addition, in 2008 in a response to the HSE Review Report which found that some bungalows were overcrowded and inadequate, the HSE provided a number of capital grants to the Centre, which are set out in Chapter 7.

8.54 The Brothers of Charity informed the Commission of the internal process it follows in determining the projects for which it should seek capital funding. This process starts at the service unit level, then moves through Sector Management, and then to the Galway Services Management Team, with a final prioritised list of proposals for capital funding being approved by the Board of Directors. It is described thus by the Brothers of Charity:

The fundamental criteria are the achievement of personal outcomes for service users, our philosophy in service provisions, and the best use of resources.

Project management and detailed specifications are only commissioned if there is a possibility of capital funding forthcoming for a particular project. Accordingly the initial prioritisation of projects is not written in stone but is matched to the availability of funding and the criteria governing that funding.....

In years gone by, the final prioritised list was presented to the WHB (now HSE) on a regular basis. In recent years we have been requested by the HSE to submit only projects that are in line with both the criteria set by the HSE and the amount of capital funding available. For 2009 no projects have yet been submitted to the HSE as no capital funding is available.<sup>448</sup>

8.55 Although this process has an individualised approach, it is clear that capital projects are primarily dependant on the national or regional availability of funding.

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<sup>447</sup> In 2004, the HSE provided a capital grant of €400,000.00 on a once off basis for the construction of the Meadow View Centre.

<sup>448</sup> Letter from the Brothers of Charity to the Commission, dated 9 October 2009.

8.56 It appears that while the allocation of operational funding to the Brothers of Charity from the HSE follows a reasonably defined procedure year by year, and indeed the nature of the arrangement to provide annual funding is presently being refined further, the situation as regards the allocation of capital funding happens on a once off funding basis. While the HSE Review Report did result in a capital allocation to the Brothers of Charity to carry out some basic improvements in relation to campus accommodation, this clearly arose on an *ad hoc* basis and was not rooted in a defined needs assessment and allocation process. Furthermore, it is noted that in July 2009 the HSE took the decision not to carry out any further capital projects apart from those projects to which it had already made a contractual commitment.<sup>449</sup> In this regard, it is noted that the HSE did not allocate any further capital funding to the Centre in 2009.

### **Part Three: Other Statutory and Non Statutory Funding**

8.57 The Brothers of Charity Galway also receives funding from other sources. In 2009 this came to a total of €2,138,631 from other statutory and non-statutory schemes.<sup>450</sup>

#### ***The Department of Education***

8.58 There is no specific statutory basis for the Department of Education to provide funding to the Brothers of Charity in relation to the individuals in the Centre given they are all now adults.<sup>451</sup> Therefore, funding provided to the Centre would appear to be granted on a case by case basis. Since 2003, the Brothers of Charity has entered into annual once off funding agreements with the Department of Education for the provision of educational services to a number of

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<sup>449</sup> Minutes of the meeting of the Board of the HSE, 11 June 2009. See [www.hse.ie](http://www.hse.ie).

<sup>450</sup> Brothers of Charity synopsis of Service Plan 2009. Department of Education and Science €528,595, St. Bridget's Hospital Balinasloe, €58,100, Bus Éireann €271,400, FAS €239,348 Ward of Court €45,700, Personal Outcomes – specific reserves €61,971, Ability West €62,643, Pobal Grants (Volunteer Project and Contract Families) €51,500, Kilcornan Transformation Fund €487,774, Pastoral Care €20,000.

<sup>451</sup> The Disability Act 2005 provided for the assessment of adults, including educational services, with disabilities. However, this part of the Act has not yet been implemented, See Chapter 5 for further information.

adults at the Centre. This refers to the sum of €70,000 following an arrangement with the Department of Education from the school year 2003/2004. The terms of that arrangement were that the Department of Education would provide the sum of €70,000 for the provision of an educational input for persons over 18 years of age in the Centre. This funding arrangement has been renewed annually, on application from the Brothers of Charity, since that time. The Department of Education has thus assisted in funding a teacher, while it also funds two special needs assistants exclusively for two individuals at the Centre.<sup>452</sup>

8.59 The Department of Education has advised the Commission that 1,200 teaching hours have also been allocated to the Centre by the Vocational Education Committee under its “*Co-operation With Other Institutes*” scheme for the 2006/07 and 2007/08 school years and that similar funding was also provided under the scheme for the 2008/09 and 2009/10 school years. The Department of Education indicated that:

These hours facilitate the Centre in employing teachers on a part-time basis to provide specialised subjects to the service users in the Centre. ... This is State funding provided by the VECs for educational purposes and is additional to the €70,000 State funding provided directly [by the Department of Education].<sup>453</sup>

8.60 According to the Brothers of Charity, this refers to the sum of €122,823 in relation to educational services provided to two individuals in the Centre.<sup>454</sup> For its part, the Brothers of Charity advised the Commission that the funding received

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<sup>452</sup> The Brothers of Charity advise that these special needs assistants are known as “care assistants” in the context of an educational environment within a healthcare setting such as the Centre rather than a school. The role of the Care Assistant is equivalent to that of a Special Needs Assistant: letter from the Brothers of Charity to the Commission, dated 23 December 2009.

<sup>453</sup> Letters from the Department of Education to the Commission, dated 1 February 2006, 14 March 2008 and 16 December 2009.

<sup>454</sup> Letter from the Brothers of Charity to the Commission, dated 23 December 2009. The Brothers of Charity advise that budgeted costs may differ from the actual expenditure, with call down invoices for actual expenditure incurred prepared twice a year in line with the school terms. These invoices are submitted to relevant personnel in the Department of Education in Athlone. It advises that these invoices contain details of actual hours worked and skills employed whose actual value may be at variance from the budgeted value.

from the Department of Education in conjunction with other funding, and the reallocation of certain resources, such as not filling vacancies:

...has allowed us to offer a day service to young adults who did not have a day service, and has enhanced the quality of day service for all adults at the Centre.<sup>455</sup>

8.61 However, as referred to in Chapter 6, the Department of Education has advised the Brothers of Charity that the cut off point for educational service funding for young adults should be 25 years of age. The Department of Education informed the Commission that this is in keeping with the criteria for funding Vocational Training Centres for adults.<sup>456</sup> The Brothers of Charity has stated that it has continued to make the point that the Department of Education that educational service should therefore continue, since the Department had not provided the statutory component for many of these adults when they were children. At the time of writing this report, an Inspector from the Department of Education had recently visited the Centre in the context of the specific circumstances of two of the individuals in the Centre.<sup>457</sup>

#### **Part Four: Income Generated by the Brothers of Charity**

8.62 The Brothers of Charity also generates income which is included in its annual budget for funding services, including the Centre. The income generated by the Brothers of Charity is set out below in Figure 8.

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<sup>455</sup> Letter from the Brothers of Charity to the Commission, dated 17 September 2009.

<sup>456</sup> Letter from the Department of Education to the Commission, dated 16 December 2009.

<sup>457</sup> *Ibid.*

**Figure 8: The income generated by the Brothers of Charity**

Source of Income Generated	2009	Amount allocated to the Centre
NHASS Staff Contributions (Pensions)	€1,400,000	
In-patient charges/contributions to the Household "Kitty"	€1,459,758	€165,830
Renting Property	€161,090	
ICT services to other Brothers of Charity Regions	€76,200	
Other income (Including Workshop net Income and Swimming Pool)	€417,581	€39,000 (Canteen) €1,900 (Phone & Postage Income)
Staff Social Welfare Receipts	€500,000	
<b>Total</b>	<b>€4,014,629</b>	<b>€206,730</b>

8.63 In-patient charges (historically referred to as the Household Kitty) are funds derived from individuals in the Centre.<sup>458</sup> As outlined in Chapter 5, individuals are required to pay charges towards the receipt of long-term care. There are two levels of charge. The first refers to a person receiving 24 hour nursing care who must pay a maximum of €153.25 per week. The second charge level refers to a service where nursing care is not provided on a 24 hour basis, in such a situation a person pays up to a maximum of €114.95 per week. The

<sup>458</sup> The Brothers of Charity advised the Commission that the Centre manages the money of individuals in the Centre where the family does not. It states this is done through the use of "debtor accounts". The Brothers of Charity state a number of guidelines guide staff when handling an individual's money, including HSE Patient Private Property – Interim Guidelines, Brothers of Charity Good Practice Guidelines in Handling Adult Service Users' Personal Assets and Authority to Proceed documentation. The Brothers of Charity states that all items spent and received are recorded in an individual's money record book and all receipts of items are retained in this book, which is broken down in a month by month recording system for internal and external audits. The books are audited internally twice a year and externally once a year. In relation to the external audit the Brothers of Charity advised the Commission that a test sample is selected randomly by external auditors in respect of all its services, and consequently, the Centre might not be included in the external audit test every year. An individual can request a statement in respect of their account, and where an individual is unable to make this request a statement is supplied to the key worker on an annual basis, or more frequently. (Letters from the Brothers of Charity to the Commission, dated 17 September 2009 and 30 November 2009).

Brothers of Charity informed the Commission that individuals in the Centre, other than those in Community Group Homes fall into the higher charge rate, i.e. those receiving 24 hour nursing care.

8.64 As outlined in Chapter 6, the Brothers of Charity has set up separate personal accounts for each individual in the Centre. Given that all individuals in the Centre are eligible for Disability Allowance, the Brothers of Charity has entered into an annual agreement with the Department of Social and Family Affairs for payments to be transferred directly to the Brothers of Charity, at first instance, to be allocated thereafter to the account of the individual and maintained by the Brothers of Charity on their behalf. This is dependant on the written consent of the individual or their parent/guardian and in some instances the families themselves may collect the payment, or it may be received directly by the individual in the Centre.<sup>459</sup> The Brothers of Charity advised the Commission that the disability payment is credited to individual accounts and the in-patient charge is then drawn from the account.<sup>460</sup> In 2009 the Brothers of Charity informed the Commission that the income expected to be collected from residents at the Centre from in-patient charges is €275,000.

8.65 The Brothers of Charity stated that the income derived from collecting “in-patient charges” is taken into account in the preparation of the HSE Vote and also by the HSE when allocating funding to the Brothers of Charity. In this regard, the Brothers of Charity informed the Commission that in 2009 the increased in-patient charges as required in the 2009 Government Health Estimates resulted in an additional deduction to its 2009 HSE allocation of €194,000.

### ***Capital Assistance from the Department of the Environment***

8.66 The Brothers of Charity, through a housing association it has established, also receives funding from the Department of the Environment under its Capital

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<sup>459</sup> Letter from the Brothers of Charity to the Commission, dated 9 October 2009.

<sup>460</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

Assistance Scheme (“CAS”) for the provision of housing accommodation by approved housing bodies.<sup>461</sup> The CAS provides mainly for the payment of a grant by the Department of the Environment to a Local Authority in respect of housing projects.<sup>462</sup> The Local Authority then lends this money in the form of a thirty year annuity mortgage to an approved housing association towards the approved costs it incurs in providing the dwelling.<sup>463</sup> Accommodation is provided under the CAS by way of new building, acquisition or new houses, or by purchase, renovation or conversion of an existing building.<sup>464</sup>

8.67 The Brothers of Charity set up the Peter Triest Housing Association in 1988, which is an approved housing association for the purpose of CAS.<sup>465</sup> To date this Association has received funding from the Department of the Environment under CAS, in respect of 4 community group homes for individuals who formerly lived at the Centre, and currently provides accommodation to 16 individuals. In addition, the John Paul Parents and Friends Housing Association was set up by the Parents and Friends Association of the Centre.<sup>466</sup> The Brothers of Charity informed the Commission that to date, through fundraising, it has purchased three houses and has built one purpose built house in the community.

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<sup>461</sup> Section 6 of the Housing (Miscellaneous Provision) Act 1992 and Section 15 of the Housing Act 1988 are the statutory bases for the CAS. Bodies which may be considered for approval are: limited companies by guarantee of their members and not having shareholding under the Companies Act, 1963 -2001; Societies registered under the Industrial and Provident Societies Acts, 1893-1978 and Trusts Incorporated under the Charities Act (p.10 of the Capital Funding Schemes Report – see below).

<sup>462</sup> The amount of funding under the Capital Assistance Scheme has increased over the last few years from 75% to 100%, with a ceiling of €150,000 per unit (per person) in urban areas and €110,000 in rural areas. The funding covers the capital cost of acquisition of the property, but does not extend to special equipment or adaptations for people with physical disabilities; letter from the Brothers of Charity to the Commission, dated 2 October 2009.

<sup>463</sup> See Part 4 of the Capital Funding Schemes for the Provision of Rental Accommodation by Approved Housing Bodies (Voluntary and Co-operative Housing) document, Department of Environment, Heritage and Local Government, May 2002, p. 30.

<sup>464</sup> *Ibid.*, p. 35.

<sup>465</sup> The Brothers of Charity informed the Commission that during 2008 the members and executive of the Peter Triest Housing Association Ltd were either board members of the Brothers of Charity Services Ireland or employees in executive positions of the Brothers of Charity Services Galway; letter from the Brothers of Charity to the Commission, dated 2 October 2009.

<sup>466</sup> This is a group of parents involved in fundraising for the Centre.

8.68 The Department of the Environment has stated that CAS is not intended for the provision of “*nursing home or similar accommodation where residents would require extensive medical, nursing or institutional type care*”.<sup>467</sup> However, projects for the provision of accommodation for persons with intellectual disabilities who also need a high level of care proceed on the basis of shared funding assistance to the approved housing association between the housing authority and the HSE office for the area in which the project is located.<sup>468</sup>

8.69 Where an application for funding for such a project is submitted by a housing association under the CAS, the Department of the Environment states that the Local Authority should in the first instance consult with the relevant HSE Office. On consulting with the HSE the Local Authority should then submit the project to the Department of the Environment for approval.

8.70 The approved housing association is the owner of the dwellings and is responsible for the management of their buildings and the operation of its letting policies, such as the fixing of rent, and providing adequate repairs; etc. However, the Department of the Environment stipulates that a housing association must demonstrate to the Local Authority that the letting policy will reflect the terms of the CAS to the greatest extent possible and that a housing association should fix rents at levels which are reasonable having regard to tenants’ incomes. The Brothers of Charity informed the Commission that most of the individuals residing in community group homes pay rent, and that this is determined by reference to Government guidelines for social housing organisations. Since January 2009, the rate of rent charged by a Brothers of Charity housing association is currently set at €58 per week, and the individuals are in turn eligible to claim a rent allowance payment from the Local Authority which is currently €40 per week, making the current net payment by tenants €18 per week.<sup>469</sup>

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<sup>467</sup> *Ibid.*

<sup>468</sup> *Ibid.*, pp. 35-36.

<sup>469</sup> The Local Authority responsible for the Rental Accommodation Scheme is also responsible for payment. However, the application process requires approval from the HSE Community Welfare Officer.

8.71 In the 2006-2007 HSE Review of Current Practices for the Protection of Service Users within the Brothers of Charity Services Galway (the 2006-2007 Review) refers to this rent requirement, noting that the *“charging structure is difficult to comprehend and it is recommended that the level of charges is discussed and clarified with the HSE Local Health Office.”*<sup>470</sup> In November 2009, the Brothers of Charity advised the Commission that this charging structure had been discussed and was now fully understood by the HSE Local Health Officer.<sup>471</sup>

### **Review of Disability Services under the Value for Money and Policy Review Initiative 2008-2011**

8.72 In September 2009, the Minister of State with responsibility for Equality, Disability and Mental Health announced the establishment of a Steering Group to oversee a review of the “efficiency and effectiveness” of disability services in Ireland within a value for money and policy framework. The Department of Health advised the Commission that the Review will undertake a structured consultation process with both service providers and services users being involved. In addition, it advised that it is intended that the new service arrangements introduced in 2009 will form the baseline data for the purposes of the review. Further, the Department of Health advised the Commission that the review will also consider alternative models of funding and budgets for services to enable people with a disability to participate in the social and economic life in their community.

8.73 “Value for Money” reviews have in the past been described as a “crude strategy” which even if unintended, appears to have directly impacted on frontline services in the Centre. It may be that the current Government Review will result in funding cuts to residential, day and respite services for persons with a severe to profound intellectual disability.

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<sup>470</sup> *Ibid.*, p. 57.

<sup>471</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

## ***Budget 2010***

8.74 In December 2009 following the announcement of the Government Budget for 2010, the Brothers of Charity addressed the issue of possible funding cuts to the Centre. Although it had no information from the HSE of the likely impact of the Government's Budget 2010 decisions on its Services, it set out the following:

### **Letter from the Brothers of Charity to the Commission – 23 December 2009**

Before assessing the impact of the Government Budget 2010, the Brothers of Charity Services Galway had projected a core funding deficit of about €630,000 going into 2010, of which John Paul Services core funding deficit is about €268,000....

Experience of recent years informs us that cuts will be imposed through a crude proportional system with no assessment of an organisation's capacity. Accordingly, our reckoning, at this point in time, is a possible cut in HSE funding of about 2% or €1 million, which, when taken with our core funding deficit of €630,000, means a reduced funding level of about €1.63 million for 2010. John Paul Services portion of that sum would be estimated at €451,000 equivalent to a loss of 9 posts. In addition one can only surmise that corresponding cuts in our multidisciplinary supports budgets and in our central services will further impact on John Paul Centre.

Without pre-empting the decisions of our Board of Directors, it is obvious that loss of funding of that magnitude would be devastating for the Centre and would require the closure of at least one residential bungalow. In practical terms the bed capacity of some bungalows would have to be increased to absorb the residents displaced with a consequential increase in the service user to staff ratio. There is no doubt that such a retrograde step will impinge on the lives of the men and women who reside in the Centre. There is no doubt that such a retrograde step will greatly challenge the Centre's capacity to maintain the basic assurances that underpin the rights of all citizens. Parents and care staff will regard any diminishing of basic assurances as a breach of trust which will be a source of challenge and tension for care managers and management in general. In addition the capacity of the Centre to respond to emergency admissions will, in reality, disappear. The hopes of those men and women and their families who are in urgent need of residential service will take a further blow. In this regard, our Board are most anxious not to reduce the respite capacity of the Centre as the availability of some respite is an essential lifeline to families whose son, daughter, or sibling are in urgent need of residential services.

8.75 It is noted that neither the HSE nor the Department of Health referred to any funding cuts to the Centre and the situation thus remained unclear at the time of writing this report.

### **Postscript**

8.76 In March 2010, shortly prior to the publication of this report, the Brothers of Charity informed the Commission that it had received its indicative funding allocation for 2010 from the HSE. According to the Brothers of Charity, it had been informed that it was to receive deeper cuts to its budget for 2010 than previously understood, including in relation to staffing and pension obligations, and that this would likely result in cuts to services.

## Chapter 9 Oversight and Accountability

9.1 There are two distinct accountability structures in the State which are of relevance to persons with intellectual disabilities. First, there is a chain of organisational oversight afforded through statutory or other reporting arrangements. Second, certain accountability mechanisms are provided for under the Health Acts of 2004 and 2007 and include a public complaints system administered by the HSE and a framework of registration and inspection by the newly created Health Information and Quality Authority (“HIQA”), which has not been commenced.

Monitoring is a precondition of accountability. Accountability provides individuals and communities with an opportunity to understand how those with responsibilities have discharged their duties. Equally, it provides those with responsibilities the opportunity to explain what they have done and why. Where mistakes have been made, accountability requires redress. But accountability is not a matter of blame and punishment. It is a process that helps to identify what works, so it can be repeated, and what does not, so it can be revised. It is a way of checking that reasonable balances are fairly struck.

In the context of health systems, there are many different types of accountability mechanisms, including health commissioners, democratically elected local health councils, public hearings, patients’ committees, impact assessments, maternal death audits, judicial proceedings, and so on. An institution as complex and important as a health system requires a range of effective, transparent, accessible, independent accountability mechanisms. The media and civil society organizations have a crucial role to play as well.

Hunt, P. & Backman, G.; ‘Health Systems and the Right to the Highest Attainable Standard of Health’, *Health and Human Rights: An International Journal*, Vol. 10, No. 1 (2008) pp 54-55.

### The Development of Statutory Regulation of Health Services to Persons with Disabilities

9.2 Historically, the management and oversight of institutions providing health services was largely an autonomous function of local health authorities. Under the Health Act 1947, for example, health authorities drew up rules for the conduct

and management of such institutions, subject to the approval of the Minister for Health.<sup>472</sup> Standards and services could thus differ between local health authority areas.

9.3 This position changed somewhat with the enactment of the Health Act 1953, which empowered the Minister for Health to make regulations for the conduct or management of such institutions.<sup>473</sup> Similarly, under this legislation health authorities could make rules in relation to the conduct and management of particular institutions, subject to the Minister's consent.<sup>474</sup>

9.4 The subsequent enactment of the Health Act 1970 extended the authority of the Minister for Health to making regulations on the nature and administration of services provided by health boards.<sup>475</sup> The Health Act 1970 was later amended by the Health (Amendment) (No. 3) Act 1996 such that the Minister could also direct the form, content and timeframe for health boards adopting and submitting annual service plans.<sup>476</sup> Subject to directions from the Minister, service plans had to include a statement of the services to be provided by the individual health board with estimates of income and expenditure for the period of the plan in line with the financial limits set by the Minister.<sup>477</sup>

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<sup>472</sup> See e.g. Section 10 of the Health Act 1947, repealed by Section 3 of the Health Act 1970.

<sup>473</sup> Section 8 of the Health Act 1953 was repealed by Section 3 of the Health Act 1970.

<sup>474</sup> Section 49 of the 1953 Act provided that a health authority entering into an agreement with any person for the provision of a service provided for under the Health Acts would have to comply with any regulation made in that regard by the Minister for Health. Section 49 of the Health Act 1953 was also repealed by Section 3 of the Health Act 1970. No such regulations were ever made. The Health Act 1953 allowed health authorities provide general medical services and also specialist and institutional services to certain persons subject to a means test, and the Minister could by Order regulate the manner and extent that such services were made available by all, or a particular, health authority (section 15 of the Health Act 1953). Persons who did not qualify for such services under the means test might still be able to avail of such services so long as the space was available in the institution, and was not required at the time by a person qualified under section 15. The health authority, with the consent of the Minister, could make rules for the provision of services under this section, which was repealed by Section 3 of the Health Act 1970.

<sup>475</sup> Section 72 of the Health Act 1970.

<sup>476</sup> Section 6 of the Health (Amendment) (No.3) Act 1996.

<sup>477</sup> *Ibid.* Where the provisions of a service plan were not complied with, the Minister could direct that the plan would be modified as appropriate, and direct the health board to resubmit an amended plan for approval. There was a mandatory obligation on the Chief Executive of each health board to implement the service plan in such a way that the net expenditure of the health board did not exceed that allowed by the Minister with further provisions in circumstances where there is either an under spend or an over spend.

9.5 Under the 1996 Act, if the Minister formed the view that a health board was not performing its functions in an effective manner or had failed to comply with any direction given, the Minister could transfer the reserved functions of the Board to the Chief Executive.<sup>478</sup> The Act further allowed the Minister to give directions in writing to a health board for any purpose in connection with the Act or other relevant enactment (including regulations).<sup>479</sup> The relevant provisions of the Health Act 2004 are discussed further below.

## **A: Oversight Mechanisms**

### *The Minister for Health*

9.6 As the designated Minister for the purpose of the Health Acts,<sup>480</sup> the Minister for Health is politically accountable to the Oireachtas for the performance of the health service. As stated in Chapter 5, the Department of Health supports the Minister in setting the objectives for health policy and in formulating the overall strategy for achieving these objectives. This includes through administering the health budget and the introduction of health related legislation in the Oireachtas.

9.7 The Minister is ultimately responsible for whether the HSE conducts its operations in accordance with the policies and objectives of the Government.<sup>481</sup> The legal relationship between the Minister and the HSE is dealt with in a number of sections of the Health Act 2004. Section 10 allows the Minister to issue general written directions to the HSE for any purpose relating to the Health Act

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<sup>478</sup> Or other person nominated by the Minister if necessary, for a period up to two years - Section 12 of the Health (Amendment) (No. 3) Act 1996. Prior to making such an Order the Minister is obliged to appoint someone to investigate the performance of the health board over a specified period, with a report to be prepared for the attention of the Minister. The Board was also entitled to make representations to the Minister as to why such an order should not be made.

<sup>479</sup> Section 13 of the Health (Amendment) (No.3) Act 1996.

<sup>480</sup> Section 2(3) of the Ministers and Secretaries (Amendment) Act 1946 (No. 38/1946).

<sup>481</sup> The Minister for Health is responsible for approving the HSE's Corporate Plan, Service Plan and its Code of Governance (section 30 Health Act 2004).

2004.<sup>482</sup> The Minister may also issue specific written directions seeking the submission by the HSE of reports, including statistical information, regarding the performance of its functions under the Health Act 2004.<sup>483</sup> The HSE is under a statutory duty to comply with such directions.<sup>484</sup> No such directions have been issued by the Minister to date. The HSE must also submit periodic corporate plans and service plans to the Minister.<sup>485</sup> In addition, the HSE must report to the Minister on its complaints procedure.<sup>486</sup>

### ***The Health Service Executive***

9.8 As stated in Chapter 5, the creation of the HSE was a key component of the Government's *Health Service Reform Programme* announced in June 2003.<sup>487</sup> The overall objective of the HSE as set out in the Health Act 2004 is:

...to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.<sup>488</sup>

9.9 The HSE, a body corporate with perpetual succession,<sup>489</sup> is accountable to the Minister for Health for the delivery of health and personal social services.<sup>490</sup>

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<sup>482</sup> Section 10(1) of the Health Act 2004. It does not appear that any general written directions have been made by the Minister for Health under this section in relation to the provision of health and personal social services to persons with intellectual disabilities in residential settings (letter to the Commission from the Department of Health, dated 08 December 2008).

<sup>483</sup> Section 10(2) of the Health Act 2004.

<sup>484</sup> Section 10(5) of the Health Act 2004.

<sup>485</sup> Sections 28 to 32 of the Health Act 2004.

<sup>486</sup> Section 55(1) of the Health Act 2004.

<sup>487</sup> This reform programme sets out the structural changes deemed necessary to achieve the State's health care objectives as set out in the 'National Health Strategy, Quality and Fairness: Health System for You' (2001). The HSE was formally established in 1 January 2005, pursuant to Section 6 of the Health Act 2004, and replaced a complex structure of ten regional Health Boards, the Eastern Regional Health Authority and a number of other different agencies and organisations. The previous structures had been in place since the early 1970s. As the largest employer in the State, the HSE has over 65,000 staff in direct employment and a further 35,000 staff employed by hospitals and bodies funded by the HSE. It has an annual budget of over €14.7 billion and is organised into four administrative areas: HSE West, HSE South, HSE Dublin North East and HSE Dublin Mid Leinster.

<sup>488</sup> Section 7(1) of the Health Act 2004. The HSE was established under Section 6(1) of the Act.

<sup>489</sup> Section 6(2) of the Health Act 2004.

<sup>490</sup> Upon approval by the Minister for Health of its Corporate Plan and Service Plan, the HSE is obliged to manage health and personal social services in accordance with those Plans (Section 33 of the Health Act 2004). In performing its functions, the HSE is required to have regard to the policies and objectives of the Government or Government Minister (section 7(5)(c) of the Health

The HSE is governed by a Board consisting of 11 members (a chairperson and 10 ordinary members) appointed by the Minister.<sup>491</sup> The HSE must submit for approval by the Minister, a service plan for the financial year (or other period, as may be determined by the Minister), specifying, *inter alia*, the type and volume of services to be provided and indicating any capital plans proposed.<sup>492</sup> The Minister's permission is required for major capital spending exceeding an amount that the Minister shall determine from time to time.<sup>493</sup> The HSE must also report to the Minister on its complaints procedure.<sup>494</sup>

9.10 The Chief Executive of the HSE is responsible to the Board for the performance of his functions.<sup>495</sup> The Chief Executive is also directly accountable to Dáil Éireann and may be required to report to an Oireachtas Committee on written request in relation to the administration of the HSE.<sup>496</sup>

### ***The Brothers of Charity***

9.11 As discussed in Chapter 6, the Brothers of Charity is bound under the terms of its Service Level Agreement with the HSE to provide services to persons with an intellectual disability within its service area. The Brothers of Charity is directed by its Board. The Chief Executive of the Brothers of Charity reports to

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Act 2004).The HSE is also obliged to prepare and submit its Annual Report to the Minister for Health (section 37 of the Health Act 2004).

<sup>491</sup> Section 11 of the Health Act 2004.

<sup>492</sup> Section 31(3) of the Health Act 2004. The HSE must submit a service plan for the financial year or other period as may be determined by the Minister for approval specifying the services and funding issues. The service plan must firstly, state the type and volume of health and personal social services to be provided by the Executive for the duration of the plan. Secondly, it must outline any capital plans proposed by the HSE. Thirdly, it must estimate the number of employees of the HSE for the period of the plan and the services to which the plan relates. Fourthly, it must provide any other information requested by the Minister and comply with any general or specific directions which are issued by the Minister. Finally, the plan must accord with the policies and objectives of the Minister and the Government.

<sup>493</sup> Sections 31 to 34 of the Health Act 2004.

<sup>494</sup> Section 55(1) of the Health Act 2004.

<sup>495</sup> Section 18(2) of the Health Act 2004. Section 19 allows the CEO to delegate all or any functions to a member of staff.

<sup>496</sup> Section 21 of the 2004 Act provides for the CEO of the HSE appearing before the Oireachtas. Under Section 21(2), the CEO is not required to give an account before an Oireachtas Committee of any matter that is or is likely to be the subject of proceedings before a court or tribunal.

the Board and is responsible for local decision-making. In turn, the Chief Executive of the Brothers of Charity is assisted by the Galway Services Management Team, the membership of which is made up of (1) the three Sector Managers<sup>497</sup>, the Heads of Organisational Services<sup>498</sup> and (3) two representatives of the Heads of Multidisciplinary Departments.<sup>499</sup> In the current enquiry, the Manager of the Centre reports to the Sector Manager of the West Galway Adult Services of the Brothers of Charity.

## **B: Accountability Structures**

### ***The HSE and the Complaints System under Part 9 of the Health Act 2004***

9.12 As part of the State's National Health Strategy 2001, a commitment was made to establishing a statutory complaints system in respect of health services.<sup>500</sup> Part 9 of the Health Act 2004, which came into effect on 1 January 2007,<sup>501</sup> established a new structure for making and processing complaints, including a review procedure, in respect of the operations of the HSE and Service Providers under the 2004 Act.<sup>502</sup> By virtue of this new structure, any person who is currently or was previously a service user of a health or personal social service provided by the HSE or a Service Provider or, alternatively, is seeking or has sought the provision of such services, may make a complaint to the HSE. There is a twelve month time limit, running from the time of the impugned action, for the making of a complaint.<sup>503</sup>

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<sup>497</sup> Namely, Children's Services, West Galway Adult Services and East Galway Adult Services.

<sup>498</sup> Namely, Finance, Quality Enhancement and Development, Human Resources and Planning.

<sup>499</sup> Namely, Psychology, Speech and Language Therapy, Social Work, Physiotherapy, Consultant Psychiatrist and Occupational Therapy.

<sup>500</sup> National Health Strategy 2001, Quality and Fairness: A Health System for You, National Goal 3, Objective 1, Action 49.

<sup>501</sup> Supplementary to the Health Act 2004 are the Health Act 2004 (Complaints) Regulation 2006 which were made by the Minister for Health further to section 53 of the Health Act 2004.

<sup>502</sup> Section 45 of the Health Act 2004. Section 2 of the Health Act 2004 defines 'Service Provider' as a person who enters into an arrangement under section 38 of the Act to provide a health or personal social service on behalf of the HSE. See further above Chapter 5 and 6. The HSE is obliged under section 49 of the Health Act 2004 to establish complaint and review procedures.

<sup>503</sup> Provision is also made at Section 46 of the Health Act 2004 for complaints being made by persons other than the person directly affected by the impugned action. Such complaints may be

9.13 Complaints may only relate to actions concerning 'fair and sound administration'<sup>504</sup> and the person concerned must have been adversely affected by the action giving rise to the complaint.<sup>505</sup> Certain matters are excluded from the complaints process, such as matters that are the subject of legal proceedings or matters relating to the exercise of clinical judgment, the consequent action taken by the HSE or a Service Provider on foot of such clinical judgment or where a complaint was previously brought to another body.<sup>506</sup>

### ***The procedure regarding (administrative) complaints***

9.14 The Health Act 2004 (Complaints) Regulations 2006<sup>507</sup> further elaborate the procedural requirements involved in the making of complaints in respect of fair and sound administration under Part 9 of the Health Act 2004. This includes guidance on the appointment of Complaints Officers, the investigation of complaints, the making of requests for review of investigation outcomes and the undertaking of reviews.<sup>508</sup>

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made where the person so affected is unable to make a complaint due to age, illness, disability or death. In such instances the complaint may be made on that person's behalf by, *inter alia*, a close relative or legal representative.

<sup>504</sup> By virtue of section 46(2) of the Health Act 2004 an action does not accord with fair and sound administrative practice if it is:- (a) taken without proper authority, (b) taken on irrelevant grounds, (c) the result of negligence or carelessness, (d) based on erroneous or incomplete information, (e) improperly discriminatory, (f) based on undesirable administrative practice, (g) in any other respect contrary to fair or sound administration.

<sup>505</sup> Section 46(1) of the Health Act 2004.

<sup>506</sup> Excluded matters are set out in full at section 48 of the Health Act 2004 and include: (a) a matter that is or has been the subject of legal proceedings before a court or tribunal; (b) a matter relating solely to the exercise of clinical judgment by a person acting on behalf of either the Executive or a service provider; (c) an action taken by the Executive or a service provider solely on the advice of a person exercising clinical judgment in the circumstances described in paragraph (b); (d) a matter relating to the recruitment or appointment of an employee by the Executive or a service provider; (e) a matter relating to or affecting the terms or conditions of a contract of employment that the Executive or a service provider proposes to enter into or of a contract with an adviser that the Executive proposes to enter into under section 24; (f) a matter relating to the Social Welfare Acts; (g) a matter that could be the subject of an appeal under section 60 of the Civil Registration Act 2004; (h) a matter that could prejudice an investigation being undertaken by the Garda Síochána; (i) a matter that has been brought before any other complaints procedure established under an enactment.

<sup>507</sup> S.I. No 652 of 2006, signed by the Minister for Health on 15 December 2006 to come into operation on 01 January 2007.

<sup>508</sup> Further information on the HSE complaint management process is set out in its document 'Your Service, Your Say': Policy and Procedures for the Management of Consumer Feedback to include Comments, Compliments and Complaints in the Health Service Executive, HSE Consumer Affairs, February 2008.

9.15 The HSE's administrative complaints procedure can be divided into four stages; (1) local resolution of verbal complaints;<sup>509</sup> (2) local investigation (i.e. by the HSE or a Service Provider, as appropriate) of complaints;<sup>510</sup> (3) HSE Internal Review;<sup>511</sup> (4) Independent Review. Complaints that cannot be resolved at a particular stage are progressed to the next stage. Regarding the issue of independent review of complaints, if a complainant is dissatisfied with a step taken in response to a complaint or a review under Part 9 of the Health Act 2004, the complainant can request the Ombudsman or the Ombudsman for Children, where relevant, to conduct an independent review of the matter.<sup>512</sup>

9.16 Where the matter is referred to the Ombudsman or the Ombudsman for Children, those bodies may instigate a preliminary examination followed by a formal investigation, where merited.<sup>513</sup> A twelve month time limit applies to the making of complaints to the Ombudsman,<sup>514</sup> while a two year time limit applies in respect of the Ombudsman for Children.<sup>515</sup> Investigations by both the Ombudsman and the Ombudsman for Children may result in a statement or report with recommendations being made to Government and appropriate follow-up where there is inadequate implementation of same.<sup>516</sup>

9.17 In relation to complaints to the HSE, where a complaint is duly made by an eligible complainant regarding an administrative practice, a Complaints Officer is

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<sup>509</sup> Verbal complaints are processed at the point of contact and if no resolution is reached, they are referred to a Complaints Officer for formal investigation.

<sup>510</sup> This includes the option of an informal resolution procedure and in the event that this does not produce a satisfactory outcome for the complainant, a formal investigation is conducted. Written complaints are automatically subject to the formal investigation process which includes set time-frames for the analysis of complaints and for communications with the complainant.

<sup>511</sup> Where the complainant is dissatisfied with the outcome of a formal complaint investigation, the person may request an internal review of the outcome.

<sup>512</sup> Section 54 of the Health Act 2004 provides that a complainant who is dissatisfied with an aspect of the complaint/ review process is not prohibited or prevented from referring the matter to the Ombudsman or the Ombudsman for Children at any stage.

<sup>513</sup> Section 4 of the Ombudsman Act 1980 and section 8 of the Ombudsman for Children Act 2002, respectively.

<sup>514</sup> Section 5(1)(f) of the Ombudsman Act 1980.

<sup>515</sup> Section 11(1)(g) of the Ombudsman for Children Act 2002.

<sup>516</sup> Section 6 of the Ombudsman Act 1980 and Section 13 of the Ombudsman Act 1980, respectively. These sections allow for special reports to be included in annual reports to be laid before each house of the Oireachtas where measures taken or proposed to be taken by the State body(s) concerned on foot of recommendations are not deemed to be satisfactory.

assigned to investigate the complaint. Following the investigation of a complaint, the Complaints Officer will prepare a report setting out the circumstances of the complaint and the relevant findings and recommendations. The HSE or Service Provider, as appropriate, are obliged to put an action plan in place for the implementation of recommendations contained in an investigation report.<sup>517</sup>

9.18 Restrictions are imposed on the type of recommendations that a Complaints Officer may make. A Complaints Officer may not make a recommendation that would require the HSE to make a material amendment to its approved service plan<sup>518</sup> or would require a Service Provider and the HSE to make such an amendment to a service arrangement between the parties as provided for by section 38 of the Health Act 2004, and as discussed in Chapter 6 above.<sup>519</sup>

9.19 A complainant who is dissatisfied with either the outcome of an investigation or an internal HSE review may request a review of the relevant decision. The timeframes for the conduct of reviews are set out in the HSE's document 'Your Service, Your Say'.<sup>520</sup> It is both a statutory duty and a condition of all service agreements with the HSE that Service Providers adhere to the complaints and review procedures as established by the HSE and also as determined by the Minister for Health by way of regulation pursuant to section 53 of the Health Act 2004.<sup>521</sup>

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<sup>517</sup> Section 51(3) of the Health Act 2004. In addition to identifying the actions required to be taken, such plans should record the persons responsible for the taking of the future actions the relevant timeframes for so doing.

<sup>518</sup> Section 51(1)(a) of the Health Act 2004.

<sup>519</sup> Where restricted recommendations are made, either the HSE or the Service Provider, as appropriate, are obliged to either amend the recommendation as necessary or reject the recommendations and take other measures as are deemed necessary in the circumstances to negate any resulting adverse effect (Section 51(2) of the Health Act 2004). Similarly, the HSE or Service Provider, as appropriate, may suspend the implementation of a recommendation pending the outcome of a review request from a complainant (Section 52 of the Health Act 2004).

<sup>520</sup> *Infra*, nt 8 at pp. 11, 53 and 55.

<sup>521</sup> Section 52 of the Health Act 2004. Separately and subject to agreement with the HSE, any Service Provider may establish its own procedures for dealing with complaints provided that such procedures are of a comparable standard to the procedures established by the HSE (section 49 of the Health Act 2004). Where such an agreement has taken place, the Service Provider is obliged to establish its complaints procedure in the form set out in the agreement (section 52(1)(b) of the Health Act 2004). In such instances, the Service Provider is obliged to furnish the

9.20 In summary, if a complainant is not happy with the outcome of a complaint made to a Service Provider, the complainant has the option of bringing the complaint to the HSE. If the complainant is then unhappy with the outcome of this latter complaint, the complainant can refer the matter to the Ombudsman or the Ombudsman for Children for investigation.

### ***Non-administrative procedure based complaints***

9.21 Non-administrative procedure based complaints, such as more serious complaints regarding allegations of abuse for instance, are not within the remit of the complaints system under Part 9 of the Health Act 2004. Complaints concerning allegations of abuse against HSE staff members, for instance, are managed under a separate HSE policy framework. Under that framework, the HSE is obliged to conduct an internal investigation into all allegations of abuse.<sup>522</sup> Again according to its own policy, where reasonable grounds are found for suspecting that an offence has been committed by a staff member of the HSE, the matter must be reported by the HSE to An Garda Síochána.<sup>523</sup> This is in addition to any remedies a person may have under the civil law generally. Unlike the administrative complaints system referred to above, any investigation by the HSE into allegations of abuse is at the discretion of the HSE and is not subject to independent review.

### ***The Brothers of Charity– Complaints System***

9.22 In July 2008, the Brothers of Charity revised its complaints procedure and accompanying guidelines for use in all areas of its services, including the Centre. It appears that this revised procedure was approved by the HSE in April 2008

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HSE with a general report on the complaints it received during the previous year. Such reports are to include the total number of complaints received, the nature of the complaints, the number of complaints resolved by informal means and the outcome of any investigations into the complaints.

<sup>522</sup> HSE, Trust in Care: Policy for Health Service Employers on Upholding the Dignity and Welfare of Patient/ Clients Abuse and the Procedure for Managing Allegations of Abuse against Staff Members, May 2005. For the purpose of this policy, abuse is considered to be any form of behaviour that violates the dignity of patients/ clients. Such abuse may consist of a single act or repeated acts. It may be physical, sexual or psychological/ emotional. It may also constitute neglect and poor professional treatment (p. 7).

<sup>523</sup> *Ibid.*, p. 23.

and is stated to be in compliance with section 49 of the Health Act 2004. It comprises a Policy Document, a Complaints Procedure Document<sup>524</sup> and Guidelines for Staff on how to handle complaints.<sup>525</sup> The Brothers of Charity states that its complaints procedure is in compliance with the requirements of the Health Act 2004. In the view of the Brothers of Charity, the complaints procedure under the legislation:

is quite restrictive and the Brothers of Charity Services hopes that any service user or family member will bring any issue, concern or complaint to the attention of staff and the Services as soon as it becomes an issue for the service user or family so the procedure is broader than is required by the Health Act 2004.<sup>526</sup>

9.23 The Brothers of Charity provides statistical information to the HSE on the level of complaints received by its services. It has indicated that from 2008 to Mid-2009, four complaints were received in respect of the Centre, two complaints were received in 2008 and two in 2009.<sup>527</sup> Details regarding the complaints are set out in Figure 9. A separate internal policy structure is engaged in respect of more serious complaints against staff of the Brothers of Charity.<sup>528</sup> The HSE's 'Trust in Care' policy may also be engaged in such circumstances.<sup>529</sup>

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<sup>524</sup> The Brothers of Charity have produced a user friendly version of its 'Complaints Procedure' which uses picture symbols to support people who do not communicate with words: letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>525</sup> Letter from the Brothers of Charity to the Commission, dated 17 October 2008.

<sup>526</sup> Letter from the Brothers of Charity to the Commission, dated 30 November 2009.

<sup>527</sup> *Ibid.*, and letter from the Brothers of Charity the Commission, dated 25 June 2009.

<sup>528</sup> *Ibid.* The Brothers of Charity, 'Policy on Reporting Abuse in the Brothers of Charity when Abuse is Suspected or Alleged which includes the regulations under Children First'. Allegations of abuse against Brothers of Charity staff are excluded matters under the section 49 scheme. It should be noted that no such allegations appear to have been made in respect of staff at the Centre.

<sup>529</sup> *Supra*, nt. 48 at p. 43.

**Figure 9: Complaints to the Brothers of Charity in connection with the Centre in 2008 and 2009**

	2008	
	COMPLAINT 1	COMPLAINT 2
<b>Date Received</b>	3 January 2008	19 July 2008
<b>Made by</b>	Parent	Unclear
<b>Subject Matter</b>	Unexplained bruising on a service user.	An allegation of physical abuse by a staff member on a service user.
<b>Process</b>	Meetings were held between family, social worker, staff and management to identify the cause of the bruising.	The complaint was screened under the HSE's 'Trust in Care' policy and a full investigation was carried out. The allegation was upheld by the investigation panel, although there was agreement between the parties that there was no intent on part of the staff member - who was deemed to be responding to a particularly difficult challenging situation.
<b>Outcome</b>	Safeguards put in place. The matter was resolved to everyone's satisfaction.	Disciplinary action was initiated and sanctions were imposed.

	2009	
	COMPLAINT 1	COMPLAINT 2
<b>Date Received</b>	10 February 2009	8 May 2009
<b>Made by</b>	Parent	Family member
<b>Subject Matter</b>	The standard of a service user's personal hygiene.	An incident which occurred when two staff members accompanied a service user on a social outing.
<b>Process</b>	Preliminary screening was carried out under the HSE's 'Trust in Care' policy. Support actions were put in place regarding the service user's personal hygiene.	A meeting was held between family, social worker, staff and management to identify cause. The family were provided with a full account of the incident, which appears to have been accidental.
<b>Outcome</b>	The matter was resolved involving family, staff and management.	Resolved.

## *The Health Information and Quality Authority*

9.24 The Health Information and Quality Authority (HIQA) was established on 15 May 2007 as part of the Government's *Health Service Reform Programme*.<sup>530</sup> HIQA is the independent statutory body responsible for developing quality, safety and accountability in the State's health and social care services.<sup>531</sup> At the time of writing this report, not all of HIQA's functions have been commenced.

9.25 The functions of HIQA are set out in Section 8 of the Health Act 2007. In summary, HIQA is the body responsible for: (1) Setting Standards in Health and Social Services; (2) Monitoring Healthcare Quality; (3) the operation of the Social Services Inspectorate; (4) Health Technology Assessment and; (5) Health Information. Functions (1) to (3) appear to be most relevant to this Enquiry in terms of the accountability of services to persons with an intellectual disability in residential care.

### *Setting Standards in Health and Social Services*

9.26 HIQA is responsible for setting national standards for the provision of health and social care services (except Mental Health Services) in the State.<sup>532</sup> The standards established by HIQA include standards for residential care for persons with disabilities (excluding children with disabilities<sup>533</sup>) and define a level of quality and safety which should be maintained by such residential services for

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<sup>530</sup> HIQA was formally established on 15 May 2007, pursuant to Section 6 of the Health Act 2007. Prior to this, in May 2005, the Minister for Health had established an interim HIQA to make the administrative and organisational arrangements for the establishment of the Health Information and Quality Authority proper. The Board of the interim Health Information and Quality Authority was formally dissolved on the establishment of the statutory Health Information and Quality Authority. Two pre-existing State bodies, the Social Services Inspectorate (SSI) and the Irish Health Services Accreditation Board (IHSAB), have been integrated into the remit of HIQA. The former SSI now has an expanded role as the Office of the Chief Inspectorate for Social Services while the former IHSAB continues its work of accreditation as part of HIQA's 'Healthcare Quality' function.

<sup>531</sup> HIQA's objective is 'to promote safety and quality in the provision of health and personal social services for the benefit of the health and welfare of the public' (Section 7 of the Health Act 2007).

<sup>532</sup> Section 8(1)(b)(i)(I) of the Health Act 2007.

<sup>533</sup> Standards on children are due to be finalised in 2010: letter from the Department of Health to the Commission, dated 14 December 2009.

persons with disabilities in the public, private and voluntary sectors,<sup>534</sup> In March 2008, the Department of Health informed the Commission of its view that:

It is important to ensure that all residential facilities for people with a disability are independently monitored and inspected by [HIQA]. This is provided for in the Health Act 2007. It gives HIQA important powers to examine the nature and quality of service and to determine whether they are of the standard to which people with a disability are entitled as a right. ... The Department understands that it is HIQA's aim to finalise formal standards in 2008 and to commence formal inspections in 2009.<sup>535</sup>

9.27 In September 2008, HIQA published 'Draft National Quality Standards: Residential Services for People with Disabilities' and opened these to public consultation.<sup>536</sup> In May 2009, HIQA published the adopted 'National Quality Standards: Residential Services for People with Disabilities'.<sup>537</sup> Speaking at the launch of the Standards, Dr Marion Witton, Chief Inspector of Social Services at HIQA said:

These standards promote a vision for how residential services for people with disabilities should be provided in the future. They embody the principles of enablement and possibility; they focus on what people with disabilities can do, when provided with the right support. Their publication today is a significant milestone for disability services in Ireland.<sup>538</sup>

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<sup>534</sup> Letter from HIQA to the Commission, dated 3 December 2009. Other HIQA standards include Standards for Infection Prevention and Control; Hygiene Standards; Standards for Residential Care Settings for Older People (completed, see HIQA website); Independent assessment of needs for people with physical and intellectual disabilities (completed, see HIQA website); Symptomatic Breast Disease Standards.

<sup>535</sup> Letter from the Department of Health and Children to the Commission, dated 14 March 2008.

<sup>536</sup> In its letter to the Commission dated 5 March 2008, HIQA advised that the draft standards being developed were based on international best practice and built on the work of the National Disability Authority who in 2003 had published National Standards for Disability Services and which had a range of good practice guidelines. The Commission later made a submission to HIQA on the Draft Standards - 'Submission of the Irish Human Rights Commission to the Health Information and Quality Authority on the Draft National Quality Standards on Residential Services for People with Disabilities' (November 2008), see [www.ihrc.ie](http://www.ihrc.ie).

<sup>537</sup> HIQA, Draft National Quality Standards: Residential Services for People with Disabilities, September 2008. The Draft Standards draw on legislation, findings from research and international best practice and build upon the work of the National Disability Authority, who, in 2003, published National Standards for Disability Services.

<sup>538</sup> Dr Marion Witton, Chief Inspector of Social Services (HIQA) at the launch of the Standards on 11 May 2009, see [www.hiqa.ie](http://www.hiqa.ie).

9.28 Regarding the purpose of the National Quality Standards, HIQA states that:

These standards have been developed for the purpose of the registration and inspection of residential services for persons with disabilities. They will assist service providers to assess the quality of the service they provide in advance of inspection. They will also act as a guide to individuals and families as to what they can reasonably expect of a residential service. The standards do not apply to residential services for children with disabilities. A separate set of standards is being developed for such services.<sup>539</sup>

9.29 The National Quality Standards cover a wide range of issues affecting the lives of adult persons with disabilities in residential services. They are grouped under seven headings which address the quality of life enjoyed in residential services as well as staffing levels and safety codes. They also set out best practice criteria for the personal development and health of individuals, the promotion of the rights of such persons and regarding the physical environment of residential services and their governance and management. Taken together, the Standards purport to define what a good quality service for people with disabilities should be. HIQA's Standards for residential services for persons with disabilities are discussed further in Chapter 10.

9.30 The development of these Standards is specifically linked to the provisions under the Health Act 2007 concerning the registration and inspection of residential services for people with disabilities. This is discussed further below in connection with the Office of the Chief Inspector of Social Services.

### *Monitoring Healthcare Quality*

9.31 HIQA has responsibility for monitoring the level of compliance with the standards for the provision of health and social care services which it has set.<sup>540</sup> This includes through undertaking site visits and working with health care

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<sup>539</sup> HIQA, National Quality Standards: Residential Services for People with Disabilities, May 2009, p. 5.

<sup>540</sup> The Office of the Chief Inspector of Social Services within HIQA is involved in monitoring the implementation by designated centres of the national standards for the provision of health and social care services as developed by HIQA and the Department of Health and Children.

organisations to identify areas for improvement. HIQA may also conduct an investigation where there is a serious risk to the safety of patients or staff in health or social care services.<sup>541</sup> HIQA has completed three such investigations to date, publishing reports on the investigations conducted.<sup>542</sup>

### *Office of the Chief Inspector of Social Services*

9.32 As stated above, the Health Act 2007 places the Social Service Inspectorate on a statutory basis as the Office of the Chief Inspector of Social Services within HIQA.<sup>543</sup> Under Section 41 of the Health Act 2007, the Chief Inspector of Social Services has responsibility for the registration and inspection of all 'designated centres', which are broadly defined as all institutions at which residential services are being provided.<sup>544</sup>

9.33 The work of the Social Service Inspectorate had previously been confined to the protection of children in care, primarily through the inspection of childrens residential centres. The Chief Inspector of Social Services has now assumed this role and is the person responsible for the registration and inspection of all residential services in the public, private and voluntary sectors for children, older people and persons with a disability.<sup>545</sup>

9.34 The Health Act 2007 envisages an accountability framework for residential disability services characterised by a standards-based regulation and inspection regime operated by the Chief Inspector of Social Services. Under Section

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<sup>541</sup> Section 9 of the Health Act 2007. HIQA may conduct an investigation either of its own volition or on request from the Minister for Health or other person.

<sup>542</sup> See further [www.hiqa.ie](http://www.hiqa.ie): Report of the Investigation into the circumstances surrounding the provision of care to Rebecca O'Malley, in relation to Symptomatic Breast Disease, the Pathology Services at Cork University Hospital and Symptomatic Breast Disease Service at the Mid Western Regional Hospital, Limerick (HIQA, March 2008); Report of the Investigation into the provision of services to Ms A by the Health Service Executive at University Hospital Galway in relation to her Symptomatic Breast Disease, and the provision of Pathology and Symptomatic Breast Disease Services by the Executive at the Hospital (HIQA, July 2008); and Report of the Investigation into the Quality and Safety of services and supporting arrangements provided by the Health Service Executive at the Mid-Western Regional Hospital Ennis (HIQA, April 2009).

<sup>543</sup> Section 40 of the Health Act 2007.

<sup>544</sup> Section 2 of the Health Act 2007.

<sup>545</sup> Section 41(1)(c) of the Health Act 2007.

41(c)(ii) of the Health Act 2007, the Chief Inspector of Social Services is obliged to assess whether such services comply with, *inter alia*, standards set by HIQA, such as the *National Quality Standards: Residential Services for People with Disabilities*.

9.35 The sections of the Health Act 2007 conferring inspection and registration functions on the Chief Inspector of Social Services in respect of disability services were expected to have commenced by 2009. In a letter to the Commission in March 2008, HIQA indicated that residential centres such as the Centre would be “designated centres” under the Health Act 2007 and as such would be subject to inspections by the inspectors of the Office of the Chief Inspector who would register those centres with HIQA on the basis of compliance with HIQA Standards.<sup>546</sup> At the time of writing this report, these sections have not yet been commenced. Indeed, in May 2009, the Government announced that these sections of the legislation would not be commenced due to cutbacks in health spending, with no indication of when inspections might be commenced. According to the Minister for Equality, Disability and Mental Health, Mr John Moloney TD:

Given the current fiscal situation, it was not proposed to move to full statutory implementation of the standards, including regulation and inspection, at this time.<sup>547</sup>

9.36 The obligation on designated centres to implement the standards and on the Chief Inspector of Social Services to register and inspect such centres have therefore not been placed on a statutory footing. Rather, it would appear that the Standards may be more regarded as a voluntary code rather than a legal obligation.<sup>548</sup> There is thus at present no registration or inspection system in the State for residential services for persons with a disability.

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<sup>546</sup> Letter from HIQA to the Commission, dated March 2008.

<sup>547</sup> Quotation attributed to the Minister for Equality, Disability and Mental Health, Mr John Moloney TD in Irish Times, ‘Cutbacks Hit Disability Guidelines’, Monday 11 May 2009.

<sup>548</sup> See discussion in Chapter 6 regarding plans to enforce HIQA standards through, *inter alia*, service level agreements. In its letter of March 2008 to the Commission, HIQA had stated that Departmental regulations would need to underpin decisions about the registration of designated centres.

9.37 In December 2009, the Department of Health indicated to the Commission that, notwithstanding the difficulties of immediate statutory implementation of the HIQA's National Quality Standards, the Department, the HSE and HIQA have agreed that progressive implementation of the Standards will now commence. Both the Department and HSE stated that HIQA's National Quality Standards will become a benchmark against which the HSE assesses both its own directly-operated facilities and other facilities that the HSE funds.<sup>549</sup>

9.38 In response to a query from the Commission, the Brothers of Charity indicated its view that the services provided at the Centre are substantially compliant with HIQA's National Quality Standards.<sup>550</sup> However, as the registration and inspection systems for such services, as provided for under the Health Act 2007, may not now be given statutory footing, it would appear that an independent assessment of the level of compliance at the Centre specially with the Standards will not be conducted in the near future and in the long term remains uncertain.<sup>551</sup>

9.39 In December 2009, the Department informed the Commission that an implementation plan (July 2009) for the recommendations of the Ryan Commission Report (into the abuse of children in institutional settings) contains a commitment that the Health Act 2007 will be commenced to allow the independent registration and inspection of all residential centres and respite services for children with a disability by December 2010.<sup>552</sup> However, it is noted that this system of registration and inspection for children with a disability, while welcome, will not benefit the individuals in the Centre.

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<sup>549</sup> Letter from the Department of Health and Children to the Commission, dated 14 December 2009. According to the letter and as noted previously, discussions are ongoing regarding the development of self-assessment tools, providing awareness training for service providers and the introduction of an appropriate level of external validation for relevant settings.

<sup>550</sup> Letter from the Brothers of Charity Services Galway to the Commission, dated 14 July 2009, pp. 7 to 10.

<sup>551</sup> *Ibid.*

<sup>552</sup> *Ibid.*

## Other Oversight/ Accountability Structures

### *HSE Review Report*

9.40 As noted previously, the HSE commissioned an *ad hoc* review of the Centre in 2007 following notification by the Commission of its decision to conduct an enquiry into services provided at the Centre. The review was conducted within a short timeframe and with limited resources available to it and the resulting report (HSE Review Report) was completed in February 2008 and is examined in Chapter 7. The HSE has now indicated that in addition to self-audits by service providers (see Chapter 6), it intends to put in place capacity in each HSE region to allow it to carry out reviews of services “where required, either on a routine basis or in response to identified concerns”.<sup>553</sup> Thus it has confirmed that regular Reviews by the HSE will occur from 2010. As noted however, despite Government plans in relation to children with disabilities, there is no independent monitoring mechanism for services to persons with intellectual disabilities, given the non-implementation of aspects of the Health Act 2007.

### *The Council on Quality and Leadership*

9.41 As discussed in Chapter 7, the Brothers of Charity informed the Commission that it has established a personal outcome plan system at the Centre for all individuals, which is provided and accredited by the Council on Quality and Leadership (“CQL”), an American based not-for-profit organisation. CQL provides this system on a four-year term and conducts three site visits over this period. The Brothers of Charity indicated that like other voluntary bodies, it had decided to engage in an external evaluation of its services in the years before HIQA was established and that it has put considerable effort into acquiring accreditation in what it describes as a robust and rigorous accreditation process by the CQL.

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<sup>553</sup> Letter from the HSE to the Commission, dated 11 December 2009.

## Chapter 10: Standards for Persons with a Severe to Profound Intellectual Disability

10.1 Established in April 1948,<sup>554</sup> the World Health Organization (“WHO”) is a specialised agency of the United Nations which acts as the directing and coordinating authority for international public health. In assessing intellectual disability, the WHO employs the International Statistical Classification of Diseases and Related Health Problems (ICD-10: World Health Organization, 1992) which defines intellectual disability using four classifications ranging from mild intellectual disability to profound intellectual disability.<sup>555</sup>

Whilst no one definition of intellectual disabilities has gained universal acceptance, it is generally accepted that the term intellectual disabilities encompasses any set of conditions, resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, that affect intellectual development. These conditions result in a lifetime of lower than average overall capacity for self-determination and general independent functioning and performance in vocational, social, and personal functions. In some instances these conditions may occur in conjunction with physical, sensory or psychiatric impairments of varying degree. Such conditions have variable impact on the individual, from minimal to severe. They can be compensated for by a variety of interventions, enrichments, training and/ or special assistance or supports in all spheres of life.

*World Health Organization (2000), Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing: Summative Report (Geneva, Switzerland, World Health Organization), at p. 5*

10.2 The most recent (2007) version of the ICD-10 classification system provides that intellectual disability is a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the early developmental period, skills which contribute to the

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<sup>554</sup> 7 April is now the annual United Nations World Health Day.

<sup>555</sup> ICD-10 was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in WHO Member States as from 1994. In addition, the WHO has developed a complementary International Classification of Functioning, Disability and Health which is discussed below.

overall level of intelligence, i.e. cognitive, language, motor and social abilities.<sup>556</sup> Intellectual disability can occur with or without any other mental or physical condition. The four classifications of intellectual disability are:

#### WHO - Four Classifications of Intellectual Disability

**Mild intellectual disability** – ICD 10 F70: Approximate IQ range of 50 to 69 (in adults, mental age from 9 to under 12 years). Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.

**Moderate intellectual disability** – ICD 10 F71: Approximate IQ range of 35 to 49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.

**Severe intellectual disability** – ICD 10 F72: Approximate IQ range of 20 to 34 (in adults, mental age from 3 to under 6 years). Likely to result in continuous need of support.

**Profound intellectual disability** – ICD F73: IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility.<sup>557</sup>

10.3 In addition, the WHO has developed a complementary International Classification of Functioning, Disability and Health (“ICF”), which aims to stress the health status of individuals, as opposed to their disability.<sup>558</sup> The ICF integrates both medical and social models of disability and defines functioning and disability as multi-dimensional concepts relating to: (1) the body functions and structures of people, (2) the activities people do and the life areas in which they participate and (3) the factors in their environment

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<sup>556</sup> Degrees of intellectual disability are conventionally estimated by standardised intelligence tests. These can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of intellectual disability and diagnosis will also depend on the overall assessment of intellectual functioning by a skilled diagnostician.

<sup>557</sup> WHO, International Statistical Classification of Diseases and Related Health Problems 10th Revision - Version for 2007. See further [www.who.int](http://www.who.int).

<sup>558</sup> The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (Resolution WHA 54.21).

which affect these experiences.<sup>559</sup> The ICF examines such factors as body functions, body structures, impairments, activity, participation, activity limitations, participation restrictions and environmental factors. In the ICF, a person's functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors.<sup>560</sup> The interaction between the components of the ICF are illustrated in Figure 10 below.

#### 10.4 According to the WHO:

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed ICF [...] records the impact of the environment on the person's functioning.<sup>561</sup>

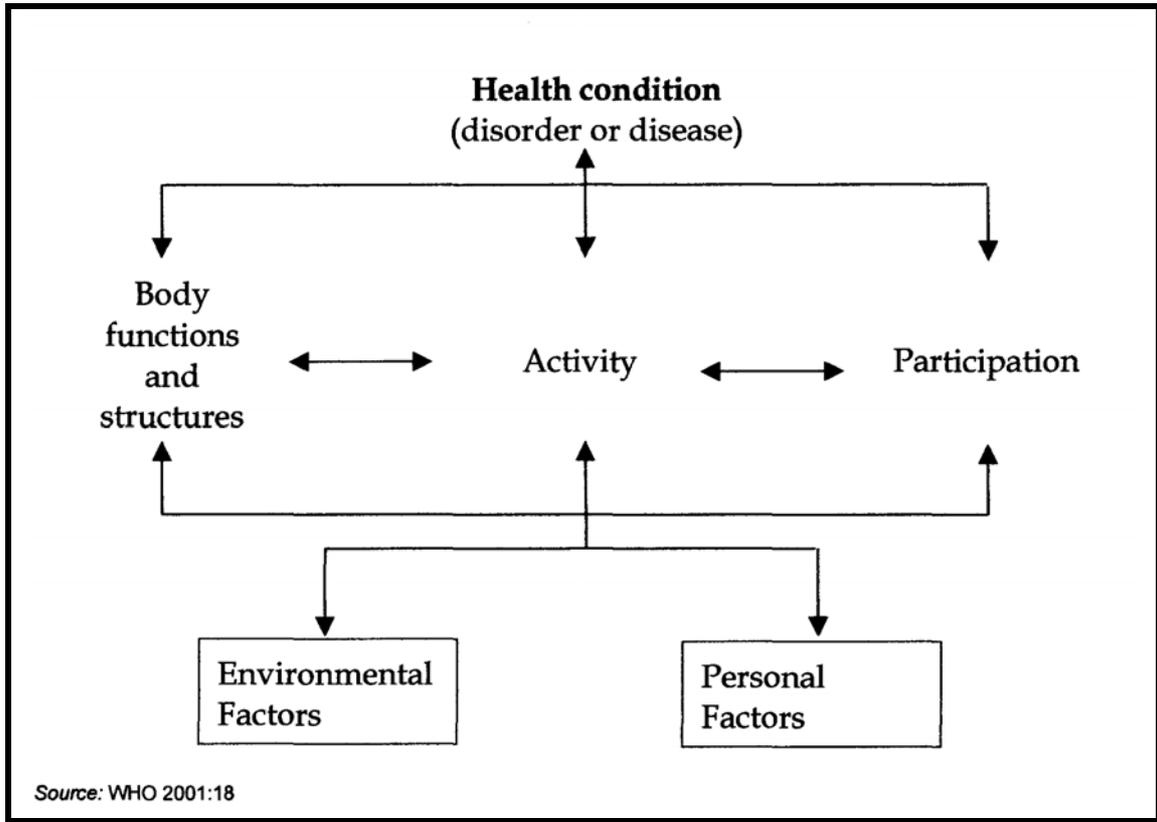
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<sup>559</sup> See further Australian Institute of Health and Welfare; ICF Australian User Guide Version 1.0, October 2003 (ISBN 1740243161).

<sup>560</sup> Although Personal Factors are recognised in the interactive model shown in Figure 9, they are not classified in, and are beyond the scope of, the ICF. Such factors might include age, sex, and Indigenous status and would be selected by users according to the application.

<sup>561</sup> WHO; International Classification of Functioning, Disability and Health (ICF), see further [www.who.int/classifications/icf/en](http://www.who.int/classifications/icf/en)

Figure 10: Interactions between the components of the ICF



10.5 The WHO states that the overriding goal of services providing physical and mental health care to persons with intellectual disabilities should include the acceptance of basic principles, such as the maintenance of respect for the individual and his or her family, inclusion of the person's needs and wishes in any support plan, and development of support plans that are minimally restrictive, culturally sensitive and which foster the growth and autonomy of the person.<sup>562</sup>

10.6 According to the WHO, the social value of properly functioning intellectual disability services can be demonstrated by positive outcomes in the lives of persons with intellectual disabilities, such as:

<sup>562</sup> WHO, Ageing and Intellectual Disabilities: Improving Longevity and Promoting Healthy Ageing, Summative Report (2000) (Geneva, Switzerland,), at p. 16.

- Practical, leisure, or life enhancing skills (such as those involved in self-determination and those which allow a person to access common opportunities offering enduring benefits);
- Improved or maintained dietary and general health status that prevents physical health factors from hindering typical activity;
- A varied rhythm of life;
- Recognition that challenge and productivity must continue throughout old age;
- An increased and well-established social network; and
- Participation on a regular basis in the general life of the community, with friends and acquaintances of one's preference.<sup>563</sup>

## WHO: Person-Centred Approach

10.7 The WHO has emphasised the importance of a 'person-centred approach' to care for people with intellectual disabilities:

It is important that health care providers and policy makers acknowledge that many people with intellectual disabilities have special needs which may require modification of standard health care practices and service models...<sup>564</sup>

10.8 The WHO notes that the conditions associated with intellectual disabilities often result in a lifetime of lower than average overall capability for self-determination and general independent functioning, but that this can be compensated for by a variety of interventions and enrichments.<sup>565</sup> Through the implementation of plans to meet the requirements of individual needs assessments, including through targeting positive lifestyle factors and the key role played by multidisciplinary care in meeting these needs, the WHO posits that there is potential to substantially improve life-expectancy rates, older-age quality of life and functional capability for persons with intellectual disabilities.<sup>566</sup>

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<sup>563</sup> *Ibid.*

<sup>564</sup> *Ibid.*, at pp. 15 to 16.

<sup>565</sup> *Ibid.*, at p. 5.

<sup>566</sup> *Ibid.*, at pp. 8 to 9.

## HIQA: Standards for the Assessment of Need

10.9 The emphasis placed by the WHO on adopting a person-centred approach to care for people with disabilities is specifically recognised in the first of the *Standards for the Assessment of Need* (Assessment Standards) adopted by HIQA in May 2007.<sup>567</sup> As discussed above in Chapter 5, the Disability Act 2005 provides for the HSE to undertake assessments of needs of persons with a disability.<sup>568</sup> Such assessments are for the purpose of determining the health service needs and, where appropriate, the education needs of persons with disabilities and for identifying the health or education services required to meet those needs.<sup>569</sup> Although the extension to adults with disabilities of the statutory requirements applicable to assessments of needs under the Disability Act 2005 had originally been scheduled for no later than 2011, the decision was taken, in Budget 2009, to defer the further implementation of the Act of 2005.<sup>570</sup> The Assessment Standards state that:

Standards for the *Assessment of Need* are the desired and achievable levels of performance against which actual performance can be measure. Each standard has a number of criteria. These criteria are measurements, by which the meeting of each standard will be judged. Under the legislation and regulations the *Assessment of Need* must be conducted in accordance with specific standards. The standards are intended to ensure that each *Assessment of Need* is conducted in a consistent manner in order to identify the needs of the person being assessed, accurately and efficiently.

These standards aim to put the “person” at the centre of the *Assessment of Need* process. The “person” referred to throughout these standards is the person undergoing the *Assessment of Need* who may have a disability and/ or special education need.<sup>571</sup>

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<sup>567</sup> Adopted by the Board of the interim HIQA. The adoption of the *Standards for the Assessment of Need* by HIQA in 2007 followed a drafting process established by the Department of Health and the Department of Education in October 2006 which involved representatives from both Departments as well as from the HSE and the National Council for Special Education. See further HIQA, *Standards for the Assessment of Need* (May 2007), p. 6

<sup>568</sup> Section 8 of the Disability Act 2005.

<sup>569</sup> See Chapter 5.

<sup>570</sup> Letters from the Department of Health to the Commission, dated 14 December 2009. See further Chapter 5.

<sup>571</sup> HIQA, *Standards for the Assessment of Need* (May 2007), p. 5.

10.10 There are six Assessment Standards as set out below, and these are now being applied to children under the age of five years but not to other children or adults:<sup>572</sup>

Heading	Assessment Standards
<b>Person Centred Approach</b>	The <i>Assessment of Need</i> is person centred at all stages. The person is enabled to express what is important to him/ her as a person. The <i>Assessment of Need</i> is built around the person, appreciates the person as an individual and focuses on outcomes important to him/ her.
<b>Information</b>	Accurate information and records regarding the <i>Assessment of Need</i> process are provided, communicated and maintained in a way that is accessible, understandable and in a manner that is appropriate for all persons.
<b>Access to the Assessment of Need</b>	The <i>Assessment of Need</i> will be easy to access, responsive to the needs of those requiring the service and conducted in a timely manner in accordance with legislation.
<b>Involving Appropriate Education and Health Staff</b>	Staff engaged in the <i>Assessment of Need</i> process will be competent in conducting or co-ordinating a high quality Assessment of Need. Recruitment, management and on-going training practices will support the achievement of a high quality <i>Assessment of Need</i> .
<b>Coordination of the Assessment of Need:</b>	<i>Assessment of Need</i> is effectively coordinated in order to accurately identify the needs of the person and to achieve a comprehensive report for the person.
<b>Monitoring and Review</b>	The implementation of the Standards is regularly evaluated by the <i>Assessment of Need</i> provider, and independently monitored by HIQA, in order to ensure that <i>Assessments of Need</i> are conducted to an agreed level of quality.

### Multidisciplinary Support Services in Ireland: Identifying Unmet Need

10.11 The Assessment Standards place emphasis on assessments taking a multidisciplinary format. Criteria 5.1 of the Assessment Standards provides that:

<sup>572</sup> See further discussion of Disability Act 2005 in Chapter 5.

### Assessment Standards - Criteria 5.1

The Assessment Co-ordinator ensures that all aspects of the *Assessment of Need* process are effectively coordinated. The Assessment Co-ordinator ensures that:

...

A multi-disciplinary format for the *Assessment of Need* is used where appropriate.

10.12 Multidisciplinary services are described as including medical services, nursing, nutrition, occupational therapy, physiotherapy, psychiatry, psychology, social work and speech and language therapy.<sup>573</sup> It is widely accepted that multidisciplinary services can be central for the development of basic life skills for individuals with intellectual disabilities. It appears, however, that there is no one single mode of multi disciplinary services that meets the needs of all persons with intellectual disabilities, as all individuals have different needs. However, assessments of needs should meet certain minimum standards and the needs, properly identified, should be met.

10.13 Regarding the early intervention of coordinated multidisciplinary services, a number of major research studies from the last two decades have established the importance of such intervention in the lives of children with intellectual disabilities.<sup>574</sup> This research provides evidence that individualised multidisciplinary programmes can have optimal outcomes for children with intellectual disabilities.

10.14 In December 2008, there were 26,023 persons with intellectual disabilities registered on the Health Research Board's National Intellectual Disability Database (NIDD).<sup>575</sup> Three quarters (19,512) of the persons registered on the NIDD require a new or enhanced multidisciplinary support service in the

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<sup>573</sup> Health Research Board, *Annual Report of the National Intellectual Disability Database Committee 2007*, p. 92.

<sup>574</sup> For a detailed discussion regarding the importance of early intervention programmes for children with disabilities see McGough et al; *Early Years Provision for Children from Birth to Six Years with Special Needs in Two Geographical Areas in Ireland*, (2006) Dublin, CECDE Research Series 2006.

<sup>575</sup> Health Research Board, *National Intellectual Disability Database Annual Report 2008*, p. 12.

period 2009 to 2013 and there is substantial demand for all the therapeutic inputs, in particular, psychology, speech and language therapy and occupational therapy.<sup>576</sup> Regarding the level of multidisciplinary support services in Ireland for people with intellectual disabilities, the Health Research Board in its NIDD Annual Report 2008 has thus identified significant unmet needs.<sup>577</sup>

10.15 While there has been recent growth in services for persons with an intellectual disability, demographic factors and historical under-funding of intellectual disability services are contributing to long waiting lists for these services.<sup>578</sup> Demand for these services is expected to continue into the future and the Health Research Board believes that considerable planning and investment is required to address this.<sup>579</sup>

### ***Preferred delivery model for services***

10.16 The issue of how best to develop future services for persons with intellectual disabilities is a complex and evolving area. Recent research funded by the National Disability Authority (“NDA”) supports the contention that the appropriate residential setting for delivering services is dispersed housing in community settings.<sup>580</sup> This type of accommodation has been determined to provide better outcomes for persons with intellectual disabilities than clustered, campus style housing.<sup>581</sup> The research found that:

Dispersed housing appears to be superior to clustered housing on the majority of quality indicators studied. The only exception to this is that village communities of people with less severe disabilities have some benefits; this is not, however, a

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<sup>576</sup> *Ibid.*

<sup>577</sup> See Chapter 6.

<sup>578</sup> Health Research Board, National Intellectual Disability Database Annual Report 2008, p. 83.

<sup>579</sup> *Ibid.*

<sup>580</sup> The National Disability Authority is the independent state agency which advises the Irish Government on disability issues. See further [www.nda.ie](http://www.nda.ie).

<sup>581</sup> Mansell, J. & Beadle-Brown, J, Dispersed or Clustered Housing for Disabled Adults: A Systematic Review (2009), Tizard Centre and National Disability Authority. The research reviewed 19 academic papers based on 10 qualitative studies comparing dispersed housing and clustered housing and analysed ‘quality of life’ domains (such as social inclusion, material well-being, self-determination, personal development and rights) and ‘physical well-being’ domains (such as access to recreational activity, health care and contact with family and friends).

model which can be feasibly provided for everyone. Clustered housing is usually less expensive than dispersed housing but this is because it provides fewer staff. There is no evidence that cluster housing can deliver the same quality of life as dispersed housing at a lower cost.<sup>582</sup>

10.17 The NDA also commissioned a literature review on the quality and costs of supported accommodation for people with intellectual disabilities in different types of residential settings.<sup>583</sup> Although it was noted that research gaps existed for persons with severe levels of disability, a number of findings of the report included consistent evidence that the personal skills of people with intellectual disabilities typically improve immediately following deinstitutionalisation from large State-run institutions. Participation in community-based activities was also enhanced following deinstitutionalisation and increased social networks and relationships were reported, particularly in community-based, smaller, and more independent settings. Other findings were that smaller and more independent residential options were seen to promote choice and self determination and that any personal skill development was more observed in smaller dwellings. Similarly, the report referred to dispersed community-based options offering a better quality of life to campus-type settings and cluster housing and that there was an increased quality of life in small to medium sized organisations and in more independent settings for people with less severe intellectual disabilities.<sup>584</sup>

10.18 As noted previously, the Brothers of Charity has informed the Commission that it plans to move a number of residential services out of the Centre – which is an example of campus style housing - over time and into dispersed community based housing, subject to the views of the individuals involved.<sup>585</sup> This process

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<sup>582</sup> *Ibid.*, p. 7.

<sup>583</sup> See National Disability Authority; Supported Accommodation Services for People with Intellectual Disabilities: A Review of Models and Instruments used to Measure Quality of Life in Various Settings, (2008). As noted, the review concluded that research gaps existed including for specific groups of residents such as those with more severe levels of disability.

<sup>584</sup> *Ibid.*, see Executive Summary pp.4-7.

<sup>585</sup> See Chapter 6. In November 2009, the Brothers of Charity indicated that its current view is to facilitate people to live in ordinary communities in the same way as the general population and in accordance with best practice standards, but that it also recognises that this may not be the desire of all and that on that basis they do not maintain that all individuals need to move from the Centre to community houses.

has already begun and is in keeping with Goal Three of the Brothers of Charity's current Strategic Plan which promotes such a move, subject to the wishes of the individuals in the Centre. Thus, as discussed in Chapter 6, it appears to be the case that the Brothers of Charity envisages that a number of residents will remain in the Centre for the foreseeable future through re-developing the current Centre site.

**Brothers of Charity - Strategic Plan 2007**

**Goal Three:** We will support people to be active citizens in their local community and to participate and interact as much as they wish.

**Objective One:** We will facilitate individuals to participate in their local community. ... We will prioritise the movement of individuals living in campus facilities to living in the community to facilitate active citizenship and inclusion. We will facilitate service users who wish to move.<sup>586</sup>

10.19 In relation to moving residential individuals in the Centre to dispersed accommodation in the community, the Brothers of Charity cite academic studies in support of this policy:

There is extensive evidence on the overall benefits of deinstitutionalisation (Keith 1990; Mansell 2006). Kim et al (2001) reviewed 29 comparative studies (institutional versus community living) that were conducted in the United States between 1980 and 1999. The majority of the studies reported the more positive effects of community living. The Center of Human Policy, Syracuse University (1997) conducted a study: 'The Community Imperative' in conjunction with lists of participating organisations which concluded that:

"Supports for people with disabilities should be provided in a manner that recognises people's inherent competence; reflects the personal preferences of each individual; conveys that the person receiving services is a valued, respected community participant; and assists individuals to achieve self-determined lives of mastery, satisfaction, and meaning. Such supports can only be provided in community settings. We therefore refute all arguments for institutionalising anyone on the basis of disability. All people have functional moral and constitutional rights. ... People with significant behavioural issues and those with significant health concerns can be provided quality care and lead quality lives in the community".<sup>587</sup>

<sup>586</sup> Brothers of Charity, 'From Vision to Action': Adult Services Strategic Plan 2007 to 2012 p. 9.

<sup>587</sup> *Ibid.*

10.20 The HSE Review Report, however, recommended an alternative model for the future development of services, including residential services, based on the re-development of the service on the existing site. As outlined in Chapter 6, some members of the Parent Group whose children are still resident at the Centre have misgivings about the proposed movement of their adult children from campus based residential services to dispersed housing in the community.

### **HIQA: National Quality Standards for Residential Services for Persons with Disabilities**

10.21 As discussed in Chapter 9, HIQA published *National Quality Standards: Residential Services for People with Disabilities* (National Quality Standards) in May 2009.<sup>588</sup> These National Quality Standards have been developed for the purpose of defining what a good quality service for persons with disabilities should be. The development of the National Quality Standards was specifically linked to the registration and inspection mechanisms for residential services for persons with disabilities under the Health Act 2007.

10.22 The National Quality Standards are designed to assist the HSE and Service Providers to assess the quality of the services they provide in advance of inspection and to act as a guide to individuals and families as to what they can reasonably expect of a residential service. As stated previously, the sections of the Health Act 2007 conferring inspection and registration functions on the Chief Inspector of Social Services in respect of disability services have not been commenced. They are, however, referred to in the transitional Service Level Arrangement between the Brothers of Charity and the HSE.<sup>589</sup>

10.23 The National Quality Standards are grouped into seven 'sections' which are deemed to reflect the dimensions of a person-centred quality service and this

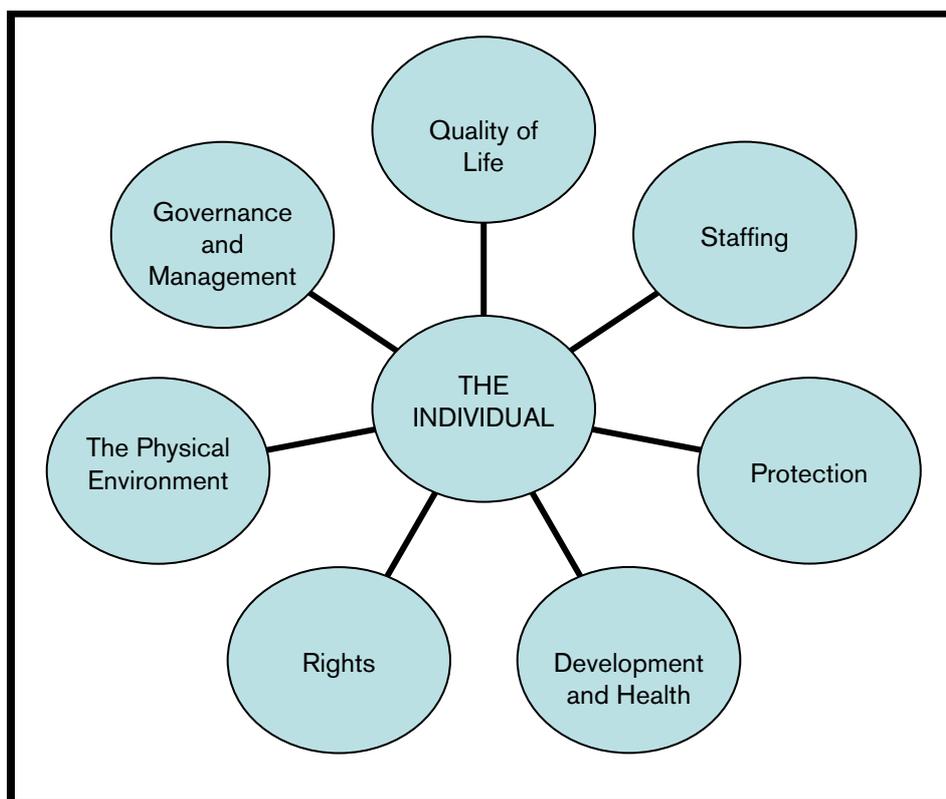
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<sup>588</sup> HIQA's *National Quality Standards: Residential Services for People with Disabilities* (National Quality Standards) are not to be confused with HIQA's *Standards for the Assessment of Need* (Assessment Standards).

<sup>589</sup> See Chapter 6.

is illustrated in Figure 11 below.<sup>590</sup> Each of these sections consist of ‘Standards’ – there are a total of nineteen Standards - setting out what is expected of services and ‘criteria’ setting out how service delivery is assessed.

**Figure 11: HIQA - The seven dimensions of a quality service**



### ***Section 1 - Quality of Life***

10.24 The HIQA National Quality Standards adopt the view that the purpose of residential services for persons with disabilities is to provide individuals with the supports necessary to lead a fulfilling life. Each individual should be facilitated to exercise choice and control over his/ her life and privacy and dignity should be respected. Daily life should be structured in such a way as to accord with each individual's preferences and support is to be afforded to developing personal

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<sup>590</sup> The seven dimensions of a quality service are taken from HIQA's 'National Quality Standards: Residential Care Settings for Older People in Ireland'.

relationships and social contacts, such as links with the community, as per each person's wishes.

1 - Quality of Life	
<b>Standard 1</b>	Autonomy and Participation: Each individual exercises choice and control over his/her life and over his/her contribution to his/her community.
<b>Standard 2</b>	Privacy and Dignity: The privacy and dignity of each individual is respected and promoted.
<b>Standard 3</b>	Daily Life: Each individual's daily life is structured in accordance with his/her preferences.
<b>Standard 4</b>	Personal Relationships and Social Contacts: Each individual is supported to develop and maintain personal relationships and links with the community in accordance with his/her wishes.

## ***Section 2 – Staffing***

10.25 The HIQA National Quality Standards recognise that staff working with persons with disabilities have a major impact on the quality of life of those individuals. While having the requisite skills is vital among staff, qualities such as respect, empathy and enthusiasm are acknowledged as being equally important. Persons with disabilities should receive sensitive and personalised support in accordance with his/ her wishes and aspirations.

2 – Staffing	
<b>Standard 5</b>	Each individual receives sensitive and personalised support in accordance with his/her wishes and aspirations from an adequate number of staff who are selected in accordance with best recruitment practice and who possess the appropriate personal qualities, experience, qualifications, competencies and skills.

### Section 3 – Protection

10.26 The HIQA National Quality Standards emphasise that freedom from fear and the assurance that basic needs will be met are prerequisites for an acceptable quality of life. Persons with disabilities living in residential care are to be safeguarded and protected from abuse.<sup>591</sup> Each individual should exercise control over personal finances and is to be protected from financial abuse and exploitation.

3 – Protection	
Standard 6	Safeguarding and Protection: Each individual is safeguarded and protected from abuse.
Standard 7	The Individual's Finances: Each individual exercises control over personal finances and is protected from financial abuse and exploitation.

### Section 4 – Development and Health

10.27 The HIQA National Quality Standards regard personal planning as a means of organising services to ensure that they support individuals with a disability in their personal development. Each individual should have a personal plan in place to maximize his/ her personal development with his/ her wishes. Individuals should enjoy the best possible health, as this is regarded as essential to the fulfilment of life plans. Health needs of each individual should be assessed and met.

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<sup>591</sup> Criterion 6.11 of the HIQA National Quality Standards governs behaviour that poses a risk to the safety of individuals. It is noted under this heading that there is no regulation or specific guidance in relation to the use of restrictive interventions in residential settings for persons with an intellectual disability. In this regard the Standards refers to the guidance documents published by the Mental Health Commission which offer guidance in relation to the use of restrictive practices in a psychiatric care setting as follows: *Rules Governing the Use of Seclusion and Mechanical Means of Bodily Restraint* (Ref No.: R-S69(2)/02/2006, *Code of Practice on the Use of Physical Restraint in Approved Centres* (Ref No.: COP-S33(3)/02/2006, *Code of Practice (2009): Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities*.

#### 4 - Development and Health

<b>Standard 8</b>	Personal Plan: Each individual has a personal plan to maximise his/her personal development in accordance with his/her wishes.
<b>Standard 9</b>	The health needs of each individual are assessed and met.

#### Section 5 – Rights

10.28 The National Quality Standards affirm that persons with disabilities are citizens with rights. They should not be expected to give up their rights in exchange for services nor should they be treated primarily by reference to their status as people with disabilities. Each individual should have access to understandable information to inform his/ her decision making. The right of each individual to make decisions is to be respected and his/ her informed consent is to be obtained in accordance with legislation and best practice guidelines. Each individual should be facilitated and supported to exercise his/ her civil and political rights. Admission and discharge procedures should be decided on the basis of fair and transparent criteria. Complaints from individuals should be listened to and acted upon in a timely and effective manner.

#### 5 - Rights

<b>Standard 10</b>	Information: Each individual has access to information provided in a format appropriate to his/her communication needs, to inform his/her decision making.
<b>Standard 11</b>	Informed Decision Making and Consent: The right of each individual to make decisions is respected and his/ her informed consent is obtained in accordance with legislation and current best practice guidelines.
<b>Standard 12</b>	Citizenship Rights: Each individual is facilitated and supported to exercise his/her civil and political rights, in accordance with his/ her wishes.
<b>Standard 13</b>	Admission Processes and Individual Service Agreements: Each individual's admission and discharge is determined on the basis of fair and transparent criteria and his/her placement is based on a written agreement with the registered provider.
<b>Standard 14</b>	Complaints: The complaints of each individual are listened to and acted upon in a timely and effective manner.

## ***Section 6 – The Physical Environment***

10.29 The National Quality Standards emphasise the importance of individuals with a disability being able to access all the facilities within residential services. The management of risks and safety concerns should be informed by, and balanced against, the need to ensure a good quality of life for individuals with a disability. Residential services should be homely and accessible and promote the privacy and dignity of each individual. The HIQA Standards aim to ensure that the health and safety of each individual, staff and visitors to the residential services are promoted and protected, while safeguarding each individual's right to a good quality of life.

<b>6 - The Physical Environment</b>	
<b>Standard 15</b>	The Living Environment: The residential service is homely and accessible and promotes the privacy and dignity of each individual.
<b>Standard 16</b>	Health and Safety: The health and safety of each individual, staff and visitors to the residential service are promoted and protected, while safeguarding each individual's right to a good quality of life.

## ***Section 7 – Governance and Management***

10.30 The National Quality Standards provide that best practice in governance and management ensures that residential services are run effectively and efficiently. Residential services are to be organised and managed to achieve the outcomes described in the Standards and should be person-centred, meeting the needs of each individual with a disability. An accurate written statement of purpose and function, describing the services provided should be created for each residential service. Appropriate records and record-keeping policies should be in place to support individuals with a disability.

## 7 - Governance and Management

<b>Standard 17</b>	Governance and Management: The residential service is governed and managed in a manner that supports the creation and continuous improvement of a person-centred service that meets the needs of each individual and achieves outcomes for him/her consistent with his/her plans and aspirations.
<b>Standard 18</b>	Purpose and Function: There is a written statement of purpose and function that accurately describes the service that is provided and the manner in which it is provided.
<b>Standard 19</b>	Records: Each individual is supported by appropriate record keeping policies and procedures.

### Consent to Treatment

10.31 One issue which has arisen in the current enquiry with which the Brothers of Charity and the Parent Group have been dealing is that of how the individuals in the Centre consent to their treatment in the absence of any legal mechanism to establish one's capacity and how supported or substituted decision-making should operate.

10.32 The Royal College of Psychiatrists in the United Kingdom has issued good practice guidance in relation to the care of patients. One of the issues addressed is that of consent. The guidelines emphasise that where patients have capacity to make a decision, a psychiatrist must ensure that the patient's valid consent to any proposed treatment is sought and their decision recorded.<sup>592</sup> However, unlike the situation in this jurisdiction, the United Kingdom has introduced mental capacity legislation in recent years which supports the general position of consultant psychiatrists in that jurisdiction.<sup>593</sup>

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<sup>592</sup> The UK Royal College of Psychiatrists has also issued guidance in relation to seeking valid consent. See *Good Psychiatric Practice*, 3<sup>rd</sup> Ed, 2009 Royal College of Surgeons, College Report CR 154, at pp. 23-24. In this jurisdiction, see *Irish College of Psychiatrists to the Report of the Inspector of Mental Health Services 2005*, Irish College of Psychiatrists, February 2007 Recommendation 10 and more recently, see *Submission to the Department of Justice, Equality and Law Reform on the Proposed Capacity and Guardianship Legislation Preliminary Submission Paper - June 2009 on the Scheme of the Mental Capacity Bill, June 2009*, Prepared by a Working Group of CPsychl Human Rights, Ethics & Law Committee, The College of Psychiatry of Ireland, 2009, Recommendation 2 and pp. 11-13 generally.

<sup>593</sup> *Ibid.*; see also *Briefing on the Mental Capacity Bill*, UK Royal College of Psychiatrists, 2004 and the subsequent UK Mental Capacity Act 2005 and the UK Mental Health Act 2007; see generally Chapter 5 regarding the position in this jurisdiction.

## “Restrictive Practices”

10.33 It will be recalled that the Brothers of Charity has stated that it would welcome a legal framework within which any responses to challenging behaviour involving the use of “restrictive practices” such as physical restraint can be supported by legal protections for any such vulnerable adult. It also indicated to the Commission that it has in the past made contact with the Mental Health Commission and the Inspector of Mental Health Services to seek advice on the issue.<sup>594</sup>

10.34 In October 2009, the Mental Health Commission issued two Codes of Practice relating to “restrictive practices”: the *Code of Practice Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities* and the *Code of Practice on the Use of Physical Restraint in Approved Centres*; the latter code providing guidance on the principles underpinning the use of physical restraint in psychiatric institutions.<sup>595</sup> The *Code of Practice Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities* defines “restrictive practices” as including, but not being limited to “*the use of mechanical restraint, physical restraint, psychotropic medication as restraint and seclusion*”.<sup>596</sup> It states that “restrictive practices” should only be used where a person “poses an immediate threat of serious harm to self or others” and as a last resort and where alternative interventions to manage behaviour have been considered. It calls for a multidisciplinary assessment to be carried out as to why the behaviour is occurring and the likely

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<sup>594</sup> The Mental Health Commission is the independent statutory body established under the Mental Health Act 2001 whose principal functions as set out in Section 33 of that Act are to promote, encourage and foster the establishment and maintenance of high standards in the delivery of mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres under that Act.

<sup>595</sup> *Code of Practice on the Use of Physical Restraint in Approved Centres*, Part 1 and *Code of Practice Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities*, Part 3. See [www.mhcirl.ie](http://www.mhcirl.ie) These Codes of Practice were prepared in accordance with Section 33(3)(e) of the Mental Health Act 2001. The Mental Health Commission’s remit extends to “approved centres” as defined under Part V of the Mental Health Act 2001. “Approved centres” refer to psychiatric institutions or hospitals rather than residential centres for persons with disabilities.

<sup>596</sup> *Ibid*; Glossary.

impact on the person if a “restrictive practice” is used. Any intervention affecting a person’s liberty should be “the least restrictive and safest intervention” and be “in proportion to the risk posed”, being of the shortest duration possible. Finally, it states that “restrictive practices” should “never be used to ameliorate operational difficulties such as where there are staff shortages or defects in the environment”.<sup>597</sup>

10.35 The second code, the *Code of Practice on the Use of Physical Restraint in Approved Centres* while not directly applicable to residential centres for persons with disabilities, stresses that physical restraint should be used “*in rare and exceptional circumstances*” only to manage a resident’s unsafe behaviour where other alternatives have been considered, it should be strictly necessary, be proportionate with minimal force applied. The *Code of Practice* further provides that physical restraint should only be initiated and ordered by a doctor, registered nurse or other member of the multidisciplinary care team and that procedural protections apply.<sup>598</sup> It further stresses principles of the resident’s dignity and safety and that of internal review. Further, the *Code of Practice* provides that each incident be recorded and notified to the Inspector of Mental Health Services on request.<sup>599</sup>

10.36 The Department of Health and the HSE have also set in train a number of policy initiatives to address challenging behaviour in the workplace and this has also been reflected in the Criminal Justice Act 2006 which creates specific offences of assaulting or threatening to assault, resisting, wilfully obstructing or impeding doctors, psychiatrists, nurses, midwives, and other health service workers and any persons assisting them in or at a hospital.<sup>600</sup>

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<sup>597</sup> *Ibid.*

<sup>598</sup> *Ibid.*, Part 2.

<sup>599</sup> *Ibid.*

<sup>600</sup> See Section 185 of the Act. The Department of Health informed the Commission that a Working Group on the Management of Violence and Aggression in the Work Place was established in early 2006 under the auspices of the Health Services National Joint Council to develop a standardised, organisation wide strategy to address the issue of violence and aggression within the services provided by the HSE. The Group developed a strategy document entitled “Linking Service and Safety – Together Creating Safer Places of Service”. The Department advised that this report, published by the HSE in 2009, identifies a range of actions

## Children

10.37 In December 2009, the Department of Health advised the Commission that National Quality Standards on Residential Services for Children, including children with disabilities will be finalised in 2010.<sup>601</sup>

## Statutory Registration for Health and Social Care Professionals

10.38 In December 2009, the Department of Health advised the Commission of developments under the Health and Social Care Professionals Act 2005 which provides for the establishment of a system of statutory registration for certain health and social care professionals.<sup>602</sup> It advised that Speech and Language Therapy and Occupational Therapy are two of the twelve designated professions for registration set out in the 2005 Act; that registration of professionals would be by a registration board for each of the professions to be registered, that a Health and Social Care Professionals Council (launched in March 2007) would have overall responsibility for the regulatory system and a committee to deal with disciplinary matters. It indicated that the Social Work Registration Board should be established by the end of 2010 with other registration boards commencing in 2010.

10.39 The Department advised that the Health and Social Care Professionals Council will enable health and social care professionals to practice in a regulated, controlled and safe environment and in a manner which will ensure the provision

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to support staff in the management of violence and aggression in the workplace, including establishing: 1) a Project Joint Governance Committee which will take responsibility for overseeing the implementation of a programme of strategic actions in line with the agreed recommendations of this strategy, and direct the Central Project Office in the implementation of this work; 2) a Central Project Office to implement an effective organisational response to the management of work-related aggression and violence in line with the strategy; and 3) a Multi Agency Advisory Forum which will provide a consultation function with external stakeholders. The Department advised that the HSE has now confirmed that the Project Joint Governance Committee, the Central Project Office and the Multi Agency Advisory Forum will be established forthwith and that these structures would be charged with the responsibility to ensure that the recommendations of the report are implemented in the shortest possible timeframe: letter from the Department of Health to the Commission, dated 14 December 2009.

<sup>601</sup> *Ibid.*

<sup>602</sup> *Ibid.*

of high-quality interventions, meeting the challenges of increasingly complex and evolving care for service users. It also stated that health and social care professionals will be facilitated in ensuring responsible and accountable practices whilst providing the highest level of patient care and service.<sup>603</sup>

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<sup>603</sup> *Ibid.*

## Chapter 11 Relevant International Human Rights Standards

11.1 At least five international human rights standards are relevant to the matters considered in this enquiry insofar as they relate to the rights of adult persons with a severe to profound intellectual disability.<sup>604</sup> They are:

- **the rights to health and bodily integrity;**
- **the right to guidance, education and vocational training for persons with disabilities;**
- **the right to equality before the law and non-discrimination in the enjoyment of rights;**
- **the right to an effective remedy where a violation of rights occurs;**
- **the right to be treated with dignity, humanity and respect.**

11.2 A number of the rights referred to above also have their counterpart in the Irish Constitution, and these are noted where relevant.

### The Legal Obligations imposed on the State

11.3 In contemporary international human rights law, States are the primary duty bearers for the promotion and protection of human rights in international law.<sup>605</sup> By ratifying a convention, the State obliges itself to uphold the rights contained therein in its laws, policy and practice. In ensuring that the obligations contained in a convention are applied, States may impose legal obligations on both individuals and private enterprises. Importantly, where a private entity can be said to exercise a function of the State in relation to which a national or international obligation arises, it may be that there is State control in relation to the exercise of the function, either through legislative requirements or regulation, or both.<sup>606</sup>

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<sup>604</sup> Information on the agreements, treaties and conventions to which Ireland is a party are available on the Commission's website, [www.ihr.org](http://www.ihr.org) and at [www.unhcr.org](http://www.unhcr.org)

<sup>605</sup> See for example Article 1 of the European Convention for the Protection of Human Rights and Fundamental Freedoms.

11.4 Conventions often include an individual complaints mechanism whereby an individual, group or organisation may be able to directly petition an international body claiming violation of their rights, for example, complaints may in certain circumstances be brought before the European Court of Human Rights (the “European Court”) or the European Court of Justice. Thus, an individual may be able to bring a case through the national system (national courts) and into the international system if they feel their rights have been violated. For the purposes of recourse to international complaints mechanisms, complaints can only be made directly against the State (as the primary duty bearer in relation to the rights involved).

11.5 The UN Convention on the Rights of Persons with Disabilities (“CRPD”) was adopted by the UN General Assembly on 13 December 2006,<sup>607</sup> and was the first comprehensive human rights treaty of the 21<sup>st</sup> Century.<sup>608</sup> Its fundamental purpose is to:

promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.<sup>609</sup>

11.6 The CRPD encompasses a range of rights that affect the everyday lives of persons with disabilities, such as, reasonable accommodation (Article 2); accessibility (Article 9); the right to life (Article 10); legal capacity (Article 12); freedom from exploitation, violence and abuse (Article 16); protection of mental and physical integrity of the person (Article 17); living independently in the community and participation in the community (Article 19); personal mobility (Article 20); freedom of expression (Article 21); health (Article 25); education (Article 24); work and employment (Article 27); habilitation and rehabilitation

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<sup>606</sup> General Comment No 5, para 11 CESCR Committee, and General Comment no. 14 CESCR Committee, para 26 (discussed below). See also UN Convention on the Rights of Persons with Disabilities, *inter alia*, Articles 4, 25 and 26.

<sup>607</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.

<sup>608</sup> Ambassador Don MacKay, *The Convention on the Rights of Persons with Disabilities, A Benchmark for Action*, 56 Int. Rehabilitation R. 1, 2 (2007).

<sup>609</sup> Convention on the Rights of Persons with Disabilities, Article 1.

(Article 26); adequate standard of living and social protection (Article 28); participation in political and public life (Article 29); participation in culture, recreation, leisure and sport (Article 30); and equality and non-discrimination (Article 5).<sup>610</sup>

11.7 The CRPD stresses that persons with a disability should be fully integrated in the community and be able to live with optimum independence and functionality. This approach is based on a presumption of the legal capacity of individuals with disabilities insofar as any consideration of capacity must start from the position that merely having a disability does not *per se* remove one's legal capacity to take decisions and that a person only loses legal capacity after a formal determination to that effect.

11.8 The CRPD was signed by Ireland in 2007 but has yet to be ratified. Due to the fact that the convention represents a contemporary international baseline for disability rights, relevant provisions of the CRPD will be noted in this Chapter. However, it must be stressed that, as the CRPD has yet to be ratified, its provisions do not yet come within the meaning of Section 2 of the Human Rights Commission Act 2000 (that is, it is not within the definition of 'human rights' for the purposes of the Commission's mandate) and accordingly neither this Chapter nor the Report's analysis or conclusions will draw conclusions on the basis of its provisions. It must also be noted that the Convention on the Rights of the Child is not discussed in this Chapter as it has relevance only to *children* with intellectual disabilities, rather than adults.

11.9 While some constitutional rights offer a strong degree of protection to individuals for example in relation to the right to due process and the right to freedom from arbitrary detention, other constitutional rights are less developed, such as the rights to health and bodily integrity and to education, guidance, vocational training and habilitation/ rehabilitation, respectively, including in relation

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<sup>610</sup> See also MacKay, *op. cit.*, at p. 2.

to persons with a severe to profound intellectual disability.<sup>611</sup> As constitutional standards come within the meaning of section 2 of the Human Rights Commission Act 2000, relevant constitutional rights are noted at the outset of each section. The enquiry focuses, however, on international human rights standards and the analysis is based on those international standards.

11.10 Similar to the United Kingdom, Ireland has a common law system.<sup>612</sup> Further, under Article 29.6 of the Irish Constitution “*no international agreement shall be part of the domestic law of the State save as may be provided by the Oireachtas*”. This reflects the position of what is known as a “dualist” State. It contrasts with ‘monist’ legal systems which are prevalent in much of continental Europe and under which international treaties once ratified by the States automatically form part of their domestic law. In contrast, while Ireland binds itself in international law upon ratifying a human rights treaty, it only gives effect to the provisions of that treaty in domestic law through Acts of the Oireachtas, or where a treaty right is already provided for under the Irish Constitution.<sup>613</sup>

11.11 It may be noted that the right to freedom from arbitrary detention is not considered in this Chapter. While persons with intellectual disabilities detained in institutions are subject to the full range of human rights protections,<sup>614</sup> in this enquiry the Commission has formed the view that the individuals in the Centre have consented to their residence in the Centre on the basis of their *de facto* consent having been exercised by their parents. So for example, Article 5 of the European Convention on Human Rights (“ECHR”) which provides for the right to

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<sup>611</sup> See for example *Sinnott v The Minister for Education*, op. cit., discussed in Chapter 5.

<sup>612</sup> The common law refers to law developed by judges through the decisions of courts rather than being based on legislative provisions.

<sup>613</sup> The Irish courts have interpreted Article 29.6 as an “insuperable obstacle” to importing ECHR provisions into Irish law other than by Constitutional amendment or legislation – see *In Re O Laighleis* [1960] IR 93, per Maguire CJ. Domestic laws are however generally presumed to be in conformity with international human rights treaties such as the European Convention for the Protection of Human Rights and Fundamental Freedoms: see *DPP v. Walsh* [1981] IR 412, *Desmond v Glackin* [1992] 2 ILRM 490. In *O Domhnaill v Merrick* [1984] IR 151, *Nwole v Minister of Justice* High Court (Finlay Geoghegan J) 31<sup>st</sup> October 2003, at p.12.

<sup>614</sup> For further information on the rights of persons detained in institutions, see the Commission’s *Policy Paper concerning the Definition of a “voluntary patient” under s.2 of the Mental Health Act 2001*, February 2010 available at [www.ihrc.ie](http://www.ihrc.ie)

liberty, can only be engaged where an individual has been deprived of their liberty and will on the face of it not be relevant where a person consents to their placement in an institution. Although the situation may be less clear where the person lacks the capacity to make a decision in this regard, it would appear from the European Court's Judgment in *HL v the United Kingdom*<sup>615</sup>, that where that person is represented by an advocate, usually a parent or family member, the placement will not ordinarily engage Article 5 provided they are free to come and go, as confirmed with the person's representative.

## The Rights to Health and Bodily Integrity

### *Constitution*

11.12 The rights to health and bodily integrity under Article 40.3 of the Constitution was established in *Ryan v. Attorney General*<sup>616</sup> and was later broadened into a more general right not to have one's health endangered by the State.<sup>617</sup> In *The State (C) v. Frawley* the High Court stated that bodily integrity should operate to prevent an act or omission by the Executive which, without justification, would expose the health of a detained person to risk or danger.<sup>618</sup> Failure to maintain proper standards of hygiene in a women's prison will violate the right to health,<sup>619</sup> which has been declared to be second only to the right to life in the hierarchy of Constitutional rights.<sup>620</sup> The right to bodily integrity must also be respected by private individuals.<sup>621</sup> In this regard, individuals can sue the State or private individuals for damages for infringement of their right to bodily integrity.<sup>622</sup>

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<sup>615</sup> *H.L. v. The United Kingdom*, Judgment of 5 October 2004, (2004) 40 EHRR 32.

<sup>616</sup> *Ryan v. Attorney General* [1965] IR 294 at p 313.

<sup>617</sup> *The State (C) v. Frawley* [1976] IR 365; *The State (Mc Donagh) v. Frawley* [1978] IR 131; *The State (Richardson) v. The Governor of Mountjoy Prison* [1980] ILRM 82. See Kelly, *The Irish Constitution*. Fourth Ed (2003), Butterworths, Dublin at pp. 1420-1421.

<sup>618</sup> *Ibid.*, at p. 372.

<sup>619</sup> *The State (Richardson) v. The Governor of Mountjoy Prison* [1980] ILRM 82, at p. 93.

<sup>620</sup> *Heeney v. Dublin Corporation*, Unreported, Supreme Court, 17 August 1998, O' Flaherty J. (ex tempore). See also Kelly, *The Irish Constitution*. Fourth Ed, at p. 1420, fn 150.

<sup>621</sup> *The People (DPP) v. Tiernan* [1988] IR 250; and *The People (DPP) v. JT* (1988) 3 Frewen 141.

<sup>622</sup> *Ibid.* See also *The State (Richardson) v. The Governor of Mountjoy Prison* [1980] ILRM 82.

11.13 In a case that centred on questions relating to property rights, the Supreme Court rejected the existence of a right to health that would create an obligation to provide free healthcare services.<sup>623</sup> Medical treatment given to a person of full capacity without consent may breach the individual's constitutional rights.<sup>624</sup> However, where there is a lack of capacity, medical treatment given without consent may be justified in an emergency.<sup>625</sup>

### *International Law*

11.14 The State is party to two international agreements which provide for or regulate the right to health and bodily integrity for all persons, with special attention to those with an intellectual or other disability: one at European regional level and one at the universal level. The CRPD also addresses this right.

### *Revised European Social Charter ("RESC")*

11.15 At the regional level, Article 11 of the RESC is entitled "The right to protection of health" and provides that:

With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed *inter alia*:

1. to remove as far as possible the causes of ill-health;
2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

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<sup>623</sup> *Re Article 26 and the Health (Amendment) (No. 2) Bill 2004* [2005] 1 IR 105, at pp. 166-168.

<sup>624</sup> *Re a Ward of Court (withholding medical treatment) (No 2)* [1996] 2 IR 79, at 156.

<sup>625</sup> *Fitzpatrick and Another v. FK and Another*, Unreported, High Court, 25 April 2008. This was the first case in which an Irish court had to consider how capacity to refuse consent to medical treatment on the part of an adult should be tested. It laid down a number of general principles, including the principle presumption of capacity.

11.16 The European Committee of Social Rights (“ECSR”),<sup>626</sup> which has responsibility for monitoring the compliance of State parties with the RESC, has confirmed that the right to protection of health guaranteed in Article 11 of the RESC complements Articles 2 and 3 of the ECHR by imposing a range of positive obligations designed to secure its effective exercise.<sup>627</sup> The ECSR has emphasised that rights relating to health embodied in the two treaties are inextricably linked, since “*human dignity is the fundamental value and indeed the core of positive European human rights law – whether under the European Social Charter or under the European Convention on Human Rights - and health care is a prerequisite for the preservation of human dignity*”.<sup>628</sup>

11.17 The ECSR has also emphasised that restrictions on the application of Article 11 may not be interpreted in such a way as to impede a disadvantaged groups' exercise of their right to health.<sup>629</sup>

11.18 Arrangements for access to care must not lead to unnecessary delays in its provision.<sup>630</sup> Access to treatment must be based on transparent criteria, agreed at national level, taking into account the risk of deterioration in either

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<sup>626</sup> Previously entitled the Committee of Independent Experts, the European Committee of Social Rights is the body which supervises the conformity of national law and practice with the RESC and its predecessor, the 1961 European Social Charter, through adopting conclusions on national reports and adopting decisions on collective complaints made to it. Further to a 1995 optional protocol, complaints of violations of the ESC/RESC may be lodged with the European Committee of Social Rights. However, only certain organisations are entitled to lodge complaints. Overall supervision of the RESC rests with the Committee of Ministers of the Council of Europe. Ireland ratified the Revised European Social Charter on 4 November 2000.

<sup>627</sup> See Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at page 81 and footnote 321.

<sup>628</sup> *International Federation of Human Rights Leagues (FIDH) v. France*, Complaint No. 14/2003, Decision on the merits of 3 November 2004, at para 31. Under Article 11, ‘health’ means physical and mental well-being, in accordance with the definition of health in the Constitution of the World Health Organisation (WHO), which has been accepted by all Parties to the Charter. Conclusions 2005, Statement of Interpretation on Article 11§5.

<sup>629</sup> See Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at page 82. This is stated to be “the logical consequence of the non-discrimination provision in Article E of the Charter, in conjunction with the substantive rights of the Charter.” Equally, the right of access to health care requires, *inter alia*, that the cost of health care must not represent an excessively heavy burden for the individual. Steps must therefore be taken to reduce the financial burden on patients from the most disadvantaged sections of the community; *ibid*, at p. 83.

<sup>630</sup> See Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at p. 83.

clinical condition or quality of life.<sup>631</sup> In addition, the number of health care professionals and equipment must be adequate.<sup>632</sup> Finally, the State has an obligation to prevent, as far as possible, accidents and diseases.<sup>633</sup>

11.19 In addition, Article 13 of the RESC entitled “The right to social and medical assistance” provides that:

With a view to ensuring the effective exercise of the right to social and medical assistance, the Parties undertake:

1. to ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition;
2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights;
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want;
4. to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11 December 1953.

11.20 Everyone thus has the right to social and medical assistance, including medical care in the case of illness, where they have inadequate resources.<sup>634</sup>

#### *International Covenant on Economic Social and Cultural Rights (“ICESCR”)*

11.21 Ireland is party to the ICESCR,<sup>635</sup> Article 12 of which provides:

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<sup>631</sup> *Ibid.*

<sup>632</sup> *Ibid.*

<sup>633</sup> See Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pp. 85 and 88.

<sup>634</sup> Medical assistance includes free or subsidised health care: Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at page 99.

<sup>635</sup> Ireland ratified the ICESCR on 8 December 1989.

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

- (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

11.22 In its General Comment No. 5 (1994) “Persons with Disabilities”, the Committee on Economic, Social and Cultural Rights (“CESCR”),<sup>636</sup> drawing on the UN’s 1993 *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (“UN Standard Rules”) gives guidance to the interpretation of the Covenant regarding persons with disabilities.<sup>637</sup> In broad terms, the General Comment recalls that the obligation on States in the case of such “a vulnerable and disadvantaged group” is to take “*positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities.*”<sup>638</sup> The CESCR also notes that “[t]his almost invariably means that additional resources will need to be made

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<sup>636</sup> The CESCR Committee is the supervisory body charged with monitoring the implementation of the ICESCR by virtue of Resolution 1985/17 of 28 May 1985 of the United Nations Economic and Social Council (ECOSOC), which established the CESCR Committee and mandated it to carry out the monitoring functions assigned to ECOSOC in Part IV of the ICESCR. The Committee performs this function through the adoption of General Comments on the ICESCR’s provisions and examination of periodic State reports under Article 16. In contrast to other international treaties, no individual or collective complaints system exists at present, although an Optional Protocol to the Covenant will provide the CESCR Committee with competence to receive and consider individual communications. The optional protocol was adopted by the General Assembly on 10 December 2008 (Resolution A/RES/63/117) and was opened for signature in September 2009.

<sup>637</sup> See for example Rule 2 of the UN Standard Rules which includes, *inter alia*, reference to the need for multidisciplinary teams.

<sup>638</sup> *CESCR Committee General comment 5. Persons with disabilities, 09/12/94. (General Comments)*, (Eleventh session, 1994); at para 9.

*available for this purpose and that a wide range of specially tailored measures will be required.*<sup>639</sup>

11.23 The General Comment makes clear that a State cannot “contract out” of its obligations by transferring responsibility for service delivery to private parties:

...while it is appropriate for Governments to rely on private, voluntary groups to assist persons with disabilities in various ways, such arrangements can never absolve Governments from their duty to ensure full compliance with their obligations under the Covenant.<sup>640</sup>

11.24 Turning to the right to health under Article 12 ICESCR, General Comment 5 affirms that “States [must] ... ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care as other members of society”.<sup>641</sup> In this regard, the CESCR confirms that this “implies the right to have access to, and to benefit from, those medical and social services - including orthopaedic devices - which enable persons with disabilities to become independent, prevent further disabilities and support their social integration.”<sup>642</sup> Similarly, such persons should be provided with rehabilitation services which would enable them “to reach and sustain their optimum level of independence and functioning”.<sup>643</sup> All such services should be provided in such a way that the persons concerned are able to “maintain full respect for their rights and dignity.”<sup>644</sup>

11.25 In its General Comment No. 14, the CESCR examines the scope and meaning of the right to health under Article 12.<sup>645</sup> It makes it clear that while Article 12(1) provides a definition of the right to health, Article 12(2) enumerates

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<sup>639</sup> *Ibid.*

<sup>640</sup> *Ibid.*, at para 12. The General Comment also addresses the obligation to eliminate disability-based discrimination, the obligation to ensure equal rights for men and women, the obligation to ensure rights relating to work, social security, protection of the family, an adequate standard of living, the right to physical and mental health, the right to education and the right to take part in cultural life and enjoy the benefits of scientific progress. See paras 5, 11 and 15-38.

<sup>641</sup> *Ibid.*, at para 34.

<sup>642</sup> *Ibid.*

<sup>643</sup> *Ibid.*

<sup>644</sup> *Ibid.*

<sup>645</sup> *CESCR Committee General Comment No. 14 (2000), The right to the highest attainable standard of health, 11/08/2000.*

illustrative, non-exhaustive examples of State parties' obligations.<sup>646</sup> Thus the right “encompasses public health, public care and the underlying determinants necessary for healthy living”.<sup>647</sup> The right to health covers both the provision of health care (the right to health facilities, goods and services (Article 12(2)(c)) and the underlying preconditions for health. The General Comment provides that health care must be available, accessible, acceptable and of a commensurate quality (“the AAAQs”).<sup>648</sup>

11.26 “Core obligations” placed on States under Article 12 are as set out in General Comment No. 14 of the ICESCR. Core obligations on States are of immediate effect rather than to be progressively implemented.<sup>649</sup> They include the obligation to ensure the right of access to health care for vulnerable or marginalised groups including persons with disabilities, without discrimination; to ensure access to minimum essential food; to ensure access to basic shelter,

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<sup>646</sup> *Ibid.*, at para. 7.

<sup>647</sup> *Ibid.*, at paras 11-12 and 14. See also *Mental Health as a Human Right*, Lance Gable and Lawrence O Gostin in Swiss Human Rights Book Vol. 3, *Realizing The Right To Health*, Andrew Clapham & Mary Robinson, Geneva, 2009 at p 254. Underlying health determinants refer to access to safe water, sanitation, food, nutrition, housing etc.

<sup>648</sup> *Ibid.*, at para 12. See also: *The Human Right to Health, Conceptual Foundations*, Eibe Riedel, in Swiss Human Rights Book Vol. 3, *Realizing The Right To Health*, Andrew Clapham & Mary Robinson, Geneva, 2009 at p 28. General Comment 14 recognises that there are a number of aspects of the right to health which cannot be addressed solely within the relationship between States and individuals; in particular, good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health. Thus, genetic factors, individual susceptibility to ill health and the adoption of unhealthy or risky lifestyles may play an important role with respect to an individual's health; *op. cit.*, at para 9.

<sup>649</sup> The CESCR Committee's General Comment No. 3 on Article 2(1) of the ICESCR emphasises that while the ICESCR provides for progressive realisation of rights and acknowledges constraints which may exist due to the limits of available resources, it also imposes various obligations which are of immediate effect. Thus, for example, a State party in which any significant numbers of individuals are deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, *prima facie*, failing to discharge its obligations under the ICESCR. If the ICESCR were to be read in such a way as not to establish such a minimum core obligation, it would be largely deprived of its *raison d'être*. By the same token, it must be noted that any assessment as to whether a State has discharged its minimum core obligation must also take account of resource constraints applying within the country concerned. Article 2(1) obligates each State party to take the necessary steps "to the maximum of its available resources". In order for a State party to be able to attribute its failure to meet at least its minimum core obligations to a lack of available resources it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations. General Comment No. 3, *The nature of State parties' obligations (Art. 2, par.1)*, at paras 1, 9 and 10. As noted, this is repeated in General Comment 14 where the CESCR Committee states that the burden of proof of claiming resource difficulties lies with the State.

housing and sanitation and to safe water; to provide essential drugs, to ensure equitable distribution of all health care and to adopt and implement a national public health strategy and plan of action as outlined.<sup>650</sup> The CESCR makes it clear that in assessing whether the right to health has been violated, these core obligations under Article 12 are non-derogable.<sup>651</sup>

11.27 An argument often employed by States to counter an allegation of a breach of the ICESCR is that the obligations under Article 2(1) are “progressive” in nature only and that accordingly the State may be excused from ensuring certain ICESCR rights on the basis of unavailability of resources.<sup>652</sup> However, as noted, “core obligations” on States are of immediate effect. In determining which actions or omissions of a State amount to a violation of the right to health, it is important to “distinguish the inability from the unwillingness of a State party to comply with its obligations under Article 12”.<sup>653</sup> Since each State party is obliged to take the necessary steps to the maximum of its available resources:

A State which is unwilling to use the maximum of its available resources for the realization of the right to health is in violation of its obligations under article 12. If resource constraints render it impossible for a State to comply fully with its Covenant obligations, it has the burden of justifying that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy, as a matter of priority, the obligations outlined above. It should be stressed, however, that a State party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations set out in paragraph 43 above, which are non-derogable.<sup>654</sup>

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<sup>650</sup> *Ibid.*, at para 43. “Core obligations” are understood to be of immediate effect, rather than to be progressively realised. See para. 47. The non-discrimination principle is reinforced by Article 2(2) of the ICESCR; see *below*.

<sup>651</sup> *Ibid.*, at para. 47.

<sup>652</sup> Article 2(1) of the ICESCR provides that: “Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.”

<sup>653</sup> General Comment 14 at para 47.

<sup>654</sup> *Ibid.*, at para 47. This repeats General Comment No. 3 wherein the CESCR Committee confirmed that every State has a minimum core obligation to ensure “the satisfaction of, at the very least, minimum essential levels of each of the rights” in the ICESCR. See ICESCR, General Comment No. 3, *The nature of States parties obligations (Art. 2, par.1)*, at paras 9-10.

11.28 Regarding progressive realisation of the right to health, States must employ a national health strategy and plan of action, although it has discretion as to what format these take.<sup>655</sup> An effective health system “should identify appropriate right to health indicators and benchmarks”.<sup>656</sup> Indicators will require appropriate disaggregated data to inform the national strategy and assist in ensuring the health system is effective.<sup>657</sup> General Comment No. 14 also makes reference to remedies and accountability and it is clear that monitoring is a precondition of accountability and should form part of any effective health system.<sup>658</sup> In its examination of Ireland’s Second Periodic Report under the Covenant in May 2002, the CESCR recommended that Ireland review its National Health Strategy with a view to embracing a human rights framework, in line with the principles of non-discrimination and equal access to health facilities and services and in doing so explicitly referred to paragraph 54 of General Comment No. 14 which states:

The formulation and implementation of national health strategies and plans of action should respect, *inter alia*, the principles of non-discrimination and people’s participation. In particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12. Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people’s participation is secured by States.<sup>659</sup>

11.29 Further, in terms of progressive realisation “*there is a strong presumption that retrogressive measures taken in relation to the right to health are not permissible*”, with the burden of proof resting with the State that such measures

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<sup>655</sup> General Comment 14 at para 43 and 53.

<sup>656</sup> General Comment 14 at para 57. The adoption of a national strategy should “ensure to all the enjoyment of the right to health, based on human rights principles which define the objectives of that strategy, and the formulation of policies and corresponding right to health indicators and benchmarks. The national health strategy should also identify the resources available to attain defined objectives, as well as the most cost-effective way of using those resources. See para. 53.

<sup>657</sup> *Health Systems and the Right to the Highest Attainable Standard of Health*, Paul Hunt and Gunilla Backman in Gostin in Swiss Human Rights Book Vol. 3, *Realizing The Right To Health*, Andrew Clapham & Mary Robinson, Geneva, 2009 at p 45.

<sup>658</sup> See “Remedies” later in this Chapter.

<sup>659</sup> General Comment 14, para 54. CESCR Committee *Concluding Observations on Ireland’s Second Periodic Report*, 5 June 2002, at para 35.

are warranted.<sup>660</sup> In its May 2002 Concluding Observations on Ireland, the CESCR stated that in view of the favourable economic climate, there were no insurmountable barriers preventing the State from effectively implementing the ICESCR.<sup>661</sup>

11.30 In relation to other specific legal obligations on States in relation to the right to health, General Comment No. 14 states these to be, first the obligation to respect the right to health which requires the State to refrain from measures which may result in bodily harm such as coercive medical treatments other than in exceptional situations.<sup>662</sup> The second obligation is the obligation to protect, for example, through adopting legislation or measures which control health care by ensuring that doctors and healthcare officials meet appropriate professional standards and in ensuring that any privatisation of the health sector or the activities of “individuals, groups or corporations” do not constitute a threat to the AAAQs.<sup>663</sup> The third obligation to fulfil involves, for example, “*the obligation to ... adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health*”.<sup>664</sup> A violation of Article 12 may occur where for example the obligation to provide sufficient hospitals, clinics and other health-related facilities or to provide “adequate housing and living conditions” is unmet.<sup>665</sup>

11.31 A violation of Article 12 can also include, *inter alia*:

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<sup>660</sup> General Comment 14 at para 32 which also provides: “If any deliberately retrogressive measures are taken, the State party has the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant in the context of the full use of the State party's maximum available resources.”

<sup>661</sup> CESCR Committee *Concluding Observations on Ireland's Second Periodic Report*, 5 June 2002, at para. 11. Indeed it is to be noted that international law is unequivocal that all treaty obligations undertaken by States are binding. Article 26 of the Vienna Convention on the Law of Treaties 1969 states: “Every treaty in force is binding upon the parties to the treaty and must be performed by them in good faith.” See also discussion document “Making Economic, Social and Cultural Rights Effective”, IHRC, December 2005 which reviews the State's Second Periodic Report.

<sup>662</sup> General Comment 14 at paras 34 and 50.

<sup>663</sup> Riedel, *op. cit.*, at p 31; General Comment 14 at paras 34 and 50-51.

<sup>664</sup> General Comment 14 at paras 33, 36-37 and 52.

<sup>665</sup> *Ibid.*, at para. 36.

the failure to adopt or implement a national health policy designed to ensure the right to health for everyone; insufficient expenditure or misallocation of public resources which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized; the failure to monitor the realization of the right to health at the national level, for example by identifying right to health indicators and benchmarks; the failure to take measures to reduce the inequitable distribution of health facilities, goods and services.<sup>666</sup>

11.32 In relation to coercive medical treatment, such treatment should only occur “on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases”. Such exceptional cases should be subject to specific and restrictive conditions, respecting best practices and applicable international standards, including the *UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (“UN Principles”).<sup>667</sup> The UN Principles provide, *inter alia*, for proper determination procedures for mental illness, that are prescribed by law and that medication “shall meet the best health needs of the patient ... and be given ... for therapeutic or diagnostic purposes and ... never be administered as a punishment or for the convenience of others”, the administration of medication being of known or demonstrable efficacy only.<sup>668</sup> The Principles also set out detailed standards for ensuring a patient’s informed consent after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- (a) The diagnostic assessment;
- (b) The purpose, method, likely duration and expected benefit of the proposed treatment;
- (c) Alternative modes of treatment, including those less intrusive; and
- (d) Possible pain or discomfort, risks and side-effects of the proposed treatments.<sup>669</sup> (Principle 11.2).

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<sup>666</sup> *Ibid.*, see para. 52.

<sup>667</sup> *Ibid.*, at para 34.

<sup>668</sup> Principle 10.1 of the *UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*.

<sup>669</sup> Principle 11.2 of the *UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*.

11.33 General Comment 14 makes clear that “*violations of the right to health can occur through the direct action of States or other entities insufficiently regulated by States.*”<sup>670</sup> Thus a contract between the State and a private entity to provide health services to persons with disabilities would be in violation of the State’s obligations under Article 12 if its terms did not allow the State to control the delivery of health care to those persons by regulating, monitoring and if necessary intervening and/ or imposing conditions or restrictions to ensure that the rights of the individuals concerned are ensured.<sup>671</sup> Similarly, a violation of the right to health may occur:

through the omission or failure of States to take necessary measures arising from legal obligations. Violations through *acts of omission* include the failure to take appropriate steps towards the full realization of everyone’s right to the enjoyment of the highest attainable standard of physical and mental health, the failure to have a national policy on occupational safety and health as well as occupational health services, and the failure to enforce relevant laws.<sup>672</sup>

11.34 Thus, in relation to the obligations to respect, protect and fulfil under Article 12, the right to informed consent in a person’s medical treatment includes the right to certain safeguards in the dispensation of a person’s medication (obligation to respect the right to health). Further, any obstacle to the ability of the most vulnerable members of society, such as those with a severe to profound intellectual disability, to access proper health care (i.e. in the form of the AAAQs) as a result of privatisation or contracting out of a service is likely to constitute a violation of the right to health by the state concerned (obligation to protect the right to health). Finally, any failure to implement national strategies or laws may result in violation of the obligation to fulfil the right to health.<sup>673</sup>

#### *Convention on the Rights of Persons with Disabilities (CRPD)*

11.35 In addition, Article 25 of the CRPD provides that:

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<sup>670</sup> *Ibid.*, at para 48.

<sup>671</sup> *Ibid.*

<sup>672</sup> *Ibid.*, para 49.

<sup>673</sup> *Ibid.*, at paras 34-37. See also McBeth, Adam “*Privatising human rights; what happens to the state’s human rights duties when services are privatised?*” [2004] Melbourne Journal of International Law 5.

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons [...]
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities [...]
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent [...]
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

11.36 In relation to multidisciplinary services, to habilitation and rehabilitation, Article 26 of the CRPD provides that:

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
- (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services [...].

## Key Points of Relevance

11.37 Nine points of relevance to this enquiry may be made on the basis of these international human rights provisions:

- (a) The State has positive obligations in respect of health care, including care provided by private organisations. These obligations entail obligations to respect, protect and fulfil the right to health.
- (b) The right to health encompasses physical and mental well-being, health care and the underlying determinants of health.
- (c) The State must reduce structural disadvantages and give appropriate preferential treatment to people with disabilities in order to facilitate their optimum level of independence and functioning in society. The State is obliged to have in place a national health strategy accompanied by benchmarks and by indicators supported by disaggregated data to secure the right to health for persons with an intellectual disability.
- (d) Access to treatment and care must be based on transparent criteria, agreed at national level, taking into account the risk of deterioration in either clinical condition or quality of life. The participation of persons with disabilities must be assured.
- (e) The number of health care professionals and equipment must be adequate and the State has an obligation to prevent, as far as possible, accidents and diseases.
- (f) Regardless of available resources, every State has a minimum core obligation to ensure access to health care for persons with intellectual disabilities without discrimination. Thus, health care must be non-

discriminatory so that persons with a physical or mental disability enjoy the same level of care as the rest of the population and so that within the group of intellectually disabled people in the State, there is no discrimination on grounds of age or health status. Deliberately retrogressive measures must be avoided.

- (g) Health care must be available, accessible (medical service and medical attention for illness), acceptable and of a commensurate quality. The participation of persons with disabilities in health planning must occur.
- (h) The State should refrain from applying coercive medical treatments other than on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases. Such exceptional cases should be subject to specific and restrictive conditions.
- (i) Medical and social services must ensure independence, prevent further disabilities and support social integration and allow the person to reach and sustain their optimum level of independence and functioning and must be provided in the same way as medical services to other members of society.

### **The Right to Education and Vocational Training for Persons with Disabilities (Habilitation and Rehabilitation)<sup>674</sup>**

#### ***Constitution***

11.38 Article 42 of the Constitution states that the primary educator of the child is the family. Article 42.4 provides that the State shall provide for free primary

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<sup>674</sup> These concepts are discussed in Chapter 5.

education. The case *O' Donoghue v. Minister for Health*<sup>675</sup> established the right to free primary education in a more expanded sense for children with a severe to profound learning disability to allow them to make the “*best possible use of their inherent and potential capacities, physical, mental and moral*”<sup>676</sup> and in order to allow them to achieve the fullest possible social integration and individual development and to develop their capabilities and skills to the maximum and to hasten the process of social integration or reintegration.<sup>677</sup> It was further held that the applicant was entitled to damages for loss and damage caused by past failure to provide free primary education in breach of Article 42.4.<sup>678</sup>

11.39 However, as noted in Chapter 5, this right to education is restricted for adults with an intellectual disability by the Supreme Court judgment in *Sinnott v Minister for Education*<sup>679</sup> where it was held that the right to primary education, even in the case of a person with a severe to profound intellectual disability, did not continue past the age of 18.

### ***International Law***

#### *European Convention on Human Rights (ECHR)*

11.40 Article 2 of Protocol 1 of the ECHR provides:

No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions.

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<sup>675</sup> *O' Donoghue v Minister for Health* [1996] 2 IR 20.

<sup>676</sup> *Ibid.*, at 65

<sup>677</sup> *Ibid.*

<sup>678</sup> *Ibid.*, at 70.

<sup>679</sup> [2001] 2 IR 545.

11.41 In the *Belgian Linguistic Case*,<sup>680</sup> the European Court defined the scope of the right to education as follows:

The first sentence of Article 2 of the Protocol consequently guarantees, in the first place, a right of access to education institutions existing at a given time, but such access constitutes only part of the right to education. For the 'right to education' to be effective, it is further necessary that, *inter alia*, the individual who is the beneficiary should have the possibility of drawing profit from the education received, that is to say, the right to obtain, in conformity with the rules in force in each State, and in one form or another, official recognition of the studies which he has completed.<sup>681</sup>

11.42 The right to education includes the right to an effective education. However, the European Court stated that the negative formulation of Article 2 Protocol 4, which provides "*no one shall be denied the right to education*" meant that there was no obligation for Contracting States to "*establish at their own expense, or to subsidize, education of any particular type or at any level*".<sup>682</sup> Further, the European Court went on to restrict the guarantee to education to accessing existing educational facilities, allowing the State a wide margin of appreciation in respect of resources it allocates to the educational system.<sup>683</sup> However, in the context of the current enquiry it is noted that there has been no case law to date under this provision in relation to persons with intellectual disabilities or other persons resident in residential centres and accordingly its direct relevance is limited.

### *Revised European Social Charter (RESC)*

11.43 Article 9 of the RESC provides that:

With a view to ensuring the effective exercise of the right to vocational guidance, the Parties undertake to provide or promote, as necessary, a service which will assist all persons, including the handicapped, to solve problems related to

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<sup>680</sup> *Case relating to certain aspects of the laws on the use of languages in education in Belgium* (Belgium linguistic Case (No. 2)), Judgment of 23 July 1968, Series A, No. 6; (1979-80) 1 EHRR 252 (cited in this chapter as the "Belgian Linguistic Case").

<sup>681</sup> *Ibid*, at para 4.

<sup>682</sup> *Ibid*, at para 3.

<sup>683</sup> *Ibid*. at para 4, wherein the Court referred to the opportunity to "avail themselves of the means of instruction existing at a given time."

occupational choice and progress, with due regard to the individual's characteristics and their relation to occupational opportunity: this assistance should be available free of charge, both to young persons, including schoolchildren, and to adults.

11.44 Under Article 9, persons with disabilities have the right to appropriate facilities for vocational guidance with a view to assisting them in choosing an occupational opportunity suited to personal aptitude and interests. Article 9 imposes obligations on States Parties to set up and operate services that assist such persons without charge so that they may solve problems relating to occupational choice and progress.<sup>684</sup> Article 10(1) of the RESC builds on Article 9 in providing that:

With a view to ensuring the effective exercise of the right to vocational training, the [States] Parties undertake:

1. to provide or promote, as necessary, the technical and vocational training of all persons, including the handicapped, in consultation with employers' and workers' organisations, and to grant facilities for access to higher technical and university education, based solely on individual aptitude

11.45 Article 15 of the RESC addresses the right of persons with disabilities to independence, social integration and participation in the life of the community.<sup>685</sup>

It provides:

With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

1. to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;
2. to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in

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<sup>684</sup> European Committee of Social Rights; Conclusions I, Statement of Interpretation on Article 9, p.53. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), p.73.

<sup>685</sup> See generally *The European Social Charter and EU Anti-Discrimination Law in the Field of Disability: Two Gravitational Fields with One Common Purpose*, Gerard Quinn in "Social Rights in Europe" edited by Gráinne de Búrca & Bruno de Witte with the assistance of Larissa Ogertschnig, Chapter 14, Oxford University Press (2005).

the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability.<sup>686</sup>

3. to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.

11.46 The European Committee on Social Rights (“ECSR”) has emphasised the importance of the non-discrimination norm under Article E of Part V of the RESC in the disability context, regarding it as an integral element of Article 15.<sup>687</sup> As the ECSR has stated in the case of *Association International Autism-Europe (AIAE) v. France*.<sup>688</sup>

The underlying vision of Article 15 is one of equal citizenship for persons with disabilities and, fittingly, the primary rights are those of “independence, social integration and participation in the life of the community”. Securing a right to education for children and others with disabilities plays an obviously important role in advancing these citizenship rights.<sup>689</sup>

11.47 In that case, the ECSR linked the right to education under Article 15(1) with the right to secure independence and participation in society under Article 15(3) (see below). In that case, on a complaint that the “*proportion of children with autism being educated in either general or specialist schools is much lower than in the case of other children, whether or not disabled*”, the ECSR found there had been a violation of Articles 15(1) and 17(1), whether alone or read in combination with Article E of the RESC.<sup>690</sup>

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<sup>686</sup> Article 15.3 provides that in certain cases, such measures may require recourse to specialised placement and support services

<sup>687</sup> Article E of Part V of the RESC provides that: “*A differential treatment based on an objective and reasonable justification shall not be deemed discriminatory.*” See also European Social Charter (Revised), Conclusions 2003, Vol. 1, p. 10.

<sup>688</sup> Complaint No.13/2002, Decision on the Merits of 4 November 2003. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pp 111-112; Conclusions 2003, Statement of Interpretation on article 15, at para. 5.

<sup>689</sup> Op. cit., at para 48. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pp 111-112; Conclusions 2003, Statement of Interpretation on article 15, at para. 5.

<sup>690</sup> Op. cit., at *Conclusion*. Article 17(1)(a) of the RESC refers to the right of children and young persons to education.

11.48 Article 15 applies to all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age.<sup>691</sup> Article 15 thus covers both children and adults with intellectual disabilities who face particular disadvantages in education. Nor does it distinguish between younger and older adults.<sup>692</sup>

11.49 In the view of the ECSR all education provided by States must fulfil the criteria of availability, accessibility, acceptability and adaptability.<sup>693</sup> The ECSR has held that, where the achievement of rights under the RESC is exceptionally complex and expensive to secure, States must take measures to achieve the objectives of the RESC; (1) within a reasonable time, (2) with measurable progress and (3) to an extent consistent with the maximum use of available resources.<sup>694</sup> State Parties are obliged not only to take legal action to implement the provisions of the RESC but also to take practical action to give full effect to the rights recognised therein.<sup>695</sup>

11.50 The ECSR has also emphasised that the right of persons with disabilities to social integration under Article 15(3) implies that barriers to communication and mobility be removed in order to enable access to transport, housing, cultural activities and leisure (social and sporting) activities.<sup>696</sup> This requires, *inter alia*, the adoption of a coherent policy, coordinated positive action measures and a clear

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<sup>691</sup> Op, cit., at para 48. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pp 111-112; Conclusions 2003, Statement of Interpretation on article 15, at para. 5.

<sup>692</sup> European Committee of Social Rights; Conclusions 2007, Statement of Interpretation on Article 15(1), p.12.

<sup>693</sup> *Mental Disability Advocacy Centre (MDAC) v. Bulgaria*, Complaint No. 41/2007, Decision on the Merits of 3 June 2008, para.37.

<sup>694</sup> *European Roma Rights Centre v. Bulgaria*, Complaint No. 31/2005, Decision on the Merits of 18 October 2006, at para. II.1.02.

<sup>695</sup> *International Commission of Jurists v. Portugal* Complaint No. 1/1998, para.32.

<sup>696</sup> European Committee of Social Rights; Conclusions 2005, Norway, p. 558. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pages 113-114.

legal basis for such measures. Persons with disabilities should also have a voice in the design, implementation and review of such a policy.<sup>697</sup>

### *International Covenant on Economic, Social and Cultural Rights (ICESCR)*

11.51 At the universal level, Article 13 of the ICESCR sets out the right to education and is regarded as being an 'empowerment right', acting as the primary vehicle by which marginalised people can obtain the means to participate fully in their communities.<sup>698</sup> Article 13(1) of the ICESCR provides that:

The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.

11.52 In the view of the Committee on Economic, Social and Cultural Rights ("CESCR"), States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities in integrated settings.<sup>699</sup>

11.53 In its General Comment No. 13, the CESCR states that "*education is the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty and obtain the means to participate fully in their communities*".<sup>700</sup> Education must meet the key principles of

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<sup>697</sup> European Committee of Social Rights; Conclusions 2007, XIX-1, Slovenia, p.1033. See further Council of Europe, *Digest of the Case Law of the European Committee of Social Rights*, (Strasbourg, 2008), at pages 113-114.

<sup>698</sup> Committee on Economic, Social and Cultural Rights; General Comment No. 13 of 1999, *Right to Education*, at para. 1.

<sup>699</sup> Committee on Economic, Social and Cultural Rights; General Comment No. 5 of 1994, *Persons with Disabilities*, at para. 35. See also Rule 6, *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*, annexed to General Assembly Resolution 48/96, 48<sup>th</sup> Session, of 20 December 1993.

<sup>700</sup> Committee on Economic, Social and Cultural Rights; General Comment No. 13 of 1999, *The right to education*; at para 1.

availability, accessibility, acceptability and adaptability.<sup>701</sup> Steps towards its realisation must be “deliberate, concrete and targeted”.<sup>702</sup> As in relation to the right to health, retrogressive steps are not generally permitted.<sup>703</sup>

11.54 In relation to technical and vocational education, the General Comment confirms that this forms part of both the right to education and the right to work under Article 6(2) of the ICESCR. In this regard, Article 6(2) of the ICESCR provides that:

The steps to be taken by a State Party to the present Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

11.55 General Comment 13 stresses that, unlike Article 13(2)(b) of the ICESCR which limits technical and vocational education to secondary level education, Article 6(2) “comprehends that [technical and vocational education] has a wider role, helping ‘to achieve steady economic, social and cultural development and full and productive employment’”. Also, the Universal Declaration of Human Rights states that “[t]echnical and professional education shall be made generally available” (art. 26 (1)). Accordingly, the CESCR takes the view that [technical and vocational education] forms an integral element of all levels of education.”<sup>704</sup> As with other vulnerable groups, the CESCR confirms that technical and vocational education must be accessible to adults with disabilities stating that it requires States to introduce specific programmes:

It consists, in the context of the Covenant's non-discrimination and equality provisions, of programmes which promote the technical and vocational education

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<sup>701</sup> *Ibid.*, at paras 6-7.

<sup>702</sup> *Ibid.*, at para 43.

<sup>703</sup> See General Comment No. 3, *The nature of State parties' obligations (Art. 2, par.1)*, op.cit., at para 9 which states: “...any deliberately retrogressive measures in that regard would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant and in the context of the full use of the maximum available resources.”

<sup>704</sup> *Ibid.*, at para 15.

of women, girls, out-of-school youth, unemployed youth, the children of migrant workers, refugees, persons with disabilities and other disadvantaged groups.<sup>705</sup>

11.56 The CESCR has also commented that the right to education under Article 13 may extend into adulthood if one's "basic learning needs" in terms of fundamental education "have not yet [been] satisfied":

It should be emphasized that enjoyment of the right to fundamental education is not limited by age or gender; it extends to children, youth and adults, including older persons. Fundamental education, therefore, is an integral component of adult education and life-long learning. Because fundamental education is a right of all age groups, curricula and delivery systems must be devised which are suitable for students of all ages.<sup>706</sup>

11.57 The minimum "core" obligation on States under Article 13 includes "*an obligation: to ensure the right of access to public educational institutions and programmes on a non-discriminatory basis*".<sup>707</sup>

#### *Convention on the Rights of Persons with Disabilities (CRPD)*

11.58 Article 24 of the CRPD provides that States Parties recognise the right of persons with disabilities to education. Article 24 provides that States Parties shall ensure an inclusive education system at all levels and life-long learning directed to the full development of human potential and sense of dignity and self-worth. Article 25 expands on this stating States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

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<sup>705</sup> *Ibid.*, at para 16(e).

<sup>706</sup> *Ibid.*, at paras 23-24. Also in this regard, the CESCR Committee affirmed its earlier comments in General Comment 5 (paragraph 35), which addressed the issue of persons with disabilities in the context of the right to education, and paragraphs 36-42 of its General Comment 6, which address the issue of older persons in relation to Articles 13-15 of the Covenant; at para 36.

<sup>707</sup> *Ibid.*, at para 57.

- (c) Reasonable accommodation of the individual's requirements is provided;
- (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

11.59 There is a strong emphasis on full and equal participation of persons with disabilities in education and as members of the community in Article 24. Article 24(3) also lists a number of appropriate measures for State Parties to achieve including to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

11.60 Article 9 of the CRPD recognises that in order to enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties must take appropriate measures to ensure access, on an equal basis with others persons, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems. Appropriate measures listed in Article 9 include implementation and monitoring of minimum standards and guidelines regarding access to facilities and services open to the public for persons with disabilities and training for stakeholders on accessibility issues facing persons with disabilities.

11.61 Article 26(1) of the CRPD focuses on habilitation as noted above. Article 26 provides that these services and programmes should begin at the earliest possible stage and be based on the multidisciplinary assessment of individual needs and strengths. It further states that they should support participation and inclusion in the community and all aspects of society, are voluntary, and are

available to persons with disabilities as close as possible to their own communities, including in rural areas.

11.62 An overarching right in the CRPD is the right, set out in Article 19, of all persons with disabilities to live in the community with choices equal to others, including their full inclusion and participation in the community. This right has been stated to be a precondition for the fulfilment of other CRPD rights, including the right to habilitation. Article 19 provides:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

11.63 Article 19 could be considered to express in a single principle a broad range of rights already recognised in international human rights standards, such as the right to personal autonomy; the right not to be discriminated against; the right to health and bodily integrity and the right to be treated with respect and dignity. Article 19 provides a vehicle or a model within which those rights may be implemented.

11.64 Article 27 of the CRPD provides for the right to work and states:

1. [...] States Parties shall safeguard and promote the realization of the right to work, [...], by taking appropriate steps, including through legislation, to, inter alia:

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training...

11.65 In order to inform the State's formulation of disability policy, Article 31(1) of the CRPD provides that:

States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

### **Key Points of Relevance**

11.66 Six points of relevance to this enquiry may be made on the basis of these international human rights provisions:

- a) The State has a duty to ensure the right to education for adults with an intellectual disability who face particular disadvantages in education.
- b) The State has a duty to ensure the effective exercise of the right to independence, social integration and participation in the community.
- c) The State has a duty to provide persons with disabilities with guidance, education and vocational training, to promote their access to employment and their full social integration and participation in the community.
- d) Habilitation and rehabilitation services and programmes must be provided, particularly in the areas of health, employment, education and social services. Such services should begin at the earliest possible stage and be based on a multidisciplinary assessment of individual needs.

- e) Habilitation and rehabilitation services must be voluntary, and available to persons with disabilities as close as possible to their own communities.
- f) The State should provide initial and continuing training for professionals and staff in habilitation and rehabilitation.
- g) The State should take appropriate steps through implementing legislation, to enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training.

## **The Right to Equality Before the Law and non-Discrimination in the Enjoyment of Rights**

### ***Constitution:***

11.67 Article 40. 1 of the Irish Constitution declares that all citizens in Ireland shall be held equal before the law. The guarantee of equality has been explicitly linked to human dignity.<sup>708</sup> However, when the State is enacting legislation, it may consider differences of capacity and of social function between individuals in society.<sup>709</sup> Article 40.1 can be used in conjunction with a substantive right.<sup>710</sup> It has generally been accepted by academic commentators that Article 40.1 has been interpreted in a restrictive fashion by the courts to date, although there would appear to be no particular restrictions on the development of more expansive jurisprudence in this area.<sup>711</sup> The courts have held that legislation which supports another constitutional value may be a legitimate differentiation and therefore may not breach Article 40.1.<sup>712</sup>

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<sup>708</sup> *Quinn's Supermarket v. Attorney General* [1972] IR 1 at 13-14.

<sup>709</sup> Article 40.1 of the Constitution. See also *The State (Nicolaou) v. An Bord Uchtála* [1966] IR 567.

<sup>710</sup> *O' Donovan v Attorney General* [1961] I.R. 114.

<sup>711</sup> Doyle, O; *Constitutional Equality law* (2004), Thomson Roundhall Press at p. 253 and Kelly; *The Irish Constitution*. Fourth Ed, (2003), Butterworths, Dublin p. 1324.

<sup>712</sup> *The State (Nicolau) v. An Bord Uchtála* [1966] IR 567; *O'B v S* [1984] IR 316.

## *International Law*

### *European Convention on Human Rights (ECHR)*

11.68 Article 14 of the ECHR provides that:

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

11.69 This Article prohibits discrimination only in the enjoyment of the rights set out in the ECHR and its Protocols; that is, it is not a free-standing guarantee of non-discrimination.<sup>713</sup>

11.70 Not all differences of treatment are prohibited under Article 14 of the ECHR. The European Court has found that:

[T]he principle of equality of treatment is violated if the distinction has no objective and reasonable justification. The existence of such a justification must be assessed in relation to the aim and effects of the measure under consideration, regard being had to the principles which normally prevail in democratic societies. A difference of treatment in the exercise of a right laid down in the Convention must not only pursue a legitimate aim: Article 14 ... is likewise violated when it is clearly established that there is no reasonable relationship of proportionality between the means employed and the aim sought to be realised.<sup>714</sup>

11.71 Therefore the European Court will ask the following questions in deciding whether there has been a breach of Article 14:

- (i) whether the matter falls within the ambit of a substantive ECHR right;

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<sup>713</sup> Protocol 12 to the ECHR has introduced such a free-standing right not to be discriminated against, but although this protocol has been signed by Ireland, it has not yet been ratified by the State. Note also that under Article 14 the other "substantive" right does not necessarily have to be breached in order for there to be a violation of Article 14, so that in this way, Article 14 can be said to have an autonomous meaning.

<sup>714</sup> *"Relating to Certain Aspects of the Laws on the Use of Languages in Education in Belgium" v. Belgium (Merits)*, Judgment of 23 July 1968, (1968) 1 EHRR 252 (*"Belgian Linguistics case"*), at para. 10.

- (ii) whether a difference of treatment on the basis of status can be demonstrated;
- (iii) whether any difference of treatment pursues a legitimate aim; and if so
- (iv) whether the measure in question is proportionate to the aim. The latter test includes an examination of whether the difference of treatment extends beyond the State's "margin of appreciation".<sup>715</sup>

*Whether the matter falls within the ambit of a substantive ECHR right*

11.72 The European Court has held that "*there can be no room for [the] application [of Article 14] unless the facts at issue fall within the ambit of one or more*" of the substantive provisions of the ECHR and its Protocols.<sup>716</sup> On the other hand, if the European Court finds that the other substantive ECHR right has been breached it will often decide not to go on to consider Article 14, on the basis that it would serve "no useful legal purpose" to do so.<sup>717</sup>

11.73 Accordingly, in considering an allegation of discrimination in relation to a substantive ECHR right such as the right to respect for one's private and family life (Article 8), the European Court will inquire first as to whether the matter comes within the ambit of Article 8 before proceeding with its analysis of difference of treatment in the case. Thus in *Glor v. Switzerland* ("*Glor*")<sup>718</sup> the European Court considered that, as the individual's physical integrity was at issue, the matter came within the scope of Article 8.<sup>719</sup> Article 14 proscribes discrimination on certain non-exhaustive grounds such as race, language, religion or birth.<sup>720</sup> The prohibitory words "on any ground such as" in Article 14 clarify that the enumerated grounds for discrimination set out in Article 14 are not exhaustive,

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<sup>715</sup> Under the case-law of the European Court a certain "margin of appreciation" is allowed to national authorities in assessing whether and to what extent differences in otherwise similar situations justify a different treatment in law. The scope of the "margin of appreciation" will vary according to the circumstances, the subject-matter and its background.

<sup>716</sup> *Abdulaziz and Others v. The United Kingdom*, 15/1983/71/107-109 at para. 71.

<sup>717</sup> *Dudgeon v The United Kingdom*, Judgment of 22 October 1981, (1982) 4 EHRR 149, at para. 69. See also *Saadi v. The United Kingdom*, 2006, at para. 57.

<sup>718</sup> Judgment 30 April 2009. Judgment only available in French at time of writing.

<sup>719</sup> *Ibid.*, At paras 54-56.

<sup>720</sup> See *Abdulaziz, Cabales and Balkandali v United Kingdom*, at paras 87-89.

*Whether a difference of treatment on the basis of status can be demonstrated*

11.74 Article 14 prohibits discrimination on certain non-exhaustive grounds such as race, language, religion or birth.<sup>721</sup> The prohibitory words “on any ground such as” in Article 14 clarify that the enumerated grounds for discrimination set out in Article 14 are not exhaustive as was the situation in *Glor*.<sup>722</sup> Accordingly a difference of treatment on the ground of disability or age may also come within the ambit of Article 14 of the ECHR, although “the scope of the intensity of the European Court’s review may vary” according to the prohibited ground of differentiation.<sup>723</sup>

11.75 Article 14 covers direct discrimination, where the difference in treatment between a member of one group and a member of another group is clear (e.g. between a woman and a man), and indirect discrimination, where the same requirement applies to both groups but a significant number of one group cannot comply with the requirement in question.<sup>724</sup> Therefore if a policy or general measure has a particularly negative effect on one group, it may be considered discriminatory even if it is not specifically aimed at that group.<sup>725</sup> The State’s “margin of appreciation” is reduced where a difference of treatment on the basis of disability occurs.<sup>726</sup>

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<sup>721</sup> See *Abdulaziz, Cabales and Balkandali v United Kingdom*, at paras 87–89.

<sup>722</sup> In *Glor*, the Court stated: “La Cour estime que l’on se trouve, à un double titre, en présence d’une différence de traitement entre personnes placées dans des situations analogues. La liste des motifs de distinction énumérés à l’article 14 n’étant pas exhaustive (« ou toute autre situation » ; voir *Stec et autres*, précitée, § 50), il n’est pas douteux que le champ d’application de cette disposition englobe l’interdiction de la discrimination fondée sur un handicap”; at para 80. Similarly, in *James v United Kingdom*, Judgment of 25 March 1986, (1986) 8 EHRR 123, the European Court found that “differences of treatment in regard to different categories of property owners in the enjoyment of the right safeguarded by Article 1 of Protocol No. 1” brought the matter within the scope of Article 14.

<sup>723</sup> See van Dijk and van Hoof, *Theory and Practice of the European Convention on Human Rights*, p. 730.

<sup>724</sup> See, for example, *Thlimmenos v. Greece*, Judgment of 6 April 2000 (2001) 31 EHRR 411, at para. 44. See also *Glor v Switzerland*, at para 84.

<sup>725</sup> *DH and others v. Czech Republic*, Judgment of 7 February 2006 (2006) 43 EHRR 923 at para. 46. See also *Posti and Rahko v. Finland*, Judgment of 24 September 2002, (2003) 37 EHRR 6.

<sup>726</sup> See *Glor v Switzerland*, at para 84.

11.76 In considering whether a difference of treatment had occurred in *Glor*, which concerned exemption from military service on the grounds of disability, the European Court considered that the Swiss authorities had treated persons in similar situations differently in two respects: firstly, the applicant was liable to a tax, unlike persons with more severe disabilities, and secondly, he was also liable for the tax unlike conscientious objectors to military service who were not.<sup>727</sup>

*Whether the difference in treatment pursues a legitimate aim*

11.77 Once the applicant has shown that there has been a difference in treatment on a prohibited ground, it is for the respondent State to show that there is a reasonable and objective justification for this treatment. The European Court will therefore consider whether the treatment pursues a legitimate aim. Not every difference in treatment is prohibited by Article 14. If the difference in treatment has an objective and reasonable justification, namely, it pursues a legitimate aim and is proportionate to that aim, it will not result in a violation of Article 14. Often the aims invoked by the State are accepted as legitimate, account being taken of democratic principles, but, occasionally, an aim is rejected.

11.78 In *Glor*, the Government advanced a number of arguments to the effect that the difference in treatment pursued a different aim. The Court considered these arguments for the imposition of a tax on a disabled person who could not perform military service. The tax was designed, according to the State Party, to restore equality between those who performed their military service and those who were exempted, on the basis that the tax was a substitute for the efforts of those who performed their service.

*Whether the measure in question is proportionate to the aim pursued*

11.79 The State must show that the measures taken were *in fact* necessary and must support this with evidence. However States enjoy a certain “margin of

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<sup>727</sup> At paras 81-90 generally.

appreciation". The European Court takes the view that the national authorities are in principle in a better position to determine what measures are necessary to implement any particular law or policy. The extent of this "margin of appreciation" given to a State will depend on the facts of the particular case but as noted, it is likely to be narrower when particularly suspect grounds of discrimination are in issue, including disability.<sup>728</sup>

11.80 In *Glor*, the European Court had noted that the ECHR's provisions fell to be considered, *inter alia*, in light of European and universal norms, noting both a 2003 Council of Europe Parliamentary Assembly Recommendation and the UN CRPD as evidence of the prohibition of discrimination on the grounds of disability.<sup>729</sup> The European Court was not satisfied that it was in the interests of the community to require the applicant to pay an exemption tax to substitute for the efforts of military service, which he had been prevented from performing on medical grounds, a factual situation outside his control. The Court also pointed out that the deterrent role of the tax was marginal only. It found that the measure did not take into account the applicant's disability, providing an exemption for persons with more serious disabilities only, and not taking into account the applicant's means or the alternatives to military service he could have undertaken. Accordingly, the European Court found the difference in treatment in the case to be unreasonable, having regard to the principles prevailing in democratic States. There had accordingly been a violation of Article 14, when read in conjunction with Article 8.<sup>730</sup>

#### *Revised European Social Charter (RESOC)*

11.81 The RESOC repeats the formula set out in Article 14 of the ECHR in relation to the prohibition of discrimination, stating at Article E of Part V of the RESOC that:

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<sup>728</sup> *Ibid.*

<sup>729</sup> *Op. cit.*, at para 54.

<sup>730</sup> *Ibid.*; at paras 96-98.

A differential treatment based on an objective and reasonable justification shall not be deemed discriminatory.

11.82 In the view of the ECSR, the insertion of Article E into a separate Article in the RESC “*indicates the heightened importance the drafters paid to the principle of non-discrimination with respect to the achievement of the various substantive rights contained therein*”.<sup>731</sup> Article E does not constitute an autonomous right which could in itself provide independent grounds for a complaint, but must be read in conjunction with a substantive RESC right, in similar manner to the ECHR.<sup>732</sup> Although disability is not explicitly listed as a prohibited ground of discrimination under Article E, the ECSR has found that it is covered by the reference to “other status”.<sup>733</sup> Article E prohibits not only “*direct discrimination but also all forms of indirect discrimination*”.<sup>734</sup> Thus the ECSR has held in a case concerning the lack of education of autistic children, that a violation of the right to education occurred “whether alone or read in combination with Article E”.<sup>735</sup>

#### *International Covenant on Civil and Political Rights (“ICCPR”)*

11.83 The ICCPR contains a guarantee of equality in Article 26 that is not limited to the enjoyment of the rights covered by the ICCPR. Article 26 prohibits discrimination in any area of the law.<sup>736</sup> To the extent that a matter is regulated by the law, that law must not discriminate between persons. It applies to any law, whether or not the law in question relates to a right protected under an international agreement.<sup>737</sup> Article 26 provides:

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<sup>731</sup> *Association International Autism-Europe (AIAE) v. France*, op. cit., at para 51.

<sup>732</sup> Op. cit., at para 51.

<sup>733</sup> Op. cit., at para 51.

<sup>734</sup> Op. cit., at para 52. “Such indirect discrimination may arise by failing to take due and positive account of all relevant differences or by failing to take adequate steps to ensure that the rights and collective advantages that are open to all are genuinely accessible by and to all”; *ibid*.

<sup>735</sup> Op. cit.

<sup>736</sup> See *Zwaan-de Vries v. The Netherlands*, 9 April 1987, twenty-ninth session of the HRC UN Doc. Supp. No.40 (A/42/40) (“*Zwaan-de Vries v. The Netherlands*”) and the HRC, General Comment No. 18, *Non-discrimination*, thirty-seventh session (1989) 10 November 1989, at para. 12 (“HRC General Comment No. 18”).

<sup>737</sup> *Ibid*.

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

11.84 In its General Comment No.18 on Non-discrimination (“General Comment No.18”),<sup>738</sup> the HRC clarified the scope of “discrimination” under Article 26 of the ICCPR; in that it prohibits discrimination in law or in fact in any field regulated and protected by public authorities. When legislation is adopted by a State Party, its content should not be discriminatory. Nor should the application of the legislation be discriminatory. Difference of treatment is assessed by reference not merely to the purpose of the law in question, but also to the impact or effect of the law. Both direct and indirect discrimination are prohibited.

11.85 General Comment No. 18, also recognises that not all difference of treatment constitutes discrimination if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the ICCPR.<sup>739</sup>

11.86 Accordingly, the test applied by the HRC in considering Article 26 complaints is to inquire:

- i. whether there was any difference of treatment between categories of person based on the ground of a person’s status; and if so,
- ii. whether the criteria for such differentiation were reasonable and objective and whether the aim was to achieve a purpose which is legitimate under the ICCPR.

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<sup>738</sup> *Ibid.*

<sup>739</sup> General Comment 18, op. cit., at para.13. See also *Zwaan-de Vries v. The Netherlands*, op cit, where the HRC observed “... not every differentiation of treatment will constitute discrimination, if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the Covenant”; op cit., at para. 13.

*Whether there was any difference of treatment between persons based on status*

11.87 The HRC will consider first whether there has been a difference in treatment based on status, such as race, colour, sex, etc or “other status”. The latter has been interpreted quite broadly and includes for example distinctions based on disability and most other grounds such as age or health status.<sup>740</sup>

*Whether the difference of treatment was reasonably and objectively justified*

11.88 The test employed by the HRC to determine whether a difference in treatment is justified is similar to that employed by the European Court in relation to Article 14 of the ECHR. A difference of treatment may be justified if the measure in question has an aim which is legitimate.<sup>741</sup> There must also be a reasonable relationship of proportionality between the means employed and the aim sought to be achieved. However, in contrast to the European Court, the HRC’s consideration of the proportionality of any difference of treatment has tended to be somewhat summary in nature.<sup>742</sup>

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<sup>740</sup> In its Concluding Observations on Ireland’s Second Period Report in 2000, the HRC recommended that further action be taken to ensure full implementation of the ICCPR in a number of matters including in “*Ensuring the full and equal enjoyment of Covenant rights by disabled persons, without discrimination, in accordance with article 26*”; *Concluding observations of the Human Rights Committee : Ireland. 24/07/2000 A/55/40, paras.422-451*; Sixty-ninth session at para. 29(e). See description of “other status” cases in A. Lester and S. Joseph, “Obligations of Non-Discrimination”, in *The International Covenant on Civil and Political Rights and United Kingdom Law*, ed. by D. Harris and S. Joseph, Oxford, 1995, chapter 17, p. 568. See also *Althammer v Austria*, 8 August 2003, seventy-eighth session of the HRC UN Doc.. CCPR/C/78/D/998/2001 where the Committee found that discrimination based on age could not be demonstrated in circumstances where “... an increase of children’s benefits is not only detrimental for retirees but also for active employees not (yet or no longer) having children in the relevant age bracket...”; at para 10.2.

<sup>741</sup> See Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR Commentary* N.P. Engel, Kehl/Strasbourg/Arlington, 1993, at p. 473, cited by Lester and Joseph, p. 586. in *Obligation of Non Discrimination* A. Lester and S. Joseph, in *International Covenant on Civil and Political Rights and United Kingdom Law* (1995) ed. By D. Harris and S. Joseph, Oxford, 1995, pp. 563-596.

<sup>742</sup> In *Zwaan-de Vries v. The Netherlands*, the HRC considered that a subsequent change to the law in the Netherlands was an acknowledgement that the difference of treatment in that case could not be said to be based upon reasonable grounds: see para. 14. Also, in *Kavanagh v. Ireland*, 28 November 2002, sixty sixth session of the HRC, Communication No. 819/1998. the HRC found that the refusal of the relevant authority to give reasons for a certain practice meant that a decision to try the person by a certain procedure could not be said to be based upon reasonable and objective grounds; at para. 10.3. In contrast, in *Blom v. Sweden*, 4 April 1988: thirty second session of the HRC, Communication No. 191/1985, a distinction between State

11.89 In determining whether the criteria for discrimination are reasonable and objective the HRC has proceeded on a case by case basis, with little specific consideration of disability discrimination cases.

*International Covenant on Economic Social and Cultural Rights (ICESCR)*

11.90 Article 2(2) ICESCR:

The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

11.91 The CESCR's General Comment No. 20 expands on the interpretation to be afforded to Article 2(2) in relation to the right to health. It states that:

Non-discrimination is an immediate and cross-cutting obligation in the Covenant. Article 2(2) requires States parties to guarantee non-discrimination in the exercise of each of the economic, social and cultural rights enshrined in the Covenant and can only be applied in conjunction with these rights. It is to be noted that discrimination constitutes any distinction, exclusion, restriction or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of Covenant rights.<sup>743</sup>

11.92 Since the right to health is a "right enunciated in the Covenant", the ICESCR guarantees this right to everyone, without discrimination on the basis of the person's status. General Comment No. 20 clarifies that for States parties to "guarantee" that the ICESCR rights will be exercised without discrimination of any kind, discrimination must be eliminated "both formally and substantively".<sup>744</sup>

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subsidies for students at private and students at public schools was found to be reasonable and objective. At para. 10.3.

<sup>743</sup> General Comment No. 20, Non-Discrimination in Economic, Social and Cultural Rights (art. 2, para. 2), at para 7; E/C.12/GC/20, 10 June 2009, Committee On Economic, Social And Cultural Rights, Forty-Second Session, Geneva, 4-22 May 2009.

<sup>744</sup> *Ibid*, at para 8.

11.93 Disability-based discrimination, while not specifically listed as a ground under Article 2(2) is prohibited and thus applies to the right to health.<sup>745</sup> The General Comment recalls the test for disability discrimination as set out in General Comment 5, namely:

... any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.<sup>746</sup>

11.94 States parties should address discrimination, such as limitations on the right to education, and denial of reasonable accommodation<sup>747</sup> in public places such as public health facilities and the workplace,<sup>748</sup> as well as in private places.<sup>749</sup>

11.95 In order to eliminate discrimination against persons with disabilities, certain “positive measures” of a permanent nature may be required.<sup>750</sup> Intended to be temporary, such special measures may exceptionally be of a permanent nature to ensure for example “reasonable accommodation of persons with sensory impairments in accessing health care facilities”<sup>751</sup>.

11.96 General Comment 20 provides that in addition to:

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<sup>745</sup> See General Comment 20 at para 28; see also General Comment 5 at paras 15 and 22.

<sup>746</sup> See General Comment No. 5, para. 15. General Comment 20 gives the definition outlined in Article 1 of the CRPD: “Persons with disabilities include, but are not limited to individuals with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. This definition is similar to that found in other international conventions. General Comment No. 20 draws attention to the similar definitions under Article 1 of the Convention on the Elimination of All Forms of Racial Discrimination, Article 1 of the Convention on the Elimination of Discrimination against Women and Article 2, Convention on the Rights of Persons with Disabilities and the Human Rights Committee’s similar interpretation in General Comment No. 18; at paras. 6 and 7.

<sup>747</sup> General Comment 20 cites Article 2 of the CRPD: Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

<sup>748</sup> See General Comment No. 5, para. 22.

<sup>749</sup> For example, as long as spaces are designed and built in ways that make them inaccessible to wheelchairs, such users will be effectively denied their right to work: General Comment 5, op. cit., at para 22.

<sup>750</sup> *Ibid.*, para 9.

<sup>751</sup> *Ibid.*, at para 9.

refraining from discriminatory actions, States parties should take concrete, deliberate and targeted measures to ensure that discrimination in the exercise of Covenant rights is eliminated. Individuals and groups of individuals, who may be distinguished by one or more of the prohibited grounds, should be ensured the right to participate in decision-making processes over the selection of such measures.<sup>752</sup>

11.97 Similarly, incentives and penalties should be employed to address systemic discrimination.<sup>753</sup>

11.98 Relevant institutions should adjudicate or investigate complaints promptly, impartially, and independently and address alleged violations relating to Article 2(2), including actions or omissions by private actors, and

[w]here the facts and events at issue lie wholly, or in part, within the exclusive knowledge of the authorities or other respondent, the burden of proof should be regarded as resting on the authorities, or the other respondent, respectively. The burden of proof of demonstrating the availability of such remedies rests with the national authorities.<sup>754</sup>

#### *CESCR Observations on Ireland*

11.99 In its 2002 Concluding Observations on Ireland, the CESCR expressed concern “*about the persistence of discrimination against persons with physical and mental disabilities, especially in the fields of employment, social security benefits, education and health.*”<sup>755</sup>

#### *Convention on the Rights of Persons with Disabilities (CRPD)*

11.100 Finally it should be noted that Article 5 of the CRPD provides:

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

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<sup>752</sup> *Ibid.*, at para 36.

<sup>753</sup> *Ibid* At para 12

<sup>754</sup> General Comment 20 at para. 40.

<sup>755</sup> Consideration of Ireland's Second Periodic Report, *Committee On Economic, Social And Cultural Rights, Twenty-eighth session, 29 April-17 May 2002* at para. 15.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

### **Key Points of Relevance**

11.101 Six points of relevance to this enquiry may be made on the basis of these international human rights provisions:

- a) Discrimination is prohibited. The State should take concrete, deliberate and targeted measures to ensure that discrimination in the exercise of convention rights is eliminated.
- b) Not all differential treatment constitutes discrimination.
- c) differential treatment is prohibited if it is based on a particular ground and has no reasonable and objective justification.
- d) Objective and reasonable justification is assessed by reference to whether the differential treatment pursues a legitimate aim and whether it draws a fair balance between the interests of the particular individual and the interests of society.
- e) Differential treatment may be prohibited even where it has no discriminatory purpose, if it has a disproportionate and unjustified adverse effect on members of a particular group.
- f) Unjustified difference of treatment in the enjoyment of a convention right on the grounds of disability, age or health status are prohibited. In

the case of the ICCPR, this prohibition extends to all acts or omissions in the fields of law.

## The Right to a Remedy

### *Constitution*

11.102 In interpreting the right to a remedy under the Constitution, the Supreme Court has adopted a role of restraint where a remedy is sought against the State in the form of judicial review proceedings. It has been held by the Courts that the allocation of public monies is a matter for the Executive not the judiciary and that the Constitution does not generally impose positive obligations on the State in relation to socio-economic rights.<sup>756</sup> Judicial review may be available to an aggrieved citizen in order to invalidate an administrative decision, to obtain damages and to seek certain reliefs such as an order to quash a decision complained of. However, a high threshold must be established.<sup>757</sup> In relation to non-judicial remedies, a person adversely affected by an action carried out in the performance of administrative functions may submit a complaint to the Ombudsman or the Ombudsman for Children if he or she can show that the procedure by which the action was taken was flawed. If the act complained of involves a breach of Garda discipline, a person may submit a complaint to the Garda Síochána Ombudsman Commission.<sup>758</sup>

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<sup>756</sup> See *O'Reilly v Limerick Corporation* [1989] ILRM 18; and *TD v Minister for Education* [2001] 4 IR 259.

<sup>757</sup> *O'Keeffe v. An Bord Plenála* [1992] 1 IR 39.

<sup>758</sup> Section 4 (2) of the Ombudsman Act 1980; Sections 8 and 9 of the Ombudsman for Children Act 2002; Part IV of the Garda Síochána Act 2005.

## *International Law*

### *European Convention on Human Rights (ECHR)*

11.103 The State is obliged to vindicate international convention rights by means of an effective remedy. Three international agreements to which the State is a party are relevant, one at the regional level and two at the international level.

11.104 At the regional level, Article 1 of the ECHR provides that:

The High Contracting Parties shall secure to everyone within their jurisdiction the rights and freedoms defined in Section I of this Convention.

11.105 In addition, Article 13 of the ECHR provides that:

Everyone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity.

11.106 Article 13 may be engaged where there is an arguable claim that there has been a breach of an ECHR right.<sup>759</sup> Article 13 requires a domestic remedy to deal with the substance of an “arguable complaint” and to grant appropriate relief.<sup>760</sup> The scope of obligations under Article 13 varies depending on the nature of the complaint. However, remedies must be “effective” in practice as well as in law and the adequacy of the remedy may be undermined where excessive delay occurs.<sup>761</sup>

11.107 The European Court has held that an effective remedy need not be judicial:

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<sup>759</sup> *Klass and others v. Germany*, Judgment of 6 September 1978, (1979-80) 2 EHRR 214, at para 64. See also *Silver and Others v. The United Kingdom*, Judgment of 25 March 1983, (1983) 5 EHRR 347, at para. 113.

<sup>760</sup> *Doran v. Ireland*, Judgment of 31 July 2003, [2003] ECHR 414 at para. 55.

<sup>761</sup> *Ibid.*, at paras 56-57. See also *Çonka v. Belgium*, Judgment of 5 February 2002, (2002) 34 EHRR 1298, at para. 75. The ‘effectiveness’ of a ‘remedy’ does not depend on the certainty of a favourable outcome for the applicant; *Çonka v. Belgium*, op. cit., at para. 75.

if it is not, its powers and the guarantees are relevant in determining whether the remedy before it is effective. In addition, even if a single remedy does not by itself entirely satisfy the requirements of Article 13, the aggregate of remedies provided for under domestic law may, in principle, do so.<sup>762</sup>

11.108 Remedies available to a litigant at domestic level may be effective if they prevent the alleged violation or its continuation, or provide adequate redress for any violation that has already occurred.<sup>763</sup> The remedy before the national authority should concern both the determination of the claim and any redress.<sup>764</sup> Where a respondent government cannot put forward an example of the application of the remedy offered to a case similar to the one put forward by the applicant, they are unlikely to satisfy the European Court that there is an effective remedy available.<sup>765</sup>

11.109 Article 13 has also been considered in conjunction with Article 3 (prohibition on torture, inhuman and degrading treatment). Hence, the failure by a State to carry out a thorough and effective investigation into an allegation of ill-treatment or to allow effective access to the investigatory procedure violates Article 13.<sup>766</sup> Similarly, in circumstances where a punishment which breached Article 3 could not be challenged during a period of detention, the European Court found a violation of Article 13.<sup>767</sup> If an applicant suffering from mental illness is not in a fit state to make use of an available remedy, there should be an automatic review of a punitive decision.<sup>768</sup> Article 13, when considered in conjunction with Article 8, requires judicial review by domestic courts to be effective and that any thresholds involved in taking a case would not effectively exclude consideration of Article 8 (i.e. whether an interference with an

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<sup>762</sup> *Ibid.*, at para. 158.

<sup>763</sup> *Ibid.*, at para. 159.

<sup>764</sup> *Silver and Others v. The United Kingdom*, Judgment of 25 March 1983, (1983) 5 EHRR 347, at para. 113.

<sup>765</sup> See for example *Vereinigung demokratischer Soldaten Österreichs and Gubi v. Austria*, Judgment of 19 December 1994, (1995) 20 EHRR 56, at para. 53.

<sup>766</sup> *Assenov and Others v. Bulgaria*, Judgment of 28 October 1998, (1999) 28 EHRR 651, at paras 101-106 and 117-118. The requirement extends to the grant of appropriate relief: see *Assenov*, at para. 117. See also *Atalay v Turkey*, Judgment of 18 September 2008, at paras 46-47.

<sup>767</sup> *Keenan v. The United Kingdom*, Judgment of 3 April 2001, (2001) 33 EHRR 903, at paras 12-127.

<sup>768</sup> *Ibid.*

applicant's rights addressed a pressing social need or was proportionate to the aims pursued).<sup>769</sup>

### *International Covenant on Civil and Political Right (ICCPR)*

11.110 At the international level, Article 2(3) of the ICCPR provides that:

Each State Party to the present Covenant undertakes:

(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;

(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;

(c) To ensure that the competent authorities shall enforce such remedies when granted.

11.111 In its General Comment No. 31,<sup>770</sup> the HRC noted that Article 2(3) of the ICCPR requires that individuals have accessible and effective remedies to vindicate those rights that are appropriately adapted so as to take account of the special vulnerability of certain categories of person, in particular children.<sup>771</sup> It also requires that States Parties make reparation to individuals whose ICCPR rights have been violated. Where appropriate, reparation can involve *inter alia*, "restitution, rehabilitation and measures of satisfaction".<sup>772</sup> It also requires investigations of allegations of ill-treatment.<sup>773</sup> The HRC has held that the right to a remedy under Article 2(3) requires States to ensure that similar violations do not occur in the future.<sup>774</sup> The HRC thus emphasises the need for measures

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<sup>769</sup> *Smith and Grady v. The United Kingdom*, Judgment of 27 September 1999, (2000) 29 EHRR 493, at para. 135; *Peck v. The United Kingdom*, Judgment of 28 January 2003, (2003) 36 EHRR 719, at para. 106; *C.G. and Others v. Bulgaria*, Judgment of 24 April 2008, at para. 62.

<sup>770</sup> General Comment No. 31 [80] *Nature of the General Legal Obligation Imposed on States Parties to the Covenant*: . 26/05/2004. CCPR/C/21/Rev.1/Add.13.

<sup>771</sup> General Comment No. 31, at para. 15.

<sup>772</sup> *Ibid.*, at para. 16.

<sup>773</sup> *Mukong v. Cameroon*, Communication No. 458 of 1991,11.

<sup>774</sup> *Njaru v. Cameroon*, Communication No. 1353/2005, at para. 8; *X v. Colombia*, Communication No. 1361/2005, at para. 9; *Chikunova v. Uzbekistan*, Communication No. 1043/2002, at para.

beyond a victim-specific remedy in preventing recurrence of violations and examines not only formal laws but also how they are implemented in practice.

### *International Covenant on Economic, Social and Cultural Rights (ICESCR)*

11.112 The second international convention of relevance is the ICESCR wherein remedies and accountability are “core” elements of the right to health under Article 12, as General Comment 14 makes clear:

Any person or group victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels. All victims of such violations should be entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition. National ombudsmen, human rights commissions, consumer forums, patients' rights associations or similar institutions should address violations of the right to health.<sup>775</sup>

11.113 In addition, General Comment No. 20 which addresses non-discrimination requires States to ensure effective remedies. Effective remedies include compensation, reparation, restitution, rehabilitation, guarantees of non-repetition and public apologies.<sup>776</sup>

### *Convention on the Rights of Persons with Disabilities (CRPD)*

11.114 Also at the universal level, Article 4(1) of the CRPD provides that:

States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention[.]

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9; *Tcholatch v. Canada*, Communication No. 1052/2002, at para. 10; *Agabekov v. Uzbekistan*, Communication No. 1071/2002, at para. 9; *Vuolanne v. Finland*, Communication No. 265/1987, at para. 11. Article 2(3) requires expeditious resolution of proceedings and prompt prosecution and conviction of those responsible for ill-treatment. *E.B. v. New Zealand*, Communication No. 1368/2005, at para. 11; *Njaru v. Cameroon*, Communication No. 1353/2005, at para. 8.

<sup>775</sup> *Ibid.*, at para. 59.

<sup>776</sup> General Comment No. 20 at para. 40.

11.115 Other substantive articles of the CRPD also refer to the right to effective remedies including in situations of detention,<sup>777</sup> ill-treatment<sup>778</sup> and exploitation, violence or abuse which must be identified, investigated and, where appropriate, prosecuted.<sup>779</sup>

### **Key Points of Relevance**

11.116 Four points of relevance to this enquiry may be made on the basis of these international human rights provisions:

- a) The State is obliged to provide an accessible and effective remedy to an individual where an arguable claim of a breach of a substantive ECHR right arises.
- b) In order for a remedy to be effective, it must be accessible and available in practice as well as in theory. A remedy may be effective when taken in conjunction with other remedies even where it would not be sufficient in isolation.
- c) Appropriate institutions must be in place to investigate complaints and to provide an effective remedy. Where these institutions are not judicial, they must nonetheless provide a remedy of value to the complainant.
- d) The right to a remedy may include the right to restitution, compensation, satisfaction or guarantees of non-repetition, thus preventing the recurrence of a more general problem.

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<sup>777</sup> Article 14(2) CRPD.

<sup>778</sup> Article 15(2) CRPD.

<sup>779</sup> Article 16(5) CRPD.

## The Right to be Treated with Dignity, Humanity and Respect

11.117 By these rights are meant the right to be treated with dignity, humanity and respect for one's private life and the right to be free from ill-treatment.

### *Constitution*

11.118 There is a general constitutional right to privacy. In *Kennedy v. Ireland*<sup>780</sup> the Supreme Court held that the right to privacy:

is one of the fundamental personal rights of the citizen which flow from the Christian and democratic nature of the state...The nature of the right to privacy must be such as to ensure the dignity and freedom of an individual in the type of society envisaged by the Constitution.<sup>781</sup>

11.119 In *Barry v. the Medical Council*, it was held that the right to privacy of a medical practitioner's patients prevailed over the doctor's right to a public hearing before a disciplinary body.<sup>782</sup>

11.120 The right to be free from ill-treatment is stated to be an obvious corollary to the Constitutional right to bodily integrity.<sup>783</sup> In *The State (C) v. Frawley*,<sup>784</sup> the Supreme Court found that insofar as the unspecified rights guaranteed in Article 40 follow in part or in whole from the Christian and democratic nature of the State, "it is surely beyond argument that they include the right to freedom from torture, and from inhuman and degrading treatment and punishment".<sup>785</sup>

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<sup>780</sup> *Kennedy v. Ireland* [1987] IR 587. See also *Norris v. The Attorney General* [1984] I.R. 36, at p. 64.

<sup>781</sup> *Ibid.*, at p. 592.

<sup>782</sup> *Barry v. Medical Council* [1998] 3 IR 368, at pp. 388 to 398.

<sup>783</sup> Kelly, *The Irish Constitution*. Fourth Edition at p. 1422.

<sup>784</sup> *The State (C) v. Frawley* [1976] IR 365.

<sup>785</sup> [1976] IR 365 at p. 374.

## *International Law*

### *European Convention on Human Rights (ECHR)*

11.121 Article 8 of the ECHR provides for the right to respect for private life:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

11.121 The European Court has held that the concept of “private life” under Article 8 is a broad term not susceptible to exhaustive definition. It covers the physical and psychological integrity of a person.<sup>786</sup> It can sometimes embrace aspects of an individual’s physical and social identity,<sup>787</sup> including their sexual life.<sup>788</sup> Article 8 also protects the right to personal development, and the right to establish and develop relationships with other human beings and the outside world.<sup>789</sup> The European Court has also held that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.<sup>790</sup>

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<sup>786</sup> In *Botta v. Italy*, Judgment of 24 February 1998, 26 EHRR 241 (1998), a case which concerned access rights to a beach for a physically disabled person, the European Court indicated that “Private life, in the Court’s view, includes a person’s physical and psychological integrity; the guarantee afforded by Article 8 of the Convention is primarily intended to ensure the development, without outside interference, of the personality of each individual in his relations with other human beings...”; see para 32. See also *Van Kück v. Germany*, Judgment of 12 June 2003, (2007) 37 E.H.R.R. 51, at para. 69; *X and Y v. the Netherlands*, Judgment of 26 March 1985, (1986) 8 EHRR 235, at para. 22, and more generally *Bensaid v. The United Kingdom*, Judgment of 6 February 2001, (2001) 33 EHRR 10, at para. 46; *Stubbings and others v. The United Kingdom*, Judgment of 22 October 1996, (1997) 23 EHRR 213, at para. 61.

<sup>787</sup> *Mikulić v. Croatia*, Judgment of 7 February 2002, [2002] 1 FCR 720, at para. 53.

<sup>788</sup> See for example *B. v. France*, Judgment of 29 March 1992, (1994) 16 EHRR 1, at para. 63; *Burghartz v. Switzerland*, Judgment of 22 February 1994, (1994) 18 EHRR 101, at para. 24; *Dudgeon v. the United Kingdom*, Judgment of 22 October 1981, (1982) 4 EHRR 149, at para. 41; *Laskey, Jaggard and Brown v. The United Kingdom*, Judgment of 19 February 1997, (1997) 24 EHRR 39, at para. 36 and *Smith and Grady v. The United Kingdom*, Judgment of 27 September 1999, (2000) 29 EHRR 493, at para. 71.

<sup>789</sup> *Ibid.*

<sup>790</sup> *Van Kück v. Germany*, Judgment of 12 June 2003, (2007) 37 E.H.R.R. 51, at para. 69; *Pretty v. the United Kingdom*, Judgment of 29 April 2002, (2002) 35 EHRR 1, at para. 61.

11.122 Article 8(1) refers to “the right to *respect* for ... private and family life [and one’s] home..”, which goes further than merely requiring the State not to ‘interfere’ with a right. Positive obligations may involve the adoption of measures designed to secure respect for private life even in the sphere of relations between individuals.<sup>791</sup> Where a law fails to meet the test that it ensures positive protection of private, family life or home it may violate Article 8 without any need to examine the limitations contained in its second paragraph.<sup>792</sup> Where an interference by the State comes within the scope of Article 8(1), the European Court will consider whether the interference is justified by reference to Article 8(2). In doing so, the European Court will have particular regard to the quality of the law at issue and whether the measure in question (such as the conditions for vulnerable persons in a residential centre) represents a proportionate means to a legitimate end.<sup>793</sup> It will also have regard to the fair balance that has to be struck between the competing needs of the individual and the community.

11.123 Inaction by the State may breach its positive obligations under Article 8.<sup>794</sup> A person with a disability must demonstrate a direct link between the alleged ‘inaction’, for example, a lack of access to buildings or places, and the effect this

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<sup>791</sup> *Van Kück v. Germany*, Judgment of 12 June 2003, (2007) 37 E.H.R.R. 51, at para. 70; *X and Y v. the Netherlands*, Judgment of 26 March 1985, (1986) 8 EHRR 235, at para. 23; *Botta v. Italy*, Judgment of 24 February 1998, (1998) 26 EHRR 241, at para. 33; *Mikulić v. Croatia*, Judgment of 7 February 2002, [2002] 1 FCR 720, at para. 57.

<sup>792</sup> *Marckx v. Belgium*, Judgment of 13 June 1979, (1979-1980) 2 EHRR 330, at para. 30.

<sup>793</sup> In relation to the quality of the law, the European Court has held that the law must be accessible and formulated in a way that a person can reasonably foresee the consequences which a given action will entail: *Halford v. The United Kingdom*, Judgment of 27 May 1997, (1998) 24 EHRR 523, at para. 49; *Copland v. The United Kingdom*, Judgment of 3 April 2007, (2007) 45 EHRR 37, at para. 46. In relation to the test as to whether the measure represents a proportionate means to a legitimate end; see *Silver v. The United Kingdom*, Judgment of 25 March 1983, (1983) 5 EHRR 347, at para. 97.

<sup>794</sup> *Botta v. Italy*, Judgment of 24 February 1998, (1998) 26 EHRR 241, at para. 34. In that case, the European Court had grounded its consideration by reference to a number of Council of Europe initiatives, including a 1992 Recommendation on a coherent policy for people with disabilities made by the Council’s Committee of Ministers, a 1992 Recommendation adopted by the Council’s Parliamentary Assembly on rehabilitation policies for the disabled and Article 15 of the Revised European Social Charter which calls for measures to promote social integration and participation of persons with disabilities, although the revised Charter had not yet come into force at the time of the European Court’s decision (the Revised European Social Charter came into force on 1 July 1999).

has on her or his life.<sup>795</sup> Imprecise details of alleged obstacles or a lack of persuasive evidence of any interference with a person's private life will not suffice in this regard. While Article 8 does not guarantee the right to have one's housing problem solved by the authorities, a refusal of the authorities to provide assistance in this respect to an individual suffering from a severe disease might in certain circumstances raise an issue under Article 8, depending on its impact on the individual.<sup>796</sup>

11.124 Where living conditions are particularly poor, Article 8 may be engaged. In *Moldovan and Others v Romania*<sup>797</sup> the European Court stated that issues in relation to both Article 8 and Article 3 (see below) arose in circumstances where a Roma community had been burnt out of their homes (by both non-State and State actors) and were left to live in "*crowded and improper conditions - cellars, hen-houses, stables, etc and frequently changed address, moving with friends or family in extremely overcrowded conditions*".<sup>798</sup>

11.125 The procedural safeguards in place and available to the individual are "especially material" in determining whether a State has remained within its "margin of appreciation" under Article 8.<sup>799</sup> In particular, the European Court will examine whether "*the decision-making process leading to measures of interference was fair and such as to afford due respect to the interests safeguarded to the individual by Article 8*". The European Court has stated that it

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<sup>795</sup> *Ibid.*, at para. 35. See also *Zehnalová and Zehnal v. The Czech Republic*, Decision of 14 May 2002. (dec.), no. 38621/97, ECHR 2002-V).

<sup>796</sup> *Marzari v. Italy*, Admissibility decision of 4 May 1999, (1999) 28 EHRR CD. In the instant case, the European Court held on the facts that the State had discharged its positive obligations through its efforts to accommodate the applicant.

<sup>797</sup> *Moldovan and Others v Romania* Application nos. 41138/98 and 64320/01, ECtHR Judgment No. 2 of 30 November 2005 ("*Moldovan and Others*").

<sup>798</sup> *Ibid.*, at para. 69. In that case, the European Court also considered that the length of time that individuals were living in these conditions would be a relevant factor in its assessment; at para. 110.

<sup>799</sup> *Ibid.*, at para. 83. The phrase "necessary in a democratic society" in Article 8(2) has been held to include consideration of a States' "margin of appreciation". This in turn has been described as the discretion afforded Member States by the European Court. Its application depends on the subject matter at issue: areas pertaining to the criminal law, public health, national security, certain issues of morality and urban planning will result in a higher margin of appreciation being afforded to States and the interference under scrutiny is more likely to be upheld by the European Court; see *Silver v. United Kingdom* 5 EHRR 347 (1983), at para. 97.

will not accept a discretion that has been drafted too widely. In terms of the type of factors that need to be included in defining the scope of such discretion, the European Court held that it would “*assess in particular whether the reasons adduced to justify such measures were relevant and sufficient and whether there were adequate and effective safeguards against abuse*”.<sup>800</sup>

11.126 Thus, medical interventions even those of only minor importance, clearly engage Article 8 insofar as a person’s body concerns the most intimate aspect of private life.<sup>801</sup> Any involuntary medical treatment would appear therefore to engage Article 8 and require justification under Article 8(2). The European Court will have regard to the State’s margin of appreciation in respect of medical decisions taken by the authorities.<sup>802</sup> In this regard, the European Court will examine whether grounds of medical necessity apply and the availability of procedural safeguards.<sup>803</sup> Thus, in a case concerning involuntary detention in a psychiatric institution, the European Court held that even a minor interference with the physical integrity of an individual must be regarded as an interference with Article 8 if it is carried out against the individual’s will.<sup>804</sup>

11.127 Where a person’s legal capacity is removed by the State, the European Court will focus its analysis on the proportionality of that decision with respect to the legitimate aim invoked by the State, with the quality of the decision-making process being key.<sup>805</sup> Any automatic presumption of incapacity, rather than a

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<sup>800</sup> *Keegan v. The United Kingdom*, Judgment of 18 July 2006, at para. 28.

<sup>801</sup> *Y.F. v. Turkey*, Judgment of 22 July 2003, (2004) 39 EHRR 34, at para. 33.

<sup>802</sup> See *Sentges v. The Netherlands*, Admissibility decision of 8 July 2003, a case in which the applicant complained that the authorities’ refusal to provide him with a robotic arm violated Article 8. The European Court held that, even assuming that a special link between the situation complained of and his or her private life existed, thus engaging positive obligations under Article 8, regard had to be had to the fair balance between the competing interests of the individual and of the community as a whole and the particularly wide margin of appreciation afforded to States in assessing priorities in the context of the allocation of limited State resources. In the current case, the European Court noted that the applicant had been provided with an electric wheelchair with an adapted joystick.

<sup>803</sup> *Storck v. Germany*, Judgment of 16 June 2005, (2005) 43 EHRR 96, at para. 143. See also Bartlett, Lewis and Thorold, *Mental Disability and the European Convention on Human Rights*, Koninklijke Brill, The Netherlands, 2007, at pp. 129-131.

<sup>804</sup> *Storck v. Germany*, op. cit., at para. 143.

<sup>805</sup> See *Shtukaturov v. Russia*, 27 March 2008, [2008] ECHR 44009/05, at paras 85-86 and 94-96.

'tailor-made' approach, could lead to a finding of a violation of Article 8.<sup>806</sup> The procedural safeguards that the State must have in place when making decisions about capacity must also include an opportunity to have the decision reviewed and to have one's legal capacity restored.<sup>807</sup>

11.128 In relation to ill-treatment, Article 3 of the ECHR provides:

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.<sup>808</sup>

11.129 The jurisprudence of the European Court under Article 3 primarily concerns cases of detention in relation to which it has consistently held that persons detained by the State are entitled to certain minimum standards. Article 3 obliges States to put proper procedures in place to guard against ill-treatment. Article 3 will only apply where there is a certain minimum level of severity and this will depend on all the circumstances of the case, such as the duration of the treatment, its physical and mental effects and, in some cases, the sex, age and state of health of the victim.<sup>809</sup>

11.130 When assessing the conditions in institutions and hospitals where individuals are under the care of the State, the European Court will take account of the cumulative effect of the conditions as well as any specific allegations of ill-treatment made by the person detained. Further, Article 3 may be breached

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<sup>806</sup> In *Shtukurov*, the European Court held that as the deprivation of legal capacity constitutes a "very serious" interference with a person's right to respect for private life, there must be sufficient reason and also a "tailor-made" and proportionate response for removing an individual's legal capacity; at paras 95-96.

<sup>807</sup> *Berková v Slovakia*, ECtHR Judgment of 24 March 2009, at para. 172.

<sup>808</sup> No exception to this principle is allowed.

<sup>809</sup> *Ireland v. The United Kingdom*, Judgment of 18 January 1978, (1980) 2 EHRR 25, at para. 162. See also *Tyler v. The United Kingdom*, Judgment of 25 April 1978 (1979-80) 2 EHRR 1, where the European Court found that birching as a punishment in schools on the Isle of Man was degrading but not inhuman punishment: "... in order for a punishment to be "degrading" and in breach of Article 3 (art. 3), the humiliation or debasement involved must attain a particular level and must in any event be other than that usual element of humiliation referred to in the preceding subparagraph. The assessment is, in the nature of things, relative: it depends on all the circumstances of the case and, in particular, on the nature and context of the punishment itself and the manner and method of its execution."; at para. 30. More recently see *Malenko v. Ukraine*, Judgment of 19 February 2009, at para. 45.

depending on the intention of the persons inflicting the ill-treatment (namely whether they acted with a deliberate intention to degrade or humiliate) or depending on the effect of the detention on the detained person.<sup>810</sup> Accordingly, the European Court has found there was degrading treatment of a person with a physical disability even where there was no intention to humiliate the person.<sup>811</sup>

11.131 The European Court has held that the State is obliged to protect the health of persons deprived of their liberty and that the lack of appropriate medical care may amount to treatment contrary to Article 3.<sup>812</sup> In such cases, the assessment of whether the particular treatment or punishment is incompatible with Article 3 must, in the case of mentally ill persons *“take into consideration their vulnerability and their inability, in some cases, to complain coherently or at all about how they are being affected by any particular treatment”*.<sup>813</sup>

11.132 Where the European Court considers that medical necessity justifies treatment which accords with psychiatric principles generally accepted at the time, it will not find a violation of Article 3, although it has stressed that the position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance.<sup>814</sup> Thus, the decision to

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<sup>810</sup> *Ibid.*, at paras 21-29.

<sup>811</sup> See *Price v. United Kingdom*, Judgment of 10 July 2001, (2001) 34 EHRR 1285 in which the applicant, who had a physical disability as a result of thalidomide, was forced to spend her first night in prison in a cold cell with a bed she could not use; was brought to the toilet by male staff and left there and, at the end of her three day sentence, required catheterisation. The European Court considered that: *“to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment contrary to Article 3 of the Convention”*; at para 30. See also *Peers v Greece*, Judgment of 19 April 2001 (2001) 33 EHRR 518, in which the applicant had to spend a considerable part of each day confined to bed in a shared cell with no ventilation and no window, which would at times become unbearably hot. He also had to use a lavatory in the presence of another inmate and be present while it was being used by his cell-mate. The European Court ruled that these prison conditions *“diminished the applicant’s human dignity and aroused in her feelings of anguish and inferiority capable of humiliating and debasing him and possibly breaking his physical or moral resistance”*; at para. 75.

<sup>812</sup> *Keenan v. The United Kingdom*, Judgment of 3 April 2001, (2001) 33 EHRR 903, at para. 111.

<sup>813</sup> *Ibid.*

<sup>814</sup> *Herczgefalvy v. Austria*, Judgment of 24 September 1992, (1993) 15 EHRR 437, concerned a case where the applicant complained of being forcibly administered food and neuroleptics, and being isolated and attached with handcuffs to a security bed, following a hunger strike. The

administer anti-psychotic medication to an involuntary patient, imposed as part of a therapeutic regime, will not breach Article 3 insofar as the decision as to what therapeutic methods are necessary is principally one for the national medical authorities.<sup>815</sup> However, the application of physical restraints on a detained person may be disproportionate and violate Article 3.<sup>816</sup>

11.133 The principles laid down by the European Court for the basic conditions in which a person should be detained may also apply to persons in residential centres in a vulnerable or powerless situation.<sup>817</sup> These principles provide that overcrowding should be avoided, sleeping facilities should be adequate, temperatures should be tolerable and ventilation and lighting should be appropriate. Sanitary conditions should reach proper standards. The amount of time the person is confined should not be excessive and there should be proper

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European Court held that there had been no violation of Article 3, given that the evidence was not sufficient to disprove the Government's argument that, according to the psychiatric principles generally accepted at the time it was the normal practice at the time; "While it is for the medical authorities to decide, on the basis of the recognised rules of medical science, on the therapeutic methods to be used, if necessary by force, to preserve the physical and mental health of patients who are entirely incapable of deciding for themselves and for whom they are therefore responsible, such patients nevertheless remain under the protection of Article 3, whose requirements permit of no derogation"; see para. 82.

<sup>815</sup> *Ibid.*, see also *Keenan v United Kingdom*, Judgement of 3 April 2001, 33 EHRR 913 in which the European Court found a violation of Article 3 where a prisoner suffering from mental illness including a risk of suicide was found hanged in his cell; a 7 days segregation punishment, an additional 28 days added to his sentence, was compounded by "the lack of effective monitoring of [the individual's] condition and the lack of informed psychiatric input into his assessment and treatment disclose significant defects in the medical care provided to a mentally ill person known to be a suicide risk"; the Court considering this to constitute inhuman and degrading treatment; at para. 116.

<sup>816</sup> *Hénaf v. France*, Judgment of 27 November 2003, (2005), 40 EHRR 44. In this case the European Court found there was a lack of medical evidence that the applicant was sufficiently dangerous to be handcuffed to his bed in a hospital overnight prior to an operation. Furthermore, the European Court found that, even had he posed a danger, the level of restraint was disproportionate, especially given that there were two police officers on guard outside the room; at paras 47-60. The difference between 'torture' and 'inhuman or degrading treatment' in Article 3 is one of severity. The European Court has stated that certain acts once classified as 'inhuman or degrading treatment' as opposed to 'torture' may be classified differently in future due to the increasingly high standard being required in the area of the protection of human rights and fundamental liberties. Similarly, certain acts previously falling outside the scope of Article 3 (in that they were not considered as sufficiently severe to amount to 'inhuman or degrading treatment') may in future be considered as reaching the level of severity of Article 3: *Hénaf v. France*, *op. cit.*, at para. 55.

<sup>817</sup> See also European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment Standards, discussed below.

periods of exercise and recreation outside the room or place of detention in addition to contact with the outside world.<sup>818</sup>

11.134 Further principles laid down by the European Court for persons in detention or analogous situations include the need for appropriate medical care including specialist medical treatment.<sup>819</sup> The European Court has stated that in assessing whether the authorities have discharged their health-care obligations to a detainee, it may analyse to what extent the person's state of health deteriorated in the course of his or her detention.<sup>820</sup> The European Court has also stated that the authorities must show that the necessary conditions were created for any prescribed medical treatment to be actually delivered.<sup>821</sup> The State cannot cite financial difficulties as a reason for refusing medical treatment to a detainee where that medical treatment is available to the other members of the public.<sup>822</sup> Further, poor conditions of detention can be considered cumulatively as amounting to a violation of Article 3.

11.135 Other obligations on the State under Article 3 include the obligation to ensure that vulnerable persons are protected from ill-treatment at the hands of private individuals<sup>823</sup> and a procedural obligation on State authorities to carry out

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<sup>818</sup> *Dougoz v Greece*, Judgment of 6 March 2001, (2002) 34 EHRR 1480, at paras 44-49; *Peers v Greece*, Judgment of 19 April 2001, (2001) 33 EHRR 1192, at paras 69-75; *Malenko v. Ukraine*, Judgment of 19 February 2009, at para. 62.

<sup>819</sup> *Malenko v. Ukraine*, op. cit. See also *Paladi v Moldova*, Grand Chamber Judgment of 10 March 2009, at paras 68 and 71-72. In *Aleksanyan v Russia*, Judgment 22 December 2008, the European Court found a breach of Article 3 in circumstances where a detainee did not have access to specialist treatment for HIV/ Aids; see paras 156-158.

<sup>820</sup> *Ukhan v Ukraine*, Judgment of 18 December 2008, at para. 73.

<sup>821</sup> *Ibid.*, at para. 74.

<sup>822</sup> *Groni v Albania*, Judgment of 7 July 2009, at paras 131-133.

<sup>823</sup> The European Court has held that Article 3, taken together with the obligation under Article 1 of the ECHR that State Parties secure to everyone within their jurisdiction the rights and freedoms defined in the ECHR, requires States to ensure that individuals within their jurisdiction are not only protected from torture or inhuman or degrading treatment or punishment by organs of the State but also protected where the treatment is at the hands of private individuals. Children and other vulnerable individuals, in particular, are entitled to State protection, *A. v. The United Kingdom*, Judgment of 23 September 1998, (1999) EHRR 611, at para. 22; see also *Z. and others v. The United Kingdom*, Judgment of 10 May 2001, (2002) 34 EHRR 97, at para. 73. with Articles 1 and 3 also imposing an obligation on States to investigate possible breaches of Article 3 which come to the attention of State authorities. *Assenov v Bulgaria*, Judgment of 28 October 1998, (1998) 28 EHRR 652.

a thorough and effective investigation into any allegation of ill-treatment contrary to Article 3.<sup>824</sup>

*European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment* (“ECPT”)

11.136 The ECPT was adopted in order to strengthen the protection against torture or inhuman or degrading treatment or punishment contained in Article 3 of the ECHR by non-judicial means of a preventive character based on visits to State Parties.<sup>825</sup> As such, its focus includes ensuring procedural safeguards so that situations of ill-treatment do not arise. Article 1 of the ECPT provides:

There shall be established a European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment ... The Committee shall, by means of visits, examine the treatment of persons deprived of their liberty with a view to strengthening, if necessary, the protection of such persons from torture and from inhuman or degrading treatment or punishment.

11.137 The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (“CPT”) is the supervisory body to the CPT and is mandated under Article 12 to submit a General Report of its activities to the Committee of Ministers of the Council of Europe, which is published. From these General Reports, the CPT has compiled a set of general standards based on the substantive issues which it pursues when carrying out its visits to places of deprivation of liberty.<sup>826</sup>

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<sup>824</sup> See *ibid.*, where the European Court held that Article 3 read in conjunction with the State's general duty under Article 1 of the Convention “...to ‘secure everyone within their jurisdiction the rights and freedoms defined in [the] Convention’, requires by implication that there should be an effective official investigation. This investigation, as with that under Article 2, should be capable of leading to the identification and punishment of those responsible” if Article 3 were not to be ineffective; at para. 102; see also *Sevtap Veznedaroglu v. Turkey*, Judgment of 11 April 2000, (2000) 33 EHRR 1412, at para. 32.

<sup>825</sup> Ireland ratified the CPT on 14 March 1988.

<sup>826</sup> See CPT Committee, *The CPT standards: “Substantive” sections of the CPT’s General Reports*, Council of Europe, Strasbourg, 2002, CPT/Inf/E (2002) 1, Rev. 2009. The CPT’s recent reports on Ireland are 2007 and 2002, respectively. The CPT again visited the State in early 2010 and met with a range of individuals and bodies, including the Commission.

11.138 The CPT Standards cover placement in psychiatric establishments, such as special hospitals or distinct units in civil hospitals. “Mentally handicapped” persons are described as being particularly vulnerable.<sup>827</sup> The Standards emphasise that the initial decision to place a person involuntarily in an institution must offer guarantees of independence, impartiality and objective medical expertise.<sup>828</sup> In this, the CPT stresses that such a placement should usually be ordered by a Judge and if not, that the detention be speedily reviewed by a court.

11.139 In addition to addressing safeguards against restraint and seclusion of patients,<sup>829</sup> the Standards stress the importance of conditions in institutions ensuring a positive therapeutic environment. There should be “*sufficient living space per patient as well as adequate lighting, heating and ventilation*” and hygiene.<sup>830</sup> Even in times of economic crisis, basic necessities must be provided, such as adequate food, heating, clothing and medication.<sup>831</sup> Both patients’ rooms and recreation rooms should be decorated to ensure visual stimulation for patients and space for locking belongings is recommended to ensure a patient’s “sense of security and autonomy”.<sup>832</sup> Sanitation facilities should allow patients some privacy with a particular focus on lavatories.<sup>833</sup>

11.140 Accommodation structures based on small groups, an individualised approach to treatment and the availability of, *inter alia*, occupational therapy, individual psychotherapy, suitably-equipped recreation rooms and education facilities are all stressed.<sup>834</sup> Informed consent to treatment is also stressed.<sup>835</sup>

11.141 The Standards require that appropriate procedures are in place to protect individuals from other patients who might cause them harm.<sup>836</sup> The

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<sup>827</sup> *Ibid.*, Part V; at para. 30.

<sup>828</sup> *Ibid.*, Part V, at paras. 51-52.

<sup>829</sup> *Ibid.*, at paras 47-50.

<sup>830</sup> *Ibid.*, at para. 34.

<sup>831</sup> *Ibid.*, at para. 33.

<sup>832</sup> *Ibid.*

<sup>833</sup> *Ibid.*

<sup>834</sup> *Ibid.*, at para. 37.

<sup>835</sup> *Ibid.*, at para. 41.

<sup>836</sup> *Ibid.*, at para. 30.

Standards provide that this requires *inter alia* adequate staff presence at all times, including at night and weekends and that further specific arrangements be made for particularly vulnerable patients.<sup>837</sup> Separately, the Standards highlight the importance of adequate staff resources in terms of categories of staff “psychiatrists, general practitioners, nurses, psychologists, occupational therapists, social workers, etc”.<sup>838</sup>

11.142 The CPT’s 2002 Report on Ireland,<sup>839</sup> which followed its visit to the State, addressed a number of concerns in relation to three establishments for mentally disabled persons it had visited; two of which catered for residents with intellectual disabilities. The concerns related to the legal framework for detention, living conditions, staff resources, care, seclusion and physical restraint.<sup>840</sup> The CPT found that satisfactory conditions could not be offered unless the facilities were “purpose-built or adequately renovated to modern standards”. It also stated that “[p]rovision of accommodation structures based on small groups is a crucial factor in preserving/ restoring residents’ dignity, and also a key element of any policy for their psychological and social rehabilitation”.<sup>841</sup> The CPT recommended that staffing levels be reviewed in these establishments and that “an individualised assessment of residents in establishments for mentally disabled persons be carried out” to ensure their treatment or transfer to an appropriate establishment.<sup>842</sup>

11.143 In 2003, the Government formally responded to the CPT’s Report.<sup>843</sup> It referred to the commitment in the National Health Strategy (2001) to complete

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<sup>837</sup> *Ibid.*

<sup>838</sup> *Ibid.*, at para 42.

<sup>839</sup> Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading treatment or Punishment (CPT) from 20 to 28 May 2002. It is noted that the report issued by the CPT on its visit to Ireland in 2007 did not revisit the issues it had raised in relation to the centres referred to in its 2002 report.

<sup>840</sup> *Ibid.*, at paras 92-105.

<sup>841</sup> *Ibid.*, at para. 99.

<sup>842</sup> *Ibid.*, at para. 104.

<sup>843</sup> Response of the Government of Ireland to the report of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) on its visit to Ireland from 20 to 28 May 2002, Strasbourg, 18 September 2003; CPT/ Inf (2003) 37.

the overall transfer of persons with an intellectual disability from psychiatric hospitals not later than 2006.<sup>844</sup> The Government also stated that national standards for residential services for adults were at an advanced stage and would come within the remit of the Social Services Inspectorate.<sup>845</sup>

11.144 Regarding the CPT's concerns about adequate staffing, the Government responded that following commissioned studies by the Department of Health, the numbers trained and recruited "*in respect of current and future need for Speech and Language Therapists, Occupational Therapists and Physiotherapists*" was doubling, while the number of nurse training places was being increased.<sup>846</sup> Finally, regarding the need for individualised assessments of residents, the Government response acknowledged this need "throughout the services" and indicated that particular attention was being paid to this area in the context of best practice and quality initiatives.<sup>847</sup>

#### *International Covenant on Civil and Political Right (ICCPR)*

11.145 Similar to the ECHR, the ICCPR includes a prohibition against unlawful interference with private life. Article 17 of the ICCPR provides that:

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, or correspondence, nor to unlawful attacks on his honour and reputation.
2. Everyone has the right to the protection of the law against such interference or attacks.

11.146 In its General Comment No. 16,<sup>848</sup> the HRC stated that this right is required to be guaranteed against all interferences and attacks whether they

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<sup>844</sup> At time of writing this report, there were still 308 persons with intellectual disability in psychiatric institutions: see *Annual Report of the National Intellectual Disability Database Committee 2008*, p. 72, Health Research Board Statistics Series 6.

<sup>845</sup> Response of the Government of Ireland to the report of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) on its visit to Ireland from 20 to 28 May 2002, Strasbourg, 18 September 2003; CPT/ Inf (2003) 37, at p. 42.

<sup>846</sup> *Ibid.*, at p. 43.

<sup>847</sup> *Ibid.*, at p. 44.

<sup>848</sup> Human Rights Committee, General Comment 16. (Twenty-third session, 1988), *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6 at p. 142 (2003).

emanate from State authorities or from natural or legal persons (such as companies). General Comment No. 16 goes on to provide that the State must adopt legislative and other measures to give effect to the prohibition against such interferences and attacks as well as to the protection of this right.<sup>849</sup>

11.147 Article 7 of the ICCPR reflects Article 3 of the ECHR and provides:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

11.148 The HRC in its General Comment No. 7 stated that Article 7 “*clearly protects not only persons arrested or imprisoned, but also pupils and patients in educational and medical institutions.*”<sup>850</sup> Public authorities are obliged to ensure protection by law against such treatment even when committed by persons “acting outside or without any official authority.”<sup>851</sup> In addition, Article 7 is supplemented by the positive requirement of Article 10(1) of the ICCPR that everyone be treated with humanity and with respect for the inherent dignity of the human person, including patients in “medical institutions”.<sup>852</sup>

*United Nations Convention against Torture and all Forms of Cruel, Inhuman and Degrading Treatment or Punishment* (“UNCAT”)

11.149 Article 2 of UNCAT<sup>853</sup> provides:

- (1) Each State Party shall take effective legislative, administrative or other measures to prevent acts of torture in any territory under its jurisdiction.

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<sup>849</sup> *Ibid.*, at para. 2.

<sup>850</sup> HRC, *General Comment No. 7, Torture or cruel, inhuman or degrading treatment or punishment, Sixteenth session, 1982*, at para. 2.

<sup>851</sup> *Ibid.*

<sup>852</sup> *Ibid.* See HRC, *General Comment No. 20, Prohibition of torture, cruel, inhuman or degrading treatment or punishment, forty-fourth session (1992)*, at paras 2 and 5. In General Comment No. 20, the HRC confirmed that the prohibition against torture or prohibited ill-treatment contained in Article 7 of the ICCPR “allows of no limitation” (at para 3). It covers acts which cause physical as well as mental suffering. States are also required to provide detailed information on safeguards for the special protection of particularly vulnerable persons (at paras 3, 5-6 and 11).

<sup>853</sup> Ireland ratified UNCAT on 11 April 2002.

- (2) No exceptional circumstances whatsoever, whether a state of war or a threat to war, internal political stability or any public emergency may be evoked as a justification of torture.
- (3) An order from a superior officer or a public authority may not be invoked as a justification of torture.

11.150 This absolute prohibition also includes “acts of cruel, inhuman, or degrading treatment or punishment” [ill-treatment] as inserted by Article 16(1) of UNCAT.<sup>854</sup> UNCAT also covers the specific obligations of a State to prevent ill-treatment. State Parties are obliged to prohibit, prevent and redress ill-treatment:

in all contexts of custody or control, for example, in prisons, hospitals, schools, institutions that engage in the care of children, the aged, the mentally ill or disabled, in military service, and other institutions as well as contexts where the failure of the State to intervene encourages and enhances the danger of privately inflicted harm.<sup>855</sup>

10.151 Protection against ill-treatment must be applied to all persons, regardless of, *inter alia*, age, “mental or other disability” or health status.<sup>856</sup>

#### *Convention on the Rights of Persons with Disabilities (CRPD)*

11.152 Article 3 of the CRPD addresses the right to private life:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

[...]

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<sup>854</sup> UN Committee Against Torture (CAT), *General Comment No. 2: Implementation of Article 2 by States Parties*, 24 January 2008, CAT/C/GC/2 holds that “the obligation to prevent torture in article 2 is wide-ranging. The obligations to prevent torture and other cruel, inhuman or degrading treatment or punishment article 16 (1) are interdependent, indivisible and interrelated.”, at para. 3.

<sup>855</sup> *Ibid.*, at para. 15.

<sup>856</sup> *Ibid.*, at para. 21. In a recent report by the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, concerning the protection of persons with disabilities from torture, it was noted that “*poor conditions in institutions are often coupled with severe forms of restraint*” and noted that “*there can be no therapeutic justification for the prolonged use of restraints, which may amount to torture or ill-treatment*”: *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, as transmitted by the Secretary General Sixty third Session of the General Assembly, Item 67(a) of the provisional agenda *Promotion and protection of human rights: implementation of human rights instruments A/63/175*, 28 July 2008, at para. 55.

(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

11.153 Article 22 of the CRPD provides that:

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

11.154 In relation to ill-treatment, Article 15 of the CRPD provides that:

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment [...].

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

### **Key Points of Relevance**

11.155 Seven points of relevance to this enquiry may be made on the basis of these international human rights provisions:

(a) Persons with a disability are entitled to be treated with dignity and respect, including respect for their private life and their right to personal development.

(b) States must ensure that vulnerable persons, such as persons with a disability are not subject to inadequate and poor living conditions. The prohibition of inhuman or degrading treatment or punishment is absolute.

- (c) Procedural safeguards concerning any interference with a person's right to respect for their dignity must be present and any discretion given to authorities to interfere with this right must be drafted with precision.
- (d) A medical intervention, even where minor, will be considered as an interference with a person's physical integrity where it is carried out against that person's will.
- (e) Clear procedures should govern all decisions concerning one's legal capacity. In particular, an automatic presumption that a person lacks the capacity to take decisions will be a violation of a person's right to private life.
- (f) To guard against ill-treatment, persons in care are entitled to certain minimum standards of treatment. Particular care is owed to persons in vulnerable or powerless situations such as persons with a severe to profound intellectual disability, particularly where situations of detention occurs.
- (g) Where possible ill-treatment comes to the attention of State authorities, they are obliged to investigate: both where those breaches may be ongoing or have already occurred. This obligation extends to the acts or omissions of private organisations.

## Chapter 12 Analysis, Conclusions and Recommendations

### A: Analysis

12.1 A group of concerned parents (the Parent Group) contacted the Commission in relation to the care and welfare of their adult children living in a residential centre for persons with a severe to profound intellectual disability in Galway. The Parent Group perceived that their children's human rights were not being fully respected in so far as the services and facilities available to their children were inadequate.

12.2 The Centre is managed by a registered charity, namely the Brothers of Charity, and funded by the HSE, which in turn receives its funding from the Exchequer. Funding is provided on the basis of a service level agreement concluded between the HSE and the Brothers of Charity, and all the services and facilities available to the individuals in the Centre are those made available through the Brothers of Charity.

12.3 Approximately 37 individuals are being provided with residential placements on campus by agreement between the Brothers of Charity and their parents or guardians. In addition to the 37 residing on campus, 21 individuals live in community group homes and 67 individuals receive a day service through the Centre. The present intention of the Brothers of Charity is to facilitate individuals residing on the campus to move to a community home setting over time and to live in ordinary communities in the same way as the general population and in accordance with best practice standards. This process commenced a number of years ago. The Brothers of Charity also recognises that this may not be the desire of all the individuals at the Centre and their families. On that basis, the Brothers of Charity do not maintain that all individuals need to move from the Centre to community houses.

## Law and Practice

12.4 At the time of writing this report, the law and practice relating to the provision of services to persons with an intellectual disability was primarily contained in the Health Acts 1947 to 2007, which set out the framework within which the State provides health and personal social services to persons with an intellectual disability in the State. The definition of health and personal social services is left undefined in the legislation, but in practice extends from purely medical care (including GP and hospital care) to social care which may be said to contribute to improving the quality of life of the individual and assisting them to achieve their full potential.

12.5 Eligibility for health and personal social services from the State is largely based on means testing. While there is a universal entitlement to hospital care, eligibility for other forms of care, such as the services of a GP or dentist, are means tested, and may be charged for. Persons of limited means, such as the individuals in the Centre will be allocated a medical card entitling them to access free medical care. The Health Acts do not confer any individualised entitlement to health or personal social services on demand, but rather place an obligation on the State to make these services generally available within the resources of the HSE.

12.6 Other legislation that confers certain entitlements, not only to personal social services, but also educational facilities are the Disability Act 2005 and the Education for Persons with Special Education Needs Act 2004 (“EPSEN Act”). As the individuals in the Centre are all over 18 years of age they would not qualify for specific measures under EPSEN, which deals solely with the needs of those under 18 years of age. Similarly, as the Disability Act 2005 only presently operates in relation to children under five years of age, the Act has had no impact on the entitlements and quality of life of the individuals in the Centre. Furthermore, although the State has adopted a National Health Strategy (2001) and a National

Disability Strategy (2004), those strategies do not directly impact on the individuals in the Centre.

12.7 In relation to the provision of formal education, while there is a constitutional and statutory right to education up to the age of 18, this right does not appear to continue into the adult life for people such as the individuals in the Centre. Therefore whatever formal education or supports most individuals were receiving up to age 18, ended abruptly at the point when they passed into adult services. Both parents and the Brothers of Charity commented on the fact that the individuals in the Centre had received very little in the way of supports as young children to allow them to participate in education, and that this had impacted on their abilities and development later in life. Only two individuals in the Centre were receiving formal special educational services at the time of the enquiry. In the case of one of these individuals, the provision of a fully qualified teacher and special needs assistant was only put in place as a result of a settlement reached between the individual's parents and the State on foot of legal proceedings initiated before he turned 18 years of age. In relation to the second individual, a special needs assistant was provided as the person had not yet reached 18 years of age when he left formal education classes. Limited funding is also provided by the Department of Education to the Centre for an educational programme for young adults up to the age of 25 years within the Centre. This involves the allocation of 1,200 teaching hours by the Department of Education under its "*Co-operation With Other Institutes*" scheme. The Brothers of Charity advised that funding for educational services was provided on an annual basis and could not be guaranteed from year to year creating considerable difficulty in recruiting suitably qualified staff and causing unnecessary stress to parents. While most school leavers in Ireland have a number of educational and further training routes open to them on leaving secondary education, those options do not appear to be open to persons with a severe to profound intellectual disability such as the individuals in the Centre. Vocational or technical education facilities may be available on a limited basis only, although life skills do appear to be taught within the Centre.

12.8 In relation to the provision of financial supports by the State, the individuals in the Centre, as persons with significant disabilities and limited means, are all entitled to a Disability Allowance payment which is similar to the level of the job seekers allowance payable to the unemployed. However the residents in the Centre are also subject to a requirement to pay for their upkeep in the Centre (in-patient charges) separately to the medical care they receive there.

### **Service provision framework**

12.9 Historically, care services in Ireland were provided by charities and health authorities, and more recently health boards, through a system of assistance grants and arrangements. Until recently the Department of Health also provided funding directly to a number of voluntary bodies to provide health and personal social services. Currently, Section 38, and to a lesser extent section 39, of the Health Act 2004 provides the framework within which arrangements are defined between the HSE and service providers in the private sector (most often registered charities). To date these agreements have been imprecise in terms of the quantity or level of services to be provided in return for the funding from the State. The agreements have had limited accountability structures in relation to the quality and quantity of services and have mostly focused on financial reporting. Although the agreements increasingly factor in review and control processes, they do not state or reflect individual service needs, but are rather based on a global set of services to be provided to an aggregate number of persons availing of the service.

12.10 This weakness in the agreements was identified by the Comptroller and Auditor General in 2005 and the HSE has sought to remedy this by the introduction of more comprehensive service arrangements. 2009 was the transitional year between the old service level agreements and the new service arrangements with the majority of service providers, including the Brothers of Charity, adopting the new format. Although further detail is required within these

documents in terms of service provision and monitoring of same it is still not clear whether the new arrangements can accurately reflect the correct quantity and level of services required by the individuals in the Centre. The agreements, and now the new arrangements between service providers and the HSE, do not confer any specific entitlement on individuals with an intellectual disability, who are largely objectified within the agreements and dealt with as units of service provision rather than individuals with differing needs.

12.11 A further feature of the agreements between service providers and the HSE is that the service provider is obliged to assume responsibility not only for their existing client base, but also any further needs arising within a defined catchment area. This places the service provider at the front line of providing public health and personal social services to persons with an intellectual disability rather than the HSE. In other words, where an arrangement under section 38 is in place the primary statutory duty holder under the Health Acts (the HSE) largely contracts out its duties to provide services to persons with an intellectual disability to a not-for-profit voluntary private entity within a defined catchment area.

## **NIDD**

12.12 Linked to service agreements and arrangements concluded at a local level is the National Intellectual Disability Database (NIDD). The NIDD provides statistical information on a national level in relation to the number of persons with an intellectual disability receiving and requiring services from the State, in addition to predicting future requirements. The NIDD compiles information from service providers and although it is a developing resource to the State, at present it provides basic statistical information only. Due to the voluntary nature of participation in the database, limitations in terms of the information captured and inconsistencies in the way individuals are reported on, it is of questionable accuracy and efficacy in planning for the provision of health and personal social services to persons with an intellectual disability in the State on an individual

basis. Despite this, the NIDD remains the basis on which funding is allocated by the Oireachtas to the HSE to further distribute to service providers at a local level. Although the Disability Act 2005 provides a more accurate indication of service needs on an individual and collective basis, the Act was still only operational in respect of children under five years of age at the time of writing this report. The Department of Health had informed the Commission that the Act would be further rolled out during 2010 and be fully implemented by 2011, and so become relevant to the individuals in the Centre and other adults with an intellectual disability in the State. However, recent Budget decisions by Government and statements by the Department of Health suggest that this will not now occur.

## **Experiences in the Centre**

### ***Overcrowding***

12.13 The Centre examined by the Commission in the present enquiry provides residential, respite and day services to some 77 individuals. The campus based residential service consists of 7 bungalows, originally designed to cater for the needs of children, but now being used to provide a home, mostly on a full time basis to 37 adults. Some of the bungalows remain overcrowded, with one bungalow still providing accommodation for nine individuals with high dependency needs. In addition a number of individuals have until recently been sharing bedroom facilities.

12.14 Overcrowding in bungalows, a lack of day activities and inadequate staffing levels have been linked by the Department of Health, the Brothers of Charity and in the HSE Review Report to the development of challenging behaviour in individuals in the Centre, resulting in incidents of challenging behaviour by some of those individuals towards other individuals or staff. This challenging behaviour has also taken the form of self injury, which caused considerable upset to the individuals in the Centre, their family and staff. Although

the number of incidents had reduced over the course of the enquiry, with two individuals in particular being removed from the confined environment of living in bungalows through the provision of single apartment accommodation and intensive staffing arrangements, the HSE Review Report still identified twelve individuals who exhibited challenging behaviour residing together in bungalows “totally” unsuited to their needs. The overcrowding remained an issue at the time of writing.

### ***Physical state of accommodation***

12.15 Many of the bungalows were found by the HSE Review Report to be physically unsuitable for the care of certain individuals in the Centre taking into account their physical disabilities. According to the HSE Review Report, more generally bungalows were found to have inadequate space, lighting and ventilation. There were other concerns about the state of repair of the bungalows, and some very basic issues such as doors missing from toilets were noted by the HSE Review. The Review also commented on the fact that bedroom doors had observational lenses, which it considered may have deprived individuals of privacy.

12.16 Although the HSE Review resulted in capital funding for certain repairs and renewals to the bungalows on the campus, the adequacy of that accommodation remains an issue. The HSE Review Report specifically recommended that no more than four individuals should be accommodated in any one of the bungalows, and further that the peer groupings of individuals should be determined on the basis of a multidisciplinary person-centred approach, with the individual at the centre of decision making. The Brothers of Charity confirmed that individuals living on campus currently do not have a choice of where and with whom they live.

12.17 In the course of the enquiry it was accepted by the Parents Group, the Brothers of Charity and the HSE that the accommodation was no longer suitable

to the needs of the adult population occupying the bungalows, however, there were differences of opinion as to how this problem should be addressed.

### ***Community Group Homes and Redevelopment of the Campus***

12.18 As noted, whereas 37 individuals reside on campus, 21 individuals reside in community group homes. The present intention of the Brothers of Charity is to facilitate individuals currently residing in the Centre to move to houses in the community over time. The rationale of the Brothers of Charity is based on the current inappropriateness of the accommodation within the Centre and also what they understand as being the emergence of international best practice in the form of a “social model” of disability. This “social model” is a move away from segregated institutional accommodation for persons with disabilities to living within the community facilitating more independence and participation in ordinary life experiences. The Brothers of Charity are, however, also open to the redevelopment of some facilities on the present site to meet the needs of those individuals in the Centre who may wish to continue living there, including through replacing existing unsuitable accommodation with more appropriately designed buildings. In this regard it has stated that the plan for “any future redevelopment of the Centre” will be to promote an “integrated community setting” to support those individuals who may wish to continue living in the Centre.

12.19 The Commission was informed by a number of parents that they were opposed to the proposed move of individuals to community group homes. The reasons cited for this included the perception that many of the community group homes were situated a considerable distance from Galway City Centre and the amenities of the Centre itself, and so created isolation rather than leading to integration. Although these parents acknowledged the superiority of the accommodation provided by community group homes, when contrasted with the bungalows in the Centre, they counterpointed this by indicating the perceived advantages of campus accommodation: such as the facilities available within the Centre, its proximity to local amenities and the city centre; the opportunities for

the individuals in the Centre to circulate in relative safety within the confines of the campus, and the perception that the individuals in the Centre would not necessarily be welcomed or integrated into the housing estates where most of the community group homes are situated. The Brothers of Charity did not accept all these arguments, stating there had been consultation with families and that the location of the community group homes are in *“vibrant and growing communities”* and close to all amenities. As noted above, the Brothers of Charity has also indicated it is open to exploring the redevelopment of some facilities on the present site to meet the needs of those individuals in the Centre who may wish to continue living there, while the HSE has also recognised the need to identify and respond to the needs of each individual in the Centre.

12.20 The Commission considered a 2009 study published by the National Disability Authority, which supports the view that the most beneficial setting for the delivery of services to persons with an intellectual disability is in dispersed settings rather than clustered campus style accommodation. This view appears to be supported by the ethos of the CRPD which emphasises the right to live independently. The HSE also informed the Commission that it is currently finalising a report on congregated settings which it had hoped to have completed by December 2009. It seems that the focus of the report is on relocating individuals from congregated settings into community settings. The report will address residential centres where people with disabilities are accommodated in campus style accommodation and any other residential arrangements where more than ten persons with a disability are accommodated in one setting. Thus the Centre will be included in the scope of the report. According to the HSE, new community models will likely “substantially alter the nature and context of how people with intellectual disabilities experience services and where they experience them”.

12.21 The HSE Review Report also considered this issue and expressed the view that all individuals should have the choice to live in, participate in and contribute to the community and that this would enhance a sense of belonging

and connection to others. The Review Report did not find that this approach necessarily required that the individuals in the Centre be moved to community group homes, but rather recommended that consideration be given to the redevelopment of the campus, taking into account its inherent advantages for the individuals concerned. The Review recommended a possible future model for the service which meets the needs of individuals incorporating social inclusion, integration, recreation and training opportunities. It recommended that a model be developed by a project team with the appropriate mix of skills and participation by management, individuals and their parents. This approach emphasised that individuals participate effectively in decisions about future choices in relation to where they live and receive services.

## **Capacity**

12.22 On the basis of the information provided by parents and the Brothers of Charity itself, it is apparent that there is no established system by which the decision making capacity of individuals is assessed within the Centre other than a general psychological assessment. The Brothers of Charity advised the Commission that recently a review of all individuals at the Centre has been carried out. It appears that the Brothers of Charity proceeds on the assumption that the individuals in the Centre do not have capacity. This has implications at a number of levels for those individuals in relation to their autonomy and life choices. This situation is not the creation of the service, but rather is a result of the fact that the legal situation as regards the determination of capacity and supported or substituted decision making remains unaddressed by Government at the present time.

## **Medical Treatment**

12.23 It became clear during the course of the enquiry that the medical needs of the individuals in the Centre as a group were extremely complex. A number of the individuals had significant physical disabilities, some having mobility difficulties

while others require assistance with basic activities such as eating and drinking. The Commission was informed that approximately half the individuals in the Centre were receiving psychiatric treatment. A number of those individuals are receiving treatment for epilepsy.

12.24 A number of the individuals in the Centre displayed challenging behaviour, in that they could be aggressive towards others or engage in significant self injury. The complexity of the individuals' needs has implications in relation to a number of aspects of their care including medical treatment. As noted above this challenging behaviour was dealt with to some extent by the provision of intensive ("wraparound") staffing.

12.25 In relation to medication, it was clear that individuals in the Centre were not in a position to provide formal consent to the administration of medication on account of their disability and as noted above there is no system for determining their decision making capacity. Within this lacuna a system of substituted decision making has developed whereby parents or family members were called on to consent to medical treatment including the administration of medication. While this may be a practical approach to the issue, even this system was less than coherent in so far as the Brothers of Charity issued general consent forms to the parents of individuals in the Centre to allow for the provision of medical care at a general level without the need for a separate consent for each and every medical intervention. It is noted that a different procedure operated in relation to hospital and dental care, where those services would require separate consents to be signed on behalf of the individual on a per treatment basis. This occurred in late 2009 in relation to the administration of the H1N1 Swine Flu vaccination, which was administered to the persons in the Centre and in relation to which parents were asked for specific consent. Additional consents are sought by the Brothers of Charity for the annual "Flu Vaccine", obtaining bloods and any other invasive procedures an individual in the Centre may require.

12.26 The Brothers of Charity advised that all parents, save the parents of one individual, had signed the consent form. Although the Brothers of Charity had no clear protocol for informing family members in relation to the medical treatment the individuals in the Centre were receiving, it did appear that there was a strong culture within the organisation of providing such information, and many parents felt that staff were very conscientious in relation to the provision of this information. Nonetheless the question of consent to medical treatment was a cause of concern to both the parents and the Brothers of Charity. The Brothers of Charity has indicated to the Commission that it would welcome clear and unequivocal guidelines in relation to consent, stating its understanding that consent by parents for the medical treatment of persons 16 years or over has no legal validity, even if it is good practice.

12.27 Another feature of the medical care provided to the individuals in the Centre is the fact that such services were not generally accessed in the community or in mainstream settings, but rather the GP and psychiatric services were organised by the Brothers of Charity and delivered within the Centre. It was particularly notable that there is only one Consultant Psychiatrist employed by the Brothers of Charity in the western region and that she has a very wide catchment area to cover and a significant case load to manage on behalf of the service.

## **Staffing**

12.28 Understaffing, in terms of care staff at the Centre was a historical problem that was a significant cause for concern for parents and was acknowledged by the Brothers of Charity. Understaffing was linked to health and safety problems, a lack of meaningful activities for individuals by day, and lack of motivation for staff dealing with high dependency clients with few supports. Specific problems identified were the fact that a number of individuals, in addition to those receiving intensive wraparound staffing, required one to one care and support and did not always receive it. There were also problems associated with a high turnover of staff and consequent lack of consistency in care, the inadequacy of staff levels at

night and the absence of temporary staff cover in the event of staff members being absent. Also staffing levels were reduced over the weekend leading to a lack of activities for the individuals in the Centre outside their week day programmes. However, in relation to the individual care givers in the Centre, parents were generally full of praise for the level of personal commitment, care and enthusiasm displayed towards the individuals, and it was clear that real relationships of trust and cooperation had developed between staff, the individuals in the Centre and their parents. The Commission also observed upon visiting the Centre that the team leaders displayed genuine warmth and care for the individuals in the Centre.

12.29 The Brothers of Charity accepted that staffing problems had existed historically but were of the view that matters had improved with increased staffing over recent years. This was also acknowledged by parents. However, problems remained at the time of writing the report, in that both parents and the Brothers of Charity accepted that staffing levels were still not adequate, particularly at night and over weekends, although there was an attempt to supplement weekend cover through volunteer recruitment. Employment ceilings established by the HSE at a national level which are universal in effect (irrespective of the particular circumstances of the service involved), non availability of funding historically and the imposition of further funding cuts more recently were three significant factors inhibiting the recruitment of further staff. This was also coupled with the fact that no specific guidelines exist at a national level to establish a baseline staffing level for services for persons with an intellectual disability, and to address differing staff requirements depending on the level of need of each individual. During the enquiry, the difficulties in establishing average costings for residential, day and respite services became clear, as did the difficulties in accessing adequate funding based on individual needs. One illustrative example of the inflexibility in staffing levels to address individuals' needs was the reference by the Brothers of Charity to its need to risk fund the provision of "wraparound" staffing to two individuals, rather than being in a position to secure additional funding on the basis of the staffing needed by those two individuals and the service in general.

12.30 Lack of staffing by day also limited the opportunities of individuals to engage in independent activity and could also have a significant impact on the implementation of their personal outcome plans and day programmes.

12.31 Lack of staffing had potential implications for the safety of individuals at night, in the event of an emergency, and also had potential implications for the protection of staff where supervision and oversight may be limited. Although the Brothers of Charity considered sufficient staff and on-call protocols were in place to respond adequately to an emergency situation, night staffing, although possibly not intended to, has been hit by Government "Value For Money" cuts and it was noted that a situation of low night cover may leave staff exposed to accusations of inappropriate behaviour or a lack of due care if an individual was injured or hurt in circumstances where a single member of staff may not be able to deal alone with a crisis that might arise.

### **Multidisciplinary services**

12.32 The importance of access to multidisciplinary services and proper planning around the needs of each individual in the Centre cannot be overestimated. The availability of multidisciplinary services, and a person-centred approach to needs assessment has been shown to have the most favourable outcomes for persons with an intellectual disability in terms of life expectancy, quality of life in older age and functional capability. The lack of such services obviously has an adverse effect.

12.33 While staffing levels within the Centre have improved somewhat over the past few years, it did not seem that there had been any significant improvement in the availability of multidisciplinary services available in the Centre. Parents were extremely frustrated by the inability of the Centre to provide access to what they regarded as essential services, such as speech and language and occupational therapy. While this situation had been ameliorated somewhat in 2008 and 2009, by the allocation of a speech and language therapist to the Centre for one day

per week, it was clear that in light of the level of need for this therapy amongst the individuals in the Centre issues arose as to whether this allocation could meet the most basic needs of the individuals who required it. Speech and language therapy was particularly identified as necessary in a very important way as it assisted with eating, drinking and swallowing, the prevention of choking and for basic communication. The lack of such therapies contrasted with the targeting of staff for the provision of the “wraparound” services occasioned by the challenging behaviour of two individuals. The Commission also noted that none of the individuals in the Centre appeared to be receiving multidisciplinary services outside the auspices of the Brothers of Charity service. Both the Parent Group and the Brothers of Charity were in agreement about the gross inadequacy of multi disciplinary services within the Centre, with the Brothers of Charity stating clearly that there were gaps in all areas.

12.34 The HSE Review Report recommended a holistic, multidisciplinary assessment be carried out in relation to each individual as a matter of urgency, to facilitate future planning and that any needs identified would then be provided to the individuals in the Centre. It was recommended that any services not then available, such as speech and language therapy, should be provided from the existing services within the Brothers of Charity Galway or by other service providers in the area. However, the Brothers of Charity has stated that it does not have the resources within its existing services to address the shortfall. It cited the difficulties involved in receiving HSE permission to recruit a therapist even where it managed to locate the monies to do so. There would thus appear to remain obstacles to converting such posts with resultant minimal provision of speech and language therapy on a one day per week basis in the Centre.

12.35 The HSE for its part informed the Commission that it was committed to the enhancement of services to persons with a disability including the development and provision of multi disciplinary supports such as speech and language therapy and that it would support any conversion of posts to therapy posts. The HSE further advised that the funding of such services would be based on the needs of

all individuals in the service rather than the individual needs of one individual. The Commission notes however, that despite this stated commitment on the part of the HSE, for many years individual parents and the Brothers of Charity had been raising the issue of the inadequacy of multidisciplinary services in the Centre with the Department of Health, politicians, the Western Health Board and now the HSE and at the time of writing, this commitment had not translated into any significant enhancement of speech and language therapy for the individuals in the Centre, and showed little prospect of doing so. It was not apparent to the Commission how this commitment on the part of the HSE was actively being addressed.

### **Personal Outcome Plans and Day Programmes**

12.36 The Brothers of Charity started rolling out a system of personal outcome plans based on personal outcome measures, for the individuals in the Centre in 2003. Due to a number of obstacles highlighted, some individuals only had a personal outcome plan put in place as late as 2008. Day programmes are one aspect of the implementation of the personal outcome plans and again it was confirmed that almost all individuals in the Centre had such a programme by 2009.

12.37 The views of parents and the findings of the HSE Review Report appeared to vary from that of the Brothers of Charity in relation to the efficacy of personal outcome plans and day programmes. While the Brothers of Charity were satisfied that all personal outcomes are in place and being implemented, some parents questioned the contribution the personal outcome plans made to the development of their adult children's life skills. On the other hand many parents acknowledged that the personal outcome plans had brought about positive changes in the social life of their children, so that they were able to attend more social events and interact with the community on a more regular basis, as well as having holidays, often for the first time in many years. Whereas the HSE Review Report stated, however, that in 2007 personal outcome plans were not being

implemented on a managed and planned basis, the situation had improved by the end of 2009, although barriers to achievement remained.

12.38 Some parents also questioned to what extent the individuals in the Centre had adequate day programmes, with some expressing the view that their adult children lacked meaningful activities during the day. The Brothers of Charity also acknowledged that some individuals were not attending a day centre for the delivery of their day programme but rather received same in their bungalow, as this was more suitable to their needs.

12.39 In the course of the enquiry the Commission reviewed 8 personal outcome plans and 8 day programmes. It was evident that in the context of underfunding, understaffing and lack of multidisciplinary staff available in the Centre, not all the aspirations in personal outcome plans were achievable insofar as many were linked to funding availability.

### **Personal Finance**

12.40 In contrast to individuals in community group homes who retain about €90 per week, the residents in the Centre retain about €55 per week after deductions are made from their Disability Allowance in accordance with the Department of Social and Family Affairs in-patient charges guidelines. The Disability Allowance of some individuals is paid directly to the Brothers of Charity under an arrangement with the Department of Social and Family Affairs. Other individuals receive their Disability Allowance directly at the local post office, collected for them by their parents or it is sent directly to some individuals in the Centre. During the enquiry, it became apparent that for various reasons not all individuals in the Centre had family members who could manage their finances or assist them in doing so. In this situation, the Brothers of Charity act as *de facto* substituted decision-maker in relation to the expenditure of individuals' money for their requirements from week to week, albeit in a legal vacuum. It was noted during the enquiry that although the Brothers of Charity has robust policies in

place concerning individuals' financial accounts which it maintains, more formalised consent procedures to handling monies could be introduced, including in the context of the introduction of mental capacity legislation.

## **Funding**

12.41 The availability of sufficient funding for the Centre was frequently identified throughout the enquiry as being a problem by both parents and the Brothers of Charity. Apart from its link to multidisciplinary services and day programmes, lack of funding is linked to the continued closure of two community group homes meant to accommodate individuals, in addition to a lack of respite services and inadequate responses to emergency situations as documented in an individual's personal outcome plan where it is listed as a barrier to achievement.

12.42 It has been noted that the HSE Review did not pursue an examination of the funding of the Centre as part of its remit. The Commission was initially advised by the HSE that other initiatives had been developed subsequent to the completion of the HSE Review Report which had addressed this requirement, namely the implementation of the recommendations of the McCoy Report, the introduction, on a pilot basis, of a guidance document on residential services for people with disabilities, an ongoing audit on the incidence of abuse in all intellectual disability services; and the extension of the requirements of Part 9 of the Health Act 2004 (complaints procedures) to all agencies. The Commission was subsequently informed by the HSE that the funding element of the review was deferred as the HSE had already commenced a review of congregated settings, which would include an implementation plan, and be relevant to the individuals in the Centre. It was also noted by the HSE that on foot of the 2008 review a substantial level of capital funding was released by it to improve conditions in the Centre.

12.43 The Commission, in examining the funding structure in place between the Brothers of Charity and the HSE, and between the HSE and central government,

noted a number of matters. While funding at a national level is based on an estimated level of need for health and personal social services to be provided by the HSE, and therefore is a block allocation, funding at a local level to individual services and to individuals is not broken down to individual needs. Although it is noted that other funding has been injected into the service over the years, through, for example, some new service development funding and the Department of Education funding, the method of allocating the base funding between the HSE and the service provider does not appear to be directly linked to any individual assessment of needs of the current individuals in the Centre and is rather based on an incremental determination system from year to year. This was clearly illustrated by the manner in which the Brothers of Charity seeks funding from the HSE for the service it provides year on year, being based on a HSE template which does not identify the cost of the individual service needs of individuals. The HSE also informed the Commission that because of the historical way that funding is provided to voluntary organisations, the HSE does not have an established average cost per service place (residential, respite or day), although there was an average cost per place established under the Multi Annual Investment Plan (based on the amount of funding available and the targets for new service places established thereunder). The wide range of costings for the individuals in the Centre was set out by the Brothers of Charity. On the basis of the information provided it is clear that there is no agreed benchmark or range cost either at a national or local level attached to even the basic care of individuals such as those in the Centre, aside from any additional specialist service provision. The absence of an agreed minimal baseline cost renders it difficult to assign funding to individual needs.

12.44 The Brothers of Charity further identified a significant difficulty in securing adequate funding for the Centre, because its baseline funding had been established when the Centre was first opened. As a result, although other funding streams (such as new developments monies) have been injected into the service over the years, current funding for the Centre is still linked to the cost of running a centre for children, with quite different needs, some thirty years ago. A further

difficulty in the system of funding from the point of view of the Centre was the manner in which new development funding is prioritised with the bulk of funding going to the development of new residential service places rather than the enhancement of existing residential services. In addition, in the allocation of HSE funding services for children and young adults were prioritised rather than older adults such as the individuals in the Centre. Further, it did not appear that the HSE had an effective system for allocation of such funding. The Brothers of Charity advised the Commission that the HSE distributes the Government Vote of new service development money to its regional offices on the basis of county population rather than individuals with intellectual disability per county population, or the intellectual disability per county needs. Further the prioritisation system at the local level for the allocation of such funding may be ineffective in circumstances where the Commission was informed that both the HSE and service providers in the Galway region no longer utilise 4 of the 6 priority criteria set by the HSE. This would appear to be on the basis of a dearth of funding allocated at a national level. In the view of the Brothers of Charity, any additional funding could only be allocated to meet urgent immediate needs rather than enhancing services and so there was little point in applying for other services where waiting lists or caps on funding preclude this possibility.

12.45 Recent developments impacting on the funding of the Centre were the “Value for Money” cuts imposed at a national level and filtered down to service providers through the HSE over the past number of years. Although the HSE suggested that the cuts might be achieved by service providers without impacting negatively on front line services, it is not clear that this can be ensured realistically. It was clear to the Commission from the proposals being made by the Brothers of Charity to meet “Value for Money” cuts in the context of its 2009 service plan, that individuals in the Centre would inevitably see a diminution in the service they receive. In addition, the Multi Annual Investment Programme, that had been intended to continue until the end of 2009, instead came to an end in 2008. The HSE decided in July 2009 not to fund any further capital projects other than those in relation to which they had already entered into a contractual obligation.

12.46 Overall the Commission questioned the connection between the funding of the Centre and the actual cost of meeting the needs of individuals such as those in the Centre. While submissions were made by the Brothers of Charity over a number of years to the HSE in relation to the funding of the Centre, this had not brought about a significant increase in funding. The HSE Review also identified gaps in service provision in the Centre, and while not dealing with the issue of funding directly, it is clear that in circumstances where the Centre already had a funding deficit additional funding would be required to address those service gaps. A separate audit report carried out by the HSE into the Kilcornan Centre found no resources that could be redirected within the Brothers of Charity Services. The issue of inadequate funding had been addressed to some extent through an agreement between the Brothers of Charity and the HSE not to take new admissions to the Centre. While this no doubt relieved some of the pressure on the services in the Centre, based on the continuing existence of overcrowding in the Centre, and the lack of multidisciplinary services, if one approaches the question of funding from the ability of the individuals in the Centre to receive those multi-disciplinary supports they need, it is clear that the Centre is still underfunded. This situation was compounded in late 2009 by uncertainty over the impact of possible funding cuts to the Centre. The Brothers of Charity estimated that it could face a €451,000 cut to its funding equivalent to a loss of 9 posts. In such a scenario it could not rule out corresponding cuts to its multidisciplinary supports budgets and its services at the Centre. Among potential impacts listed was the closure of at least one residential bungalow, with bed capacity of some bungalows likely being increased to absorb the residents displaced, with a consequential increase in the ratio between the individuals in the Centre and staff. Further, it was stated that the capacity of the Centre to respond to emergency admissions could “disappear”. As a postscript, this situation was further compounded at the time of publication of this report at which time the Brothers of Charity indicated that it faced deeper cuts to its budget for 2010 than previously understood and that this would likely result in cuts to services.

## HSE Review

12.47 The HSE Review of the Centre was initiated as a result of the decision of the Commission to carry out the present enquiry. The HSE Review Report did not consider funding, despite this being one of its terms of reference, but included a number of other matters that have direct relevance to the issues identified in the present enquiry. The Brothers of Charity had previously provided a response to the Review. The Commission requested both the Brothers of Charity and the HSE to further respond to the recommendations in the Review and both organisations stated that most recommendations in the review have now been addressed. However, a number of matters remain outstanding. As noted above, the bungalows were identified by the HSE as 'unfit for purpose' but are still occupied by individuals in the Centre. The Review Report made observations on the use of "restrictive practices" in the Centre and considered them to be inappropriate. The Brothers of Charity in its response to the HSE, explained the rationale for using such practices. In its subsequent response to the Commission, the Brothers of Charity provided a detailed response to this issue, including forwarding a number of new policies introduced since 2008, indicating that "restrictive practices" were part of a reactive strategy in the case of a severe incident of challenging behaviour and that appropriate procedures were in place to govern its exceptional use.

12.48 The HSE Review identified certain training needs of staff in relation to crisis management techniques such as the reporting of incidents and in core competencies. Separately it identified social inclusion and training programmes for the individuals in the Centre. The Brothers of Charity has indicated that its practice for many years has been to annually undertake both a training needs analysis and the rollout of training for staff. It also indicated that its training programmes emphasise the importance of building autonomy and independence for persons with disabilities and that this emphasis will continue in the future.

12.49 The recommendation in the HSE Review Report that the Brothers of Charity consider different future models for developing the Centre, under an options appraisal approach, does appear to be somewhat reflective of the process commenced in 2002 by the Brothers of Charity when it established a Project Team to examine a future model for the service, followed by the establishment of an Implementation Group. As noted, the Brothers of Charity has stated that while it aims to facilitate individuals currently residing in the Centre to move to houses in the community over time, it is open to the possibility of redeveloping some facilities on the present site to meet the needs of those individuals in the Centre who may wish to continue living there.

12.50 Prior to the HSE Review Report and the current enquiry, the Brothers of Charity had secured Pobal funding of €300,000 to improve two residential bungalows at the Centre. In relation to its own Review, initiated following the Commission's decision to conduct the enquiry, the HSE informed the Commission that as a direct consequence of the recommendations of the Review, it made available capital funding in the order of €677,678 for projects at the Centre. At present it is unclear whether the HSE will take any further steps on foot of its own Review of the Centre. The Review made a considerable number of significant recommendations that were directed to improving the quality and availability of accommodation and services within the Centre. In this regard, the HSE has stated that the recommendations have been taken on board and are being implemented "to the greatest extent possible". The question as to precisely who is responsible for ensuring the full implementation of the recommendations of such reviews is not immediately clear – whether it is the responsibility of the service provider or the HSE. Issues thus arise as to whether the HSE can be regarded as failing to implement its own policy decisions where all recommendations are not implemented within a specified period of time. This issue is important to resolve given the fact that the HSE will be embarking on more regular Reviews from 2010 under the new Service Arrangements and given the absence of independent inspections or monitoring by HIQA. Whereas the service provider is under a contractual obligation to the HSE to provide health

and personal social services, the HSE is under a contractual obligation to the service provider to provide appropriate funding and to ensure its proper application. It is also the HSE which will conduct the Reviews.

## **Communications**

12.51 Many members of the Parent Group acknowledged the efforts of staff to keep them informed about their adult children in relation to matters such as engagement in day to day activities, reporting any key developments or incidents occurring in the Centre, or if their adult child was sick or unwell. Parents also felt in general that staff were very approachable if they were seeking any information on a day to day basis and found having a key worker a very useful channel for communications. Parents also reported on the quality of relationships between the individuals in the Centre and staff members, and the lead which staff members were taking in improving the quality of life of their children. The Social Work service in the Centre also seemed to be a frequent point of contact for parents in relation to any concerns arising.

12.52 The majority of parents and individuals in the Centre thus have very good relationships with frontline staff who are providing care on a daily basis. However parents did not report the same satisfaction in relation to communications with the management of the Centre. While this was most particularly evident in relation to the proposed move of individuals to community group homes, where many parents were concerned that they not be presented with a *fait accompli*, there were also other issues of concern. Some parents did not have copies of their children's personal outcome plans and day programmes. It also appeared that some parents had more information and engagement in the consultation process around personal outcome plans than others. Many parents were unaware of any multidisciplinary assessments carried out in relation to their adult children, although the Brothers of Charity indicated that 41 individuals had been assessed by the part time speech and language therapist as of November 2009, and also reported on occupational therapy, social work and psychological services.

12.53 In general parents reported that the openness of communications with care staff working immediately with their children was not replicated at a managerial level. The HSE Review Report also expressed concern about supervisory grades being somewhat removed from front line activity, and although this view was strongly refuted by the Brothers of Charity, it may be that parents similarly feel that management is not as available as front line staff. On the other hand, the Brothers of Charity has stated that it promotes openness of communications between frontline care staff and parents, empowering its care staff to communicate directly with parents, thus bringing decision-making closer to the individuals in the Centre. It states that this in itself demonstrates its commitment to good communication with families. While the Brothers of Charity has put in place communications mechanisms to take into account the views of individuals and their parents, parents did not perceive these mechanisms to be working properly. Similarly, the Parent Group felt it did not have opportunities to engage in meaningful consultation with the HSE although it did acknowledge that there were some opportunities to access useful information. Most notably, the HSE Review Report was not provided to the individuals in the Centre and their parents by the HSE, and it was the Brothers of Charity that undertook to distribute the report (accompanied by its own response) of its own volition. This apparent communication gap with both the Brothers of Charity and the HSE led to some concern amongst parents about how significant decisions are taken in relation to their children. The Brothers of Charity informed the Commission that it accepts that communications can always be improved and that it is happy to work towards achieving a more effective communication system with the families of the individuals who use the service.

### **Accountability**

12.54 Two specific accountability mechanisms in relation to the provision of services to persons with an intellectual disability are identifiable. At a general level is the complaints system of the HSE under Part 9 of the Health Act 2009, which is replicated at a local level by the service provider. The Brothers of Charity has

put in place such a complaints mechanism procedure, which operates within the Centre. There are legal limitations to the general complaints mechanism, a fact recognised by the Brothers of Charity, in so far as it can only relate to actions concerning fair and sound administration, rather than other matters. This removes a large swathe of decision making from the complaints mechanism in relation to service provision to the individuals in the Centre, although the Brothers of Charity has indicated that any issue, concern or complaint by an individual or a family member can be made to it. However, according to the legislation, a complaint under Part 9 cannot concern substantive health or health care issues and cannot result in a change in a service agreement or arrangement between the service provider and the HSE, again removing another level of decision making from the scope of the local complaints mechanism. While there is some independent oversight of complaints by the Ombudsman or the Ombudsman for Children, neither of these two bodies have the competence to make binding decisions (which are usually a judicial or quasi judicial function), and as such are limited to making recommendations. Although it would be surprising if their recommendations were not adhered to in the vast majority of cases, nonetheless it is questionable to what extent the complaints mechanism under Part 9 of the Health Act 2004, leads to real accountability on the part of service providers.

12.55 At a more specific level the other accountability mechanism identified is contained in the Health Act 2007, which established the Health Information and Quality Authority (HIQA). HIQA has established National Quality Standards: Residential Services for People with Disabilities. Following the enactment of the 2007 Act, these National Quality Standards were intended to be placed on a statutory footing, by reference to which the Office of the Chief Inspector of Social Services would carry out inspections of residential services such as the Centre. The outcome of the inspections would in turn determine whether a residential service would be registered under the Act, with such registration being compulsory. The National Quality Standards are reflective of best practice in the delivery of services to persons with a disability, and take into account relevant human rights principles. However, in 2009 the Government announced that the

Standards, having been finalised, would not now be placed on a statutory footing, with the result that no inspection and registration system has been put in place. Compliance with the standards is thus on a voluntary basis only, although the standards are indirectly referred to in the latest service arrangement documentation issued by the HSE. While the Standards provide very useful guidelines for individuals and service providers, it is questionable whether they will lead to any real accountability in service provision when not backed up with an enforcement mechanism based on independent inspections taking place. The Department of Health and HSE believe that self-audit followed by meetings with the HSE and separately, HSE Reviews will result in accountability in service provision. However, this remains to be seen. The Commission was advised that the new service arrangements are not envisaged at present “to itemise the needs of individual clients“, but rather to identify the processes and quality management systems required “to ensure the needs of each individual are both identified and being addressed“. The Brothers of Charity indicated that like other voluntary bodies, it had decided to engage in an external evaluation of its services in the years before HIQA was established and that it has put considerable effort into acquiring accreditation in what it describes as a robust and rigorous accreditation process by the Council on Quality and Leadership, an American based not-for-profit organisation. However, it is noted that this private accreditation system does not provide for an enforcement mechanism nor for independent inspections by a statutory authority. The same situation will pertain to planned HSE Reviews, although they will mark an advance on the current situation.

12.56 As was noted in Chapter 7, the HSE Review of the Centre took place on an *ad hoc* basis in response to the present enquiry. The Review has unquestionably resulted in some improvements for the individuals in the Centre. However, the Review also illustrates the weakness of oversight mechanisms that do not lead to real accountability, not least insofar as the HSE did not provide the Report to the parents of the individuals in the Centre.

## **Application of Relevant International Human Rights Standards**

12.57 The enquiry report now moves to the application of the human rights standards set out in Chapter 11 to the issues raised in the enquiry. In this regard, it will be recalled that while the Commission may not adjudicate upon whether a human rights violation has occurred, as a Court would do, it may conclude that the enquiry has revealed a deficiency in the law/ practice in the State relating to the protection of human rights and this conclusion may in turn form the basis of a recommendation on the measures required to address the situation. In the following section it will be observed that while it also considers that civil and political rights issues arise, the Commission considers the situation in the Centre to predominantly raise issues of economic and social rights: the rights to health and bodily integrity and to education, guidance, vocational training and habilitation/ rehabilitation, respectively.

### **The rights to health and bodily integrity**

12.58 The Health Acts do not define or confer any individualised entitlement to health and personal social services, but rather place an obligation on the State to make same available within the resources available to the HSE. While the State has introduced a public health strategy in the form of the *2001 Quality and Fairness, A Health System for You* and a National Disability Strategy, the fact that the Disability Act and EPSEN Act have had no impact on the entitlements or quality of life of the individuals in the Centre places in doubt how effective or targeted the health strategy or the disability strategy have been for this group of vulnerable individuals.

12.59 The public-private framework provided by the Health Acts under which the HSE and service providers operate, has resulted in imprecise agreements governing the quantum and quality of services to be provided for the funding from the State. The agreements have contained limited accountability structures in relation to the quality and quantity of services. The agreements do not state or

reflect the individual's service needs. The individuals are largely objectified within the agreements and dealt with as units of service provision rather than individuals with differing needs, even where the service provider aims to deliver a person-centred service and introduces person-centred plans as in the case of the Brothers of Charity. Where cause for a State review of the services provided has occurred, such as in relation to the HSE Review Report, there has been some follow-up by the HSE with capital funding provided and meetings convened to discuss the report. The follow-up to many of the recommendations, however, appear predicated upon the completion of a different HSE-initiated process, which puts in doubt whether appropriate accountability and oversight is being exercised by the HSE apart from financial oversight.

12.60 Further, State funding is based on a national database which, while it is playing an important developing role, provides general statistical information on intellectual disability of questionable accuracy and efficacy in planning for the provision of health and personal social services to the population of persons with an intellectual disability in the State on an individual basis. It is further noted that the NIDD in December 2008 reported that three quarters of the individuals with an intellectual disability registered on the database require a new or enhanced multidisciplinary support service in the period 2009 to 2013. Whereas more accurate planning for the individuals in the Centre may have been possible under the Disability Act's individual assessments, as noted, these are only in place for children under 5 years and not for other children or adults. Similarly, there is no scope at present for reflecting individualised personal outcome programmes in funding protocols. This lack of emphasis or attention to individual needs is a serious deficiency of the current system and has resulted in clear detriment to the individuals in the Centre.

12.61 The obligation to ensure the highest attainable standard of physical and mental health for persons with an intellectual disability without discrimination is a "core obligation" under Article 12 of the ICESCR. Yet it is questionable how this can be achieved under the framework for intellectual disability services outlined above.

12.62 The right to health extends beyond the medical care available to the residents in the Centre and includes both the underlying determinants of their health and the AAQOs, namely accessible, appropriate, acceptable and quality health care. It is questionable whether the multidisciplinary services available to the individuals meet these standards. While some services, such as psychiatry may meet the requisite standards, the same cannot be said about occupational therapy or speech and language therapy. From its assessment of the present case, the Commission considers that the State may not be fulfilling its obligations under Article 12 of the ICESCR to the individuals in the Centres in relation to these specific therapies.

12.63 Whereas the State is obliged to take concrete measures to achieve the highest attainable standards of health for the individuals in the Centre, their physical environment and lack of appropriate services may suggest a failure to take such measures. Quality of healthcare includes habilitation services; physical environment and staffing supports for the individuals in the Centre.<sup>857</sup> In this regard, their homes are bungalows, originally designed for children which in some cases remain overcrowded, and in others are undersized. While there are no national standards developed as to what the correct ratios of resident per bungalow or per living space should be, it is clear that the current accommodation arrangements are unsatisfactory. It is noted that the HSE Review suggested that no more than four individuals should reside in a bungalow and that there should be a review of peer groupings in each bungalow to ensure their compatibility, with individuals being central to decision making. Overcrowding in bungalows had been linked in the past to the challenging behaviour in some individuals, resulting in aggressive incidents. The State has introduced legislation and a policy framework seeking to protect health service personnel.

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<sup>857</sup> To habilitate a person means to develop his/her maximum growth potential, in terms of self-help, language, personal, social, educational, vocational and recreational skills.

12.64 Apart from the issue of overcrowding, conditions in bungalows were also described in the HSE Review as being physically unsuitable for residents and lacking adequate space, lighting and ventilation.

12.65 Despite the assurances to the Commission by the HSE that it was and is committed to the enhancement of services to persons with a disability including the development and provision of multidisciplinary supports such as speech and language therapy, this does not appear to be borne out in the current case. In relation to people with a severe to profound intellectual disability, such therapy is of critical importance. Speech and language therapy assists individuals in basic requirements such as swallowing food and drink and in not choking and also developing basic communication skills. The inability of the Centre to provide full access to essential multidisciplinary services, such as speech and language and occupational therapy suggest a failure, on the part of the State, to enable the Brothers of Charity to ensure available, accessible, acceptable and quality healthcare in the form of these specific services. This is particularly so given the fact that the State indicated to the CPT in 2003 that particular attention was being afforded to training and employing staff to provide these specific therapies.

12.66 Where a “core” right to health is concerned, it does not suffice for the Department of Health to advise that it is a matter of implementation for the HSE and for the HSE to advise that it is a matter of funding for the Department as was the case in relation to the individuals in the Centre. Notwithstanding the difficulties inherent in costing residential, respite and day services for the ranges of conditions of persons with an intellectual disability, the fact that the HSE, arguably because of historical funding arrangements, does not have an established average cost per service place, raises serious questions as to whether the national health and disability strategies are effectively working for the individuals in the Centre and thus enabling the State to uphold its duty towards

those individuals.<sup>858</sup> This is in the context of historical underfunding of disability services as acknowledged by the HSE.

12.67 Further, untargeted across the board “Value for Money” cuts imposed by central government raise issues in relation to the adequacy of funding to the Centre. In this regard, the human rights presumption against retrogressive measures would raise serious issues if the concerns articulated by the Brothers of Charity in relation to possible funding cuts were to come to pass. In this regard, the State would bear the burden of demonstrating that such cuts had been introduced after the most careful consideration of all alternatives; that they were duly justified by reference to the totality of the rights provided for in the ICESCR in the context of the full use of the State party's maximum available resources. Given the fact that the individuals in the Centre and similar individuals in other centres are particularly vulnerable individuals by virtue of their severe to profound intellectual disabilities and given that they are already experiencing State inaction as detailed in this report, the burden required of the State to demonstrate that it would not be infringing their rights would be high.

### **The Right to Education, Guidance and Vocational Training for Persons with Disabilities and the Right to Habilitation and Rehabilitation**

12.68 In relation to education, guidance and vocational training, it will be recalled that under Irish law, children with intellectual disabilities are entitled to formal education. This right ends once the person turns 18 years of age. Whatever formal education or supports the individuals in the Centre were receiving up to age 18, for the majority ended abruptly at that point when they passed into adult services, although some minimal education funding was provided by the Department thereafter. The right to education under Article 15 of the RESC and Articles 6 and 13 of the ICESCR refers to basic education, which extends into adulthood for persons with intellectual disabilities who face particular

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<sup>858</sup> It is noted in this respect that there was an average cost per place established by the HSE under the MAIP.

disadvantages in education. Insofar as the majority of individuals in the Centre did not receive adequate educational supports as children, notwithstanding the position articulated by the domestic courts in *Sinnott v Minister for Education*,<sup>859</sup> as a matter of international law, it is questionable whether the State can justify the non-provision of any educational facilities to them in their adulthood. Clearly, the capacity of the individuals in the Centre will differ on a case by case basis as will their learning abilities, but to remove all educational or training routes to them on a blanket basis by reference to their age, must raise serious issues under these international standards. Its impact on the individuals in the Centre was clear.

12.69 Similarly, it is difficult to see how the individuals in the Centre can socially integrate and participate in the community in circumstances where implementation of their personal outcome plans cannot be ensured due to financial restraints, including the deduction of much of the Disability Allowance of the individuals in the Centre, affecting their economic independence.

12.70 In relation to social integration and participation in the community, in any decisions taken regarding the proposed move to community group homes, the autonomy and self-determination of individuals must be ensured and appropriate consultation occur. To this end, it is clear that best international practice suggests that while on the one hand, community living in small units for persons with disabilities is recommended, this should guard against isolation. Furthermore, the physical location of the home of a person with intellectual disabilities should be a secondary condition to ensuring that the individual is at the centre of service provision and choice. Under such a model, it is clear that reconfigured housing on the current campus or in community homes may be appropriate, provided that the services for the individual are ensured and provided that their ability to interact with the outside world and to enjoy opportunities for habilitation and rehabilitation are assured. All individuals should have the choice to live in, participate in and contribute to the community to enhance their sense of belonging and connection to others. The consent and

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<sup>859</sup> *Op. cit.*, see Chapters 5 and 11.

participation of the individuals in the Centre and their families in relation to their living arrangements, including in relation to any proposed relocations, must be thus ensured.

### **The Right to Equality Before the Law and Non-Discrimination in the Enjoyment of Rights**

12.71 Issues of potential discrimination were raised in the course of the enquiry, most notably in the difference in treatment between the individuals in the Centre and other younger adults with a severe to profound intellectual disability in relation to “enhanced service” funding. According to the Brothers of Charity, it is difficult to draw down this funding under the New Service Development Protocols as they prioritise school leavers over older individuals in need of such services. Accordingly, this difference in treatment appears to be on the basis of the age of the group of persons living in the Centre.

*Whether there was any difference of treatment between persons based on status*

12.72 Under human rights standards, discrimination based on disability, age or health status is prohibited. In the current case, it is clear that a number of issues directly related to prioritisation of such services as speech and language therapy for different age groups raise issues, for example, under Article 26 of the ICCPR, where a difference in treatment on the basis of one’s status in any field regulated by law falls to be considered.

12.73 The State funding structure of New Development Funding prioritises individuals of school leaving age over other older adults with a severe to profound intellectual disability. Accordingly, a difference of treatment on the basis of age can be demonstrated.

*Whether the difference in treatment was reasonably and objectively justified*

12.74 The question then turns to whether the difference in treatment pursues a legitimate aim. If it is accepted that the State's aim in treating like persons differently (and this has not been clearly articulated) is to emphasise the continuum of education from childhood to young adulthood for persons with an intellectual disability and to promote lifelong learning and social interaction and participation by prioritising such supports for this age group, the question then turns to whether this difference in treatment has a reasonable relationship of proportionality between the means employed and the aim sought to be achieved.

12.75 Taking the discrete areas of occupational therapy and speech and language therapy, it is not clear how such a policy can be regarded as legitimate, if one takes into account the minimal State interventions which would be involved in affording those services to the individuals in the Centre. It will be recalled in this regard that the State's "margin of discretion" will narrow where the treatment of vulnerable individuals such as persons with a disability are concerned. Within that group, the current group of individuals in the Centre are a particularly vulnerable group. Accordingly, a difference of treatment on the basis of the age of the individuals in the Centre would appear to be disproportionate to any aim pursued.

12.76 In relation to New Development Funding, the State's "margin of appreciation" would be greater where significant capital expenditure is involved. However, given the fact that the State is moving away from a congregated settings model in favour of individualised services and independent living, there must be doubt whether the exclusion in practice of an older group of persons with a severe to profound intellectual disability would be justified under these standards.

12.77 In relation to the non-discrimination standards under the ICESCR, these standards are more onerous than those pertaining under the ICCPR and ECHR and at least similar considerations would arise.

## The Right to a Remedy

12.78 The response to the HSE Review Report by both the Brothers of Charity and the HSE is an interesting counterpoint for consideration of this right insofar as the question as to precisely who is responsible for ensuring the full implementation of the recommendations of such reviews is not immediately clear as is also the case in relation to the level of accountability to the individuals in the Centre.

12.79 It will be recalled that the State is obliged to provide an accessible and effective remedy to an individual where an arguable claim of the breach of a substantive ECHR right occurs. In addition, under Article 12 of the ICESCR (as elaborated by the CESCR), the State is obliged to provide a right to a remedy which will include the right to restitution, compensation, satisfaction or guarantees of non-repetition, thus preventing the recurrence of a more general problem.

12.80 The question then arises as to whether the present remedy or remedies are effective, being accessible and available to the individuals and their families and capable of resulting in the rights enumerated above. Remedies need not be judicial provided they are effective and provide a remedy of value to the complainant.

12.81 In relation to appropriate non-judicial remedies available to the individuals and their families, it is clear that certain institutions can consider complaints. For administrative complaints, individuals can complain to the Brothers of Charity's complaints procedure, then to the HSE and later to the Ombudsman. However, it is noted that apart from mal-administration, these bodies cannot consider substantive health or health care issues, while broader decision-making processes considered in this report may be beyond the scope of their respective remits.

12.82 Similarly, it has been noted that HIQA has no inspection or monitoring role in relation to the Centre; those powers having not been commenced by recent Government decision. HIQA, can exceptionally, undertake own-volition inquiries, but is not a complaint-receiving body. The HSE and the Department of Health believe that mooted self-audits, with the results to be discussed in regular meetings with the HSE and separately HSE Reviews planned from early 2010, will ensure the HIQA Standards are implemented. This remains to be seen. The individuals and their families may theoretically petition these authorities, however, the arrangement governing the health and care of their adult children is between the HSE and the Brothers of Charity.

12.83 In relation to quasi-judicial remedies, as noted in Chapter 5, the Equal Status Acts prohibit disability-based discrimination in the supply of goods and services, however, certain exceptions apply, including in relation to health care provided pursuant to a statutory obligation. In relation to the Courts, as noted in Chapters 5 and 11, the Supreme Court has held that the allocation of public monies is a matter for the Executive under the Separation of Powers doctrine. Accordingly, the question arises as to whether it can be stated with any confidence that the individuals or their families would have an effective, available remedy as required under international standards.

12.84 The right to a remedy, including as it does the right to restitution, compensation, satisfaction or guarantees of non-repetition, as set out above, appears not to be available to the individuals in the Centre or their families.

## **The Right to be Treated with Dignity, Humanity and Respect**

12.85 A number of conditions in the Centre potentially raise issues under human rights standards. In this regard, the HSE Review questioned aspects of past physical conditions in the Centre which it stated may have deprived individuals of their privacy. The fact that some individuals have until recently shared bedroom accommodation with others raises issues under Article 8 of the ECHR and Article 17 of the ICCPR (the right to respect for one's private life) when it is recalled that the Centre is the permanent home of the individuals, rather than a temporary place of detention or setting for medical treatment.

12.86 Further issues arise in relation to the protocols governing capacity and consent to medication. Insofar as there was no established system by which the decision making capacity of individuals is assessed within the Centre, issues under Article 8 of the ECHR arise. This places the Brothers of Charity in a very difficult position where it has to act according to its view of best practice in a legal vacuum. In this regard, the failure of the State to enact legislation and legal codes of practice concerning the assessment of capacity suggests that the right to private life of the residents has been heavily impacted in relation to their autonomy, including where any exceptional coercive medical treatments may need to occur. Without the enactment of mental capacity legislation as promised by Government, it would appear that the State may be unable to ensure that the right to private life of the individuals in the Centre are sufficiently protected under Article 8 of the ECHR or Article 17 of the ICCPR.

12.87 It will be recalled that international standards on ill-treatment place emphasis on the importance of ensuring that proper safeguards are in place to avoid situations of ill-treatment arising. Where a resident is subject to "restrictive practices" such as those referred to in the HSE Review Report (see Chapter 7), international standards (for example, the CPT Standards, Article 3 of the ECHR, Articles 7 and 10 of the ICCPR and Articles 2 and 16 of UNCAT) provide that certain procedural safeguards must be in place. Included in these standards are

the State's obligations to prevent, investigate and ensure remedial measures for individuals at risk of foreseeable harm. In the present case, a number of procedures have been put in place by the Brothers of Charity concerning "restrictive practices", including those introduced following the HSE Review. Further, a certain level of review of "restrictive practices" is instigated by management in the Centre and reviewed by a committee it established. The Brothers of Charity are to be commended in this regard, although the timeframes for the review could be shorter and all instances of "restrictive practices" could be formally reported to the HSE against HIQA's National Standards and the guidance (Code of Practice) issued by the Mental Health Commission in relation to the use of "restrictive practices", including physical restraint. However, the precise role of the State appears removed in terms of its specific obligations under international standards to investigate and prevent possible ill-treatment. In this regard, it is noteworthy that limited follow-up by the HSE occurred following its own Review Report recommendations on this serious matter. Similarly, as noted, HIQA has no formal role in relation to the inspection and registration of residential care centres for persons with disabilities at present.

12.88 Similarly, in relation to the conditions in the Centre and similar centres, it must be recalled that given the fact that the residents are persons with a severe to profound intellectual disability in a vulnerable situation, the minimum level of severity threshold for prohibited ill-treatment will not be set unduly high. In addition, a violation of the prohibition on ill-treatment may occur where a person suffers foreseeable ill-treatment at the hands of another individual and where the State owes an obligation to the person to protect him or her. This is because the State authorities are obliged to investigate possible incidents of ill-treatment which come to their attention, including ensuring proper investigations in a residential centre whether run by a public or private body.

12.89 Thus, insofar as overcrowding in bungalows had been identified as linked to challenging behaviour in some individuals and to aggressive incidents against individuals and staff, care must always be taken to ensure that conditions meet

the requisite standards under the CPT and Article 3 of the ECHR and Article 7 of the ICCPR. At the time of the Health and Safety Authority review in 2004, the Brothers of Charity's own internal review of challenging behaviour incidents resulted in the introduction of an intensive "wraparound" staffing arrangement for two individuals. However, the situation did not end there. Ongoing overcrowding in bungalows and the foreseeable risks posed by the challenging behaviour of 12 individuals were referred to in the 2008 HSE Review Report. The State authorities had in 2006 informed the Commission that they recognised the link between adequate services (such as sufficient staffing and multidisciplinary services) and challenging behaviour. Apart from additional funding, the State's follow up to the 2008 report was in the form of meetings between the HSE and the Brothers of Charity through which a number of the recommendation were pursued. Indeed, inadequate funding was compounded by further funding cuts, resulting in a community group home remaining closed and respite places being unavailable. In these circumstances, particular care is required by the State authorities in employing appropriate prevention or remedial measures to address foreseeable risks.

12.90 As noted, the ongoing shortage of staff, worsened by recent blanket ("Value for Money") budgetary cuts to the Brothers of Charity had potential implications for the safety of individuals at night, in the event of an emergency, and also had potential implications for the protection of staff where supervision and oversight was limited.

## **B: Conclusions and Recommendations/ Suggestions for Action**

### ***Conclusions***

12.91 The report now moves towards its Conclusions. These conclusions have been informed on the basis of the enquiry's analysis as to whether the issues raised in this enquiry have revealed a deficiency in the law/ practice in the State relating to the protection of human rights. As indicated previously, the

Commission considers the situation in the Centre to predominantly raise issues under the rights to health and bodily integrity and to education guidance, vocational training and habilitation/ rehabilitation, respectively.

12.92 The individuals in the Centre receive health, habilitation and social services in the form of residential, respite and day services from the Brothers of Charity on foot of a service level agreement between the charity and the HSE. The conclusions of this enquiry are that while service levels have improved in recent years, the services provided may be inadequate on two fronts: first, physical accommodation is in bungalows which despite recent improvements were designed for children not adults, second, staffing levels appear insufficient to deal with the particular needs of the individuals in the Centre, including in relation to multidisciplinary services, where specific therapies of Speech and Language and Occupational Therapy, required in order to enable the individuals to reach and sustain their optimum level of independence and functioning, were not adequately provided.

12.93 The inadequacy of these services appears to reflect inattention by the State authorities to the individuals' needs. While the Government has planned to provide for the needs of individuals with disabilities for a number of years in the form of the Health Strategies (1994 and 2001), the Disability Strategy (2004), the Health Acts 1947 to 2007, the Disability Act 2005, the EPSEN Act 2004 and the Citizens Information Acts 2000-2007, the net impact of these initiatives for the individuals in the Centre has been limited. The needs of these individuals as determined through individual assessments – either under individual assessments mooted in the Disability Act, or locally devised personal outcome plans – are not properly reflected in annual funding applications or allocations which tend to focus on an estimation of global (or collective) needs.

12.94 Although the State has invested significant monies in recent years under its Multi-Annual Investment Programme as part of the National Disability Strategy, the HSE has stated that access to multidisciplinary services in the Centre needs

to be seen in the context of the relative underdevelopment of multidisciplinary services in health provision in Ireland compared to international norms.

12.95 In relation to individualised assessments of need, although the National Intellectual Disability Database is an important tool, at present it does not capture sufficiently individualised data to allow it to inform service needs planning. Rather, funding for existing centres is mostly based on the previous year's funding allocation under an incremental funding determination process for the Centre. While changes to funding have occurred in recent years, these changes have tended to prioritise other groups such as children and young adults with intellectual disabilities rather than the individuals in the Centre. In the Centre, the baseline funding allocated still has links to the baseline set 30 years ago when the Centre was opened for children, although adults reside in the Centre now. It was also noted during the enquiry that an agreed national average cost or range of costs for residential, day or respite services for persons with a severe to profound intellectual disability in the State did not appear to be employed, while the difficulties in accessing adequate funding based on individual needs was also made clear. Along with blanket funding cuts year on year in the form of HSE "Value for Money" cuts, and the fact that New Service Development funding for new accommodation was not available to the individuals in the Centre in similar manner as to younger adults with a severe to profound intellectual disability, it is clear that planning for adequate funding levels for this vulnerable group cannot be accurately made by the HSE or the Department of Health under the current funding arrangements. In the case of the Centre, funding for the individuals' needs would appear to be inadequate.

12.96 Although not of relevance to the individuals currently in the Centre, it may be that individuals who are accommodated in the Centre in future will have availed of recent improvements for children with intellectual disabilities. In this regard, improvements have been made to the treatment and care of children under 5 years of age with a severe to profound intellectual disability. Changes being introduced under the Disability Act and the EPSEN Act for this cohort

means that in later years the high-level dependency needs of some persons with a severe to profound intellectual disability could be lessened on account of early-intervention supports. This, however, is a recently commenced process and cannot be guaranteed. Regardless of these initiatives, as stated, they do not provide any supports for the individuals in the Centre who under international human rights standards are entitled to certain minimum standards of health care, habilitation, non-discrimination, dignity and respect, in addition to the right to effective remedies, which are set out in Chapter 11.

12.97 State accountability mechanisms were considered by the Commission to be inadequate. The primary relationship between the HSE and the Brothers of Charity appeared to focus on financial accountability as much as on standards and accountability for service provision. In its turn, the HSE was ultimately accountable to the Department of Health. Where the State (HSE) conducted an internal review in response to the Commission's decision to conduct this enquiry, the key recommendations of that review appear to have been implemented by late 2009. This brought improvements to a number of areas in the Centre, notably to accommodation. However, the Review itself declined to examine one of its most important terms of reference, namely that of funding. The opportunity to review the link between individual service provision in the Centre and the funds made available to the Brothers of Charity to provide multi-disciplinary services to the individuals in the Centre to an adequate level was thus not availed of.

12.98 Apart from the Department of Health, independent oversight of the HSE's arrangements with charities such as the Brothers of Charity has only been conducted by the Comptroller and Auditor General (in 2005). Key elements of his recommendations are unimplemented. While there is no doubt that the new HSE service arrangements are a significant advance on the previous service level agreements in place at the time this enquiry commenced, and while the HIQA Standards may in the short term be progressed through their inclusion in Service Agreements and through mooted self-assessments by service providers and subject to further HSE review, the HSE advised that those reviews will continue

to focus on processes and systems rather than assessing whether individual needs in Centres are met. As significantly, the independent monitoring and inspection functions of HIQA, due to be rolled out in 2009, which may have provided the necessary independent oversight, have been stopped by the Government.

12.99 More specific issues examined by the enquiry include protocols for restraint, managing challenging behaviour, consent protocols for medication in the absence of capacity legislation, overcrowding, adequacy of staffing, adequacy of activities and questions over future plans to move individuals to community group homes. The communication between the Brothers of Charity and the Parent Group was also considered. In particular the need for additional supports for psychiatric services, speech and language and occupational therapies became clear during the course of the enquiry.

12.100 In the current enquiry, the Commission has assessed whether or not a deficiency in the law/ practice in the State relating to the protection of human rights has occurred. It considers that international human rights standards may not have been entirely respected in relation to the following:

12.101 Firstly, in relation to the right to health, the AAAQs – available, accessible, acceptable and quality health care - were not fully available to the individuals in the Centre insofar as key therapies which they required were not available.

12.102 Secondly, in relation to education, guidance and vocational training, all part of a person's habilitation, the absence of access to these facilities, including basic education for persons who had not received it in childhood, on the basis of their age alone is highly questionable.

12.103 Thirdly, in relation to equality before the law and non-discrimination in the enjoyment of rights, it would appear that age discrimination may have occurred in

the current case. There must be serious doubt as to whether the State is in a position to disprove allegations of unjustified difference of treatment between the individuals in the Centre and younger adults with a severe to profound intellectual disability who have a greater opportunity to receive enhanced service funding and hence more therapies.

12.104 Fourthly, in relation to the right to an effective remedy, the lack of safeguards and oversight (apart from a theoretical judicial remedy) must place in doubt whether the individuals' right to a remedy under international human rights standards has been vindicated, particularly in relation to the right to health, where it is open to question whether administrative mechanisms can address substantive human rights concerns, such as the rights to restitution, compensation, satisfaction or guarantees of non-repetition in the case of a violation and where safeguards against repetition of rights violations cannot be ensured.

12.105 Fifthly, in relation to the rights to be treated with dignity, humanity and respect, the international human rights obligations of the State would appear to have been largely satisfied in the current case. However, some doubts arise in this regard with respect to the cumulative nature of living conditions, including undersized bedrooms and living space, previous sharing of bedrooms and lack of specific therapies. Similarly, the Commission remains concerned that certain procedural safeguards including those pertaining to capacity and consent were found to be lacking. Given the vulnerability of the individuals in the Centre as a group, care must always be taken by the State authorities in employing appropriate prevention or remedial measures to address foreseeable risks posed by the challenging behaviour of individuals, such as the incidents of challenging behaviour referred to in the 2008 HSE Review Report. This is particularly so given the fact that the State authorities have recognised the link between the provision of adequacy of services (such as sufficient staffing and multidisciplinary services) and challenging behaviour.

12.106 Finally, the Commission notes that international human rights standards provide the State with a choice of means in providing services to individuals with a severe to profound intellectual disability. The State can either provide those services directly to the individuals concerned or it can enter into agreements or arrangements with private actors to do so, such as is the case in the Centre. However, international standards make clear that if the State chooses to enter into a contract with a private body (such as a voluntary not for profit body), it must ensure human rights protection for the individuals concerned and accountability for the services being provided to ensure those rights on behalf of the State.

12.107 The Commission has on occasion recommended that the Government incorporate particular international human rights agreements into domestic law.<sup>860</sup> It is recognised that the State is not legally obliged to incorporate into Irish law all the international human rights agreements to which it is party, provided it can give effect to the obligations which it has assumed under these agreements. This places a special onus on the State, when it has not incorporated an agreement, to ensure that the standards guaranteed by it have legal effect in the State. However, this enquiry has found that the State does not appear to have ensured a number of international human rights standards through law or practice. If it is unable to give effect to these obligations through unincorporated means, it should reconsider the question of direct incorporation of these convention rights, not least so that effective remedies can be secured through the judicial system.

### ***Recommendations/ Suggestions for Action***

12.108 The enquiry report now considers whether the conclusions reached by the Commission should in turn form the basis of recommendations on the

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<sup>860</sup> See Submission on the European Convention on Human Rights Bill 2001 to the Joint Oireachtas Committee on Justice, Equality, Defence and Women's Rights, June 2002; Submission to the UN Committee on the Elimination of Racial Discrimination, December 2004; Submission to the UN Committee on the Elimination of Discrimination Against Women, January 2005; Submission to the UN Committee on the Rights of the Child, May 2006; Submission to the UN Human Rights Committee on the Examination of Ireland's Third Periodic Report on the International Covenant on Civil and Political Rights, March 2008. These submissions are available on [www.ihrc.ie](http://www.ihrc.ie).

measures required in order to strengthen, protect and uphold human rights in the State. The Commission thus makes recommendations on those measures required and in doing so, also makes certain suggestions for action. In this latter regard, the Commission considers that its suggestions for action fall within its remit insofar as they are considered incidental to it performing its function to make recommendations on the measures required to strengthen, protect and uphold human rights in the State. In making its recommendations/ suggestions for action on the basis of the conclusions of this report, the Commission is conscious that issues of funding of disability services arise and it may be that solutions will need to be identified at the macro level if the human rights of the individuals in the Centre and those in similar centres are to be fully ensured.

12.109 As a general point, the Commission recommends that the international human rights standards raised in this report be considered against current health and social services law and practice in the State. More specifically, it recommends that the Department of Health, in conjunction with the Department of Justice, Equality and Law Reform and the Department of Foreign Affairs, take steps to enable the State to ratify the UN Convention on the Rights of Persons with Disabilities without delay.

### **Department of Health**

12.110 As the Department with responsibility for health and social care to persons in the State, including for the individuals the subject of the current enquiry, the Department of Health should review the recommendations in this report carefully to identify those areas where existing legislation and practice may not fully reflect the State's human rights obligations as raised in this report. Where a gap in human rights protection exists, steps should be taken to remedy the situation within a short time frame.

12.111 The Commission recommends that the Department, in conjunction with the Department of Justice, Equality and Law Reform and the Department of

Foreign Affairs, should take steps to enable the State to ratify the UN Convention on the Rights of Persons with Disabilities without delay. The Commission also recommends that a clear and comprehensive definition of “health and personal social services” be set out in primary legislation.

12.112 The Commission recommends that the Department, together with the HSE, review in conjunction with sections 38 and 39 of the Health Act 2004 the imprecise nature of service agreements governing the quantum and quality of services to be provided under State funding, including their accountability structures. These agreements should be redesigned so that funding levels and accompanying protocols are delivered “bottom up” rather than “top down”; insofar as individual needs assessments, informed by personal outcome or similar programmes inform the service levels, staffing levels and the capital funding levels required to ensure private life and dignity and the highest attainable standard of health. The Commission recommends that a “core” funding contingent be identified to ring-fence front line services from budget cuts and thus insulate front line services from “Value for Money”, other administrative cuts, or employment ceilings or bans which may prevent recruitment or replacement of core staff. Special attention should be afforded to certain positions which are difficult to recruit, for example, teaching supports.

12.113 The Commission recommends that the Department of Health convene a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, day and respite services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery. The recommendations of this working group should inform the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland.

12.114 The Commission further recommends that the Department revise the workings of the National Intellectual Disability Database to ensure that it provides

appropriate reliable data on service needs for persons with an intellectual disability in the State. The Commission similarly recommends that the remaining provisions of the Disability Act be commenced without delay.

12.115 Noting that previous “Value for Money” reviews have resulted in funding cuts to the Centre and similar centres, it is recommended that the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland be informed by a “bottom up” approach whereby individual assessments inform service level funding. Noting the international presumption against retrogression under the right to health which corresponds also to the principle inherent in the HSE’s Existing Level of Service funding protocols, it is further recommended that both this review and ongoing budgetary decisions should ensure that retrogressive measures in relation to the provision of core services in the Centre are guarded against.

12.116 The Commission recommends that the Department should set out clear guidelines, possibly in the form of regulations on the minimum required staff-to-client ratios for centres caring for persons with an intellectual disability, broken down by reference to day and night cover (including weekends) and also broken down by reference to varying levels of intellectual disability and any other disability. It is recommended that these guidelines be directed towards the provision of adequate living space in a community setting and be predicated upon optimising socialisation, habilitation and night and weekend cover. It is further recommended that these guidelines refer also to campus-type settings insofar as they continue to be residential centres for individuals.

12.117 The Commission recommends that the Department of Health introduce protocols governing HSE Reviews. In addition, it recommends that there be a statutory requirement on the HSE to report on such reviews including their terms of reference and their implementation by way of written report to the Oireachtas. It also recommends that the Department consider strengthening the limited complaints mechanisms currently available under Part 9 of the Health Act 2004.

12.118 The Commission recommends that the Department of Health, in conjunction with the Department of Justice, Equality and Law Reform, enact without any further delay, legislation and enforceable codes of practice concerning assessment of capacity for persons with an intellectual disability with clear recognition of the principle of the presumption of one's capacity. Where supported decision-making is not possible protocols should be provided for next friend/ relatives giving consent to placement in residential services and to medication or other forms of treatment. These protocols should be introduced into service agreements without delay thus affording certainty and predictability to all individuals with an intellectual disability, their families and health care professionals. The agreements should confer specific entitlements on the individuals receiving services, who should be referred to in the agreements as individuals with specific needs rather than objects receiving State largesse.

12.119 The Commission recommends that the Department of Health, in consultation with the HSE and relevant statutory bodies, such as HIQA and the NDA, set out clear protocols for the prevention of foreseeable risks to vulnerable persons with an intellectual disability living in institutions or residential centres through timely and appropriate intervention strategies. Such intervention strategies should ensure that any remedial measures are swiftly identified and implemented.

12.120 The Commission recommends that the Department review the Government's 2003 Report to the CPT and the commitments made at that time. It recommends that the Department ensure that all CPT recommendations on foot of its 2002 report concerning centres for persons with an intellectual disability are met. In particular, the Department should review those aspects that refer to detention in psychiatric institutions and that refer to multidisciplinary training and recruitment needs.

12.121 The Department should ensure that HIQA's inspection and monitoring role in relation to residential care for persons with disabilities as provided for in

the Health Act 2007, are immediately introduced and that the Authority receives adequate resourcing to carry out inspections and monitoring for all residential centres for persons with an intellectual disability. Further, the Department should consider the Enquiry's recommendations on remedies and seek to secure the availability of either effective accessible judicial or non-judicial remedies for similar cases in the future.

## **HSE**

12.122 The public-private framework provided by the Health Acts under which the HSE and service providers operate should be reviewed to ensure that service agreements are "bottom up", being based on individual assessments. The HSE should stipulate in the agreements the precise nature of accountability structures in place, not only those governing financial accountability, but also in relation to the quality and quantity of services to be provided.

12.123 The Commission has recommended to the Department that it convene a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, day and respite services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery. The Commission recommends to the HSE that it work closely with the Department in driving this process.

12.124 In order to ensure that the AAAQs are satisfied, that is, accessible, appropriate, acceptable and quality health care, the HSE should stipulate in its individual service agreements the precise level of multidisciplinary services available to the individuals in each centre to meet these standards. Adequate speech and language therapy and occupational therapy should be available to the individuals in the Centre and others in a comparable situation. In line with the international presumption against retrogression under the right to health which corresponds also to the principle inherent in Existing Level of Service funding

protocols, it is further recommended that any cuts to the current core services available to the individuals in the Centre be guarded against.

12.125 Insofar as the HSE has, pursuant to Section 38 of the Health Act 2004, largely contracted out its duties to provide services to the individuals in the Centre and other similar centres, it should ensure that its service agreements reflect sufficient control and accountability mechanisms to ensure that the State's human rights obligations can be met in the delivery of health, habilitation and social care in the Centre and similar centres. Further, it recommends that service agreements should be available to the persons who avail of the services outlined therein and to their families.

12.126 The Commission has recommended to the Department that it introduce protocols governing HSE Reviews, such as the Review conducted in 2007-2008 and that the HSE be statutorily obliged to report on such reviews and their implementation by way of written report to the Oireachtas. Noting the HSE intention to conduct more regular Reviews from early 2010 as part of its service arrangement monitoring, it further recommends to the HSE that pending the introduction of any such protocols by the Department, the HSE introduce the practice of providing written reports to both the Department and the Oireachtas Committee on Health and Children. Further, the Commission recommends that each Review sets out an Action Plan for implementation of its recommendations and that the findings of all Review reports are circulated to the individuals in the relevant centre and to their parents.

12.127 In relation to the HSE's National Review of Day Services and its mooted Community Integration Model of Service Provision arising from its Review of Congregated Settings, the Commission recommends that the five demonstration sites to explore in practice the recommended model arising from the latter Review in 2010, be informed by the recommendations in this report. Specifically, it recommends that the Day Services component be informed by individualised need assessment and that a form of personal outcome programme for the

individuals concerned be put in place and monitored. It recommends that the residential, day and any respite services components in the demonstration sites inform the deliberations of a Working Group on national average costings which is recommended in this report. It also recommends that the communication model between the service provider and the families of the individuals in the centres as suggested in this report be put in place during the roll-out of these community integration models.

12.128 The Commission recommends that the HSE instigates investigation and prevention strategies where areas of foreseeable risk (such as, overcrowding, staff shortages, challenging behaviour) may lead to situations of harm or neglect. Where investigations or reviews are conducted, recommendations should be followed up in a short timeframe. Reports of investigations and reviews should be laid before the Houses of the Oireachtas.

12.129 In relation to the availability of remedies, the Commission has made recommendations to the Department of Health that the Government review the availability of both judicial and non-judicial remedies to both the individuals in the Centre and to persons in a similar situation. Pending such review and amendment, it recommends to the HSE that it further explore its system of non-judicial remedies to situations currently outside the respective remits of the Ombudsman and Ombudsman for Children with a view to identifying whether other non-judicial remedies can be introduced which would address issues such as multidisciplinary services, health care provision and overcrowding.

12.130 In relation to the individuals in the Centre, the subject of the enquiry, the Commission recommends that the HSE provide an adequate level of capital funding to the Brothers of Charity for the development of appropriate residential services for the individuals in the Centre. Further, the Commission recommends that those twelve individuals in the Centre, who have been on a residential waiting list for between 1 and 12 years are immediately provided with a full time service to meet their needs. In relation to respite services it recommends that

sufficient funding be ring fenced to allow for at least a minimum service to continue to be available in the future. In addition, noting the delegated sanction of the HSE for therapy posts within certain ceilings, it specifically recommends that the HSE fund the Brothers of Charity to engage an additional full-time Speech and Language therapist and a full-time occupational therapist. It recommends that the HSE, in conjunction with the Brothers of Charity, subsequently undertake an evaluation of these additional services. It also recommends that provision be made for an additional Consultant Psychiatrist to support the work of the present Consultant in the Centre on a needs basis.

12.131 In relation to the financial independence of the individuals in the Centre, the Commission recommends that the HSE immediately undertake a review of its Guidelines on in-patient charges to remove any disparity in personal income left to persons residing in congregated settings on the one hand, and hostels or community homes on the other hand, after in-patient charges have been deducted from a person's Disability Allowance. The said review should seek to ensure that each individual has sufficient income left from their Allowance or other social welfare payment, after paying any in-patient charges, to allow them achieve optimum independence and to avail of opportunities for socialisation and integration with the community. The HSE should maintain an oversight function in relation to the assessment of the level of in-patient charges that each individual is liable to pay.

### **Department of Education**

12.132 The Commission recommends that the Department of Education review, on a national level, the extent to which provision is made for adults with an intellectual disability in relation to the right to education as set out in this enquiry report. It recommends that provision be explicitly made for education for persons with an intellectual disability in adulthood, tailored to the individual's learning capacity and separately that provision be made for further education, guidance and vocational training for adults with intellectual disabilities. In the interests of

clarity, the Department should consider setting out such provision in legislation. These education facilities should be guided by accessibility protocols.

12.133 The Department should ensure that a review takes place as to the educational services currently available in the Centre and that these services are augmented to ensure at least a minimal level of educational facilities for all the individuals in the Centre.

### **Brothers of Charity**

12.134 Pending the introduction of protocols matching individualised assessments to funding for the individuals in the Centre under the Disability Act 2005, the Commission recommends that the Brothers of Charity explore ways of identifying, and a format for capturing specific data on, individual needs, possibly through the personal outcome plan process. These individual needs and the quantum of funding associated with same should be drawn to the attention of HSE as part of its annual service agreements. Documenting individual needs in a systematic manner will allow the Centre to demonstrate that it is taking all necessary steps to ensure the private life, dignity and right to the highest attainable standard of health and habilitation for the individuals in the Centre.

12.135 Pending the introduction of mental capacity legislation, the Commission recommends that the Brothers of Charity formalise a system for both supported decision-making by the individuals in the Centre, and where necessary, substituted decision-making by parents for individuals in appropriate forms and that consent to medication and medical treatment continues to be regularly recorded in this manner.

12.136 In relation to multidisciplinary services, the Commission has made specific recommendations to the HSE in respect of speech and language and occupational therapy and has also recommended that additional supports to the Consultant Psychiatrist be afforded. The Commission recommends to the

Brothers of Charity that it continue to press for these supports in its meetings with the HSE.

12.137 In relation to individuals' accounts managed by the Brothers of Charity, the Commission, while noting the robust procedures in place, recommends that the Brothers of Charity continue to introduce more formalised consent procedures to govern its handling of individual monies, to promote the autonomy and self-determination of the individuals in the context of the introduction of mental capacity legislation.

12.138 In relation to the proposed move of some residents of the Centre to community group homes, the Commission recommends that the Project Team comprising the Brothers of Charity and family members convene with clear terms of reference underpinned by ensuring that the autonomy and self-determination of individuals be promoted and that appropriate consultation and consent occurs. Noting that the wishes of the individual will have been taken into account, it recommends that any such moves of individuals to community group homes involve concrete steps to guard against isolation and to ensure that the individual is at the centre of service provision in the new setting. It recommends that a qualitative survey of the individuals already moved to community group homes take place in order to inform this ongoing process. Finally, all individuals residing in community group homes should be issued with appropriate tenancy agreements.

12.139 In relation to the ongoing care and support which the Brothers of Charity undertake in relation to the individuals in the Centre, the Commission recommends that the Brothers of Charity continue to engage with the parents of the individuals in the Centre and that new protocols be devised to ensure accessible and transparent communication between Centre management, care staff and the parents. While recognising that much has been done in this regard, the Commission considers that a more formal approach to meetings and consultations can supplement the informal approaches which are already

working. In this regard, parents should be clearly informed in relation to their opportunities for engagement in relation to decisions concerning their adult children, and how to avail of those opportunities, many of which opportunities may continue to be through the Centre's frontline care staff empowered to engage with parents. Where parents or advocates engage in supported decision making with the individuals in the Centre, it is important that the process be approached in a consultative and engaged manner and that it be documented where possible. A similar approach should be taken in relation to substituted decision making where it arises.

### **To the Parent Group and the Individuals in the Centre**

12.140 The Commission commends the Parent Group for the energy and determination parents have shown in seeking to obtain the best possible standards for their adult children in the face of considerable administrative and financial obstacles. It recommends that the Parent Group engage with the Centre Management and care staff in devising communication protocols that suit all parties, noting the other responsibilities of Centre Management and care staff as set out in this report.

12.141 In relation to multidisciplinary services, the Commission recommends that the Parent Group liaise with the Brothers of Charity in reviewing multidisciplinary needs on an ongoing basis and that the input of the parents (and by definition the individuals themselves) forms part of the annual review of multidisciplinary needs recommended to the Brothers of Charity; that annual review to feed into its annual service meeting with the HSE.

12.142 In relation to any transfer to community group homes, the Commission has recommended to the Brothers of Charity that the Project Team be convened with Terms of References and that this process proceed in consultation with the parents of the individuals concerned. Appropriate consent must occur and safeguards against isolation must be adopted, with a survey of existing

community home residents to inform future plans. It recommends to the Parent Group that it engage with the Brothers of Charity in these processes, noting that international standards suggest that a move from the existing accommodation to reconfigured accommodation on-Campus or alternatively, in community group homes, should occur where appropriate.

12.143 The Commission recognises the dedication, courage and strength of the individuals in the Centre and the members of the Parent Group and hopes that, in the light of this report, all parties will act speedily to respond appropriately, thereby respecting the dignity of the individuals who reside at or avail of a service in the Centre.

## Chapter 13: Summary of Recommendations/ Suggestions for Action

### To the Department of Health

#### *General:*

- The Department should review the recommendations in this report carefully to identify those areas where existing legislation and practice may not fully reflect the State's human rights obligations as raised in this report. Where a gap in human rights protection exists, steps should be taken to remedy the situation within a short time frame.
- The Department, in conjunction with the Department of Justice, Equality and Law Reform and the Department of Foreign Affairs, should take steps to enable the State to ratify the UN Convention on the Rights of Persons with Disabilities without delay.
- The Department should introduce a clear and comprehensive definition of "health and personal social services" in primary legislation.
- The Department, in conjunction with the HSE, should review the imprecise nature of service agreements governing the quantum and quality of services to be provided under State funding, including their accountability structures. These agreements should be redesigned so that funding levels and accompanying protocols are delivered "bottom up" rather than "top down"; insofar as individual needs assessments, informed by personal outcome plans or similar programmes, inform the service levels, staffing levels and the capital funding levels required to ensure private life and dignity and the highest attainable standard of health. A "core" funding contingent should be identified to ring-fence front line services.

- The Department should convene a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, respite and day services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery. The recommendations of this working group should inform the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland.
- The Department should revise the workings of the National Intellectual Disability Database to ensure that it provides appropriate reliable data on service needs for persons with an intellectual disability in the State.
- The Disability Act 2005 should be fully commenced without delay.
- The Department should ensure that the recently announced Review of the Efficiency and Effectiveness of Disability Services in Ireland be informed by a “bottom up” approach whereby individual assessments inform service level funding. Both this review and ongoing budgetary decisions should ensure that retrogressive measures in relation to the provision of core services in the Centre are guarded against.
- The Department should set out clear guidelines, possibly in the form of regulations, on the required staff-to-client ratios for centres caring for persons with an intellectual disability, taking into account adequate living space, socialisation, habilitation and night and weekend cover.
- The Department should introduce protocols governing HSE Reviews. There should be a statutory requirement on the HSE to report on such reviews including their terms of reference and their implementation by way of written report to the Houses of the Oireachtas.

- The complaints mechanisms currently available under Part 9 of the Health Act 2004 should be reviewed.
- The Department, in conjunction with the Department of Justice, Equality and Law Reform, should enact without any further delay, legislation and enforceable codes of practice concerning assessment of capacity and supported decision making for persons with an intellectual disability, in addition to protocols for next friend/ relatives giving of consent to placement in residential services and to medication or other forms of treatment. These protocols should also be introduced into service agreements.
- The Department, in consultation with the HSE and relevant statutory bodies, such as HIQA and the NDA, should set out clear protocols for the prevention of foreseeable risks to vulnerable persons with an intellectual disability living in institutions or residential centres through timely and appropriate intervention strategies.
- The Department should review the Government's 2003 Report to the CPT and the commitments made in that report. The Department should ensure that all CPT recommendations on foot of its 2002 report concerning centres for persons with an intellectual disability are met, including those aspects that refer to detention in psychiatric institutions and that refer to multidisciplinary training and recruitment needs.
- The Department should ensure that HIQA's inspection and monitoring role as provided for in the Health Act 2007, are immediately introduced and that the Authority receives adequate resourcing to carry out inspections and monitoring in all residential centres for persons with an intellectual disability.

## To the Health Service Executive (HSE)

### *General*

- The HSE should review its public-private frameworks to ensure that service agreements are “bottom up”, being based on individual assessments. The HSE should stipulate in the agreements the precise nature of accountability structures in place, not only those governing financial accountability, but also in relation to the quality and quantity of services to be provided.
- The HSE should work closely with the Department of Health in driving a working group comprising the Department, the HSE and service providers to establish an agreed national average cost for residential, respite and day services, informed by the range of individual needs assessments, which can be employed in Service Agreements and allow for both clarity and flexibility of approach to service delivery.
- The HSE should stipulate in its individual service agreements the precise level of multidisciplinary services available to the individuals in every residential, respite or day centre to meet the standards of accessible, appropriate, acceptable and quality health care (AAAQ's). Any retrogressive measures in relation to the provision of core services in the Centre should be guarded against.
- The HSE should ensure that service agreements reflect sufficient control and accountability mechanisms to ensure that the State's human rights obligations can be met in the delivery of health, habilitation and social care in the Centre and similar centres. Service agreements should be available to the persons who avail of the services outlined therein and to their families.

- The HSE should introduce protocols so that HSE Reviews planned from 2010, have their recommendations implemented over a stipulated period of time. The HSE should also introduce the practice of providing written reports on its reviews to both the Department of Health and the Oireachtas Committee on Health and Children and the findings of all such Review reports should be circulated to the individuals in the relevant centre and to their parents.
- The recommendations in this report on individualised assessments informing service needs should be applied by the HSE in the five demonstration sites being explored in 2010 for a recommended community living model. Specifically the Day Services component should be informed by individualised need assessment and that a form of personal outcome programme for the individuals concerned be put in place and monitored. Further, the residential, day and any respite services components in the demonstration sites should inform the deliberations of a Working Group on national average costings which is recommended in this report. A communication model between the service provider and the families of the individuals in the centres as suggested in this report should also be put in place.
- The HSE should instigate investigation and prevention strategies where areas of foreseeable risk (such as, overcrowding, staff shortages, challenging behaviour) may lead to situations of harm or neglect in centres for persons with intellectual disabilities. Recommendations should be followed up in a short timeframe. Reports of investigations and reviews should be laid before the Houses of the Oireachtas.
- The HSE should explore its system of non-judicial remedies in relation to situations currently outside the remits of the Ombudsman and Ombudsman for Children with a view to identifying whether other non-judicial remedies can be introduced which would address issues such as

multidisciplinary services, health care provision and overcrowding in residential care settings for persons with an intellectual disability.

### *Specific*

- The HSE should ensure that adequate speech and language therapy and occupational therapy is available to the individuals in the Centre and others in a comparable situation. It should immediately fund the Brothers of Charity to engage an additional full-time Speech and Language therapist and an additional full-time occupational therapist. It should also make provision for an additional Consultant Psychiatrist to work with the present Consultant in the Centre on a needs basis.
- The HSE should provide an adequate level of capital funding to the Brothers of Charity for the development of appropriate residential services for the individuals in the Centre or in community group homes.
- The HSE should immediately provide the twelve individuals in the Centre who have been on a residential waiting list for between 1 and 12 years, with a full time service to meet their needs. Sufficient funding for respite services should be ring fenced to allow for at least a minimum service to continue to be available in the future.
- The HSE should immediately undertake a review of its Guidelines on in-patient charges to remove any disparity in personal income left to persons residing in congregated settings and hostels or community homes after in-patient charges have been deducted from a person's Disability Allowance. The said review should seek to ensure that each individual has sufficient income left from their Allowance or other social welfare payment, after paying any in-patient charges, to allow them achieve optimum independence and to avail of opportunities for socialisation and integration with the community. The HSE should maintain an oversight function in

relation to the assessment of the level of in-patient charges that each individual is liable to pay.

- In the event that the HSE imposes cuts to funding for the Centre in the future, it should be in a position to clearly demonstrate that any such measures can meet the international human rights standards set out in this report.

## **To the Department of Education**

### ***General***

- The Department of Education should ensure that educational provision is explicitly made for persons with an intellectual disability in adulthood; and that this educational provision is tailored to the individual's learning capacity. Separately, the Commission recommends that the Department of Education ensures that provision be made for further educational guidance and vocational training for all adults with intellectual disabilities. In the interests of clarity, the Department should consider setting out such provision in legislation.
- The Department of Education should ensure that these educational facilities should be guided by accessibility protocols.

### ***Specific***

- The Department of Education should ensure that a review takes place as to the educational services currently available in the Centre with a view to augmenting these services to ensure at least a minimal level of educational facilities for all individuals in the Centre.

## To the Brothers of Charity

- Pending the introduction of protocols matching individualised assessments to funding for the individuals in the Centre, the Brothers of Charity should explore ways of identifying individual needs, possibly through the personal outcome plan process. These individual needs and the quantum of funding associated with same should be drawn to the attention of HSE as part of its annual service arrangements.
- Pending the introduction of mental capacity legislation, the Brothers of Charity should formalise a system of supported decision making for each individual in the Centre and where necessary any substituted decision-making by parents for individuals in appropriate forms and that consent to medication and medical treatment continue to be regularly recorded in this manner.
- In relation to multidisciplinary services, the Brothers of Charity should follow up with the HSE in respect of the specific recommendations made concerning speech and language therapy, occupational therapy and psychiatric services made in this report.
- In relation to individuals' accounts managed by the Brothers of Charity, the Brothers of Charity should introduce more formalised consent procedures to govern its handling of individual monies, to promote the autonomy and self-determination of the individuals concerned, in the context of the introduction of mental capacity legislation.
- Concerning the proposed move to community group homes, the Brothers of Charity should work with the Parent Group in a project team with clear terms of reference. The Brothers of Charity should work with parents to ensure that appropriate consultation and consent to any planned moves occurs, with concrete steps being taken to guard against isolation and to

ensure that the individual is the centre of service provision in the new setting. A qualitative survey of the individuals who have already moved to community group homes should take place in order to inform this ongoing process.

- Any individual residing in a community group home should be provided with an appropriate tenancy agreement.
- The Brothers of Charity should continue to engage with the parents of the individuals in the Centre. New protocols should be devised to ensure accessible and transparent communication between Centre management, care staff and the parents which may include a more formal approach of meetings and consultations to supplement the informal approaches which are already working. Parents should be clearly informed in relation to their opportunities for engagement in relation to decisions concerning their children. Where parents or advocates engage in supporting individuals in the Centre to make decisions or where necessary substituted decision-making occurs, the process of decision-making should be approached in a consultative and engaged manner and be documented where possible.

#### **To the Parent Group and the Individuals in the Centre**

- The Parent Group should engage with the Centre Management and care staff in devising communication protocols that suit all parties.
- The Parent Group should continue to liaise with the Brothers of Charity in reviewing multidisciplinary needs on an ongoing basis and ensure that their input (and by definition the input of the individuals in the Centre) forms part of the annual review of multidisciplinary needs recommended to the Brothers of Charity; so that it can feed into the Brothers of Charity's annual service meeting with the HSE.

- In relation to any transfer to community group homes, the parents of the individuals concerned should engage in consultations on this issue with the Brothers of Charity as part of the project team referred to.

## Appendix I Guidelines on Enquiry Requests

### *Guidelines for dealing with requests under Section 9(1)(b) and Applications under Section 10 of the Human Rights Commission Act, 2000*<sup>861</sup>

#### Requests for an Enquiry

Under Section 9(1)(b) of the Human Rights Commission Act, 2000 (the Act), the Irish Human Rights Commission (the Commission) can decide to conduct an enquiry into a relevant human rights matter at the request of any person, subject to certain conditions.<sup>862</sup> Although the Commission has wide discretion in deciding whether to conduct an enquiry or not, it can only do so where the purpose of the enquiry is clearly linked to at least one of the following functions of the Commission, namely:

1. a review of law and practice or
2. the Commission consulting with national or international bodies or agencies or
3. making recommendations to the Government or
4. the promotion of understanding and awareness of the importance of human rights.<sup>863</sup>

If the purpose of an enquiry is not clearly linked to one of these four functions, the Commission cannot conduct an enquiry as to do so would be to act beyond its powers.

The Commission can also decide to conduct an enquiry into any relevant human rights matter at the request of any person if the Commission considers it necessary or expedient to do so, subject to certain conditions (outlined below). The Commission can only conduct an enquiry if the purpose of the enquiry is

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<sup>861</sup> Adopted 29 July 2004.

<sup>862</sup> It should be noted that the criteria under Section 9(1)(b) of the Act are subject to the provisions of the Act and of any amending legislation.

<sup>863</sup> These are the functions outlined in Sections 8(a), (c), (d) and (e) of the Act.

clearly linked to one of the four functions outlined above. In conducting an enquiry, the Commission can require persons to furnish relevant information, documentation or things to the Commission and it can require such persons to attend before the Commission for that purpose.<sup>864</sup> An enquiry may be conducted in public or in private as the Commission, in its discretion, considers appropriate and the Commission can determine the procedure for conducting an enquiry.<sup>865</sup>

### **How does the Commission decide whether to conduct an enquiry?**

Under Section 9(1)(b) of the Act, a person can request the Commission to conduct an enquiry into a relevant matter.

The Act sets out strict criteria which the Commission must apply in deciding whether to accede to a request for an enquiry. If a request comes within the jurisdiction of the Commission, the Commission exercises its discretion in conformity with the Act when making a decision whether to conduct an inquiry into a relevant matter. The consideration of a request will ordinarily follow a four-stage process, which is carried out before the decision is made.

#### **Stage 1: Does the subject matter of the request come within the competence of the Commission?**

- Is the matter a human rights matter?
- Does the matter come within the jurisdiction of the State?
- Is the purpose of an enquiry clearly linked to either:
  - a review of law and practice or
  - the Commission consulting with national or international bodies or agencies or
  - the making of recommendations to the Government or
  - the promotion of understanding and awareness of the importance of human rights

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<sup>864</sup> See Section 9(6) of the Act.

<sup>865</sup> See Sections 9(12) and 9(13) of the Act.

- Is an enquiry considered either necessary or expedient for the purpose of the performance of any of the abovementioned Commission functions (Could any of these four functions be otherwise performed in relation to the matter)?
- Is the matter one that should be more appropriately referred to another body (eg a court, tribunal or other body which can award redress or grant relief?)
- Is the matter before or likely to be before another competent body (in which case the Commission must postpone considering the request)?

## **Stage 2: Exclusionary provisions**

The Act does not allow the Commission to conduct an enquiry under Section 9(1)(b), and requires the Commission to discontinue an enquiry if any of the following circumstances apply, in the opinion of the Commission:

- is the matter to which the request relates trivial or vexatious?
- is any alleged violation of human rights manifestly unfounded?
- has the person making the request an insufficient interest in the matter concerned?
- have the human rights issues concerned been addressed and properly and finally determined by a court, tribunal or other person in whom powers are vested to award redress or grant relief in respect of the matter?

The criteria at Stages 1 & 2 must be satisfied in order for the Commission to consider exercising its discretion to conduct an enquiry into a relevant human rights matter. If these criteria are satisfied, the Commission will consider the following stages:

## **Stage 3: Issues relating to the specific complaint**

- Is the request anonymous?

- Is the information provided by the person seriously inadequate, seriously incorrect or seriously misleading?
- Has the person co-operated with the Commission in relation to the request?
- Would it be very difficult to establish facts accurately due to the lapse of time since the events complained of?
- What are the projected costs of conducting an enquiry?

#### **Stage 4: Strategic test**

- Would the enquiry fall within the priority areas of work as identified in Goal 4 of the Commission's *Strategic Plan 2007-2011*?
- Does the request relate to a right which is adequately protected in the State?
- Does the request raise urgent, long-standing or systemic human rights issues?

The Commission may exercise its discretion to conduct an enquiry under Section 9(1)(b) of the Act into a relevant matter notwithstanding that the matter does not conform to all or some of the sub-heads set forth at Stages 3 and 4 above.

#### **Discontinuance**

Persons requesting an enquiry should be aware that the Commission reserves the right to rescind the decision to conduct an enquiry and/ or to discontinue the enquiry. For example, if, having decided to conduct an enquiry into a relevant matter under Section 9(1)(b) of the Act, the Commission, in the light of information coming to its attention (including information which could have been disclosed to the Commission by the person requesting the conduct of the enquiry), considers that it would not have exercised its discretion to conduct an enquiry had it been appraised of such information at the outset, the Commission reserves the right to rescind the decision to conduct an enquiry and/ or to discontinue the enquiry. This right is in addition to that outlined at Stage 2 above.

## Appendix II      Terms of Reference

### The decision to conduct the enquiry

On 4 April 2007, having considered the nature of the enquiry request, the law on the matter, the human rights issues involved, the responses to Commission's queries and its legislation and guidelines, the Commission decided to accede to the request for an enquiry. It was of the view that the conducting of an enquiry could be considered expedient for the performance of two of its functions, as specified in the Human Rights Commission Act 2000 ("the Act"), namely:

An enquiry is considered expedient for the performance of the following relevant functions of the Commission, namely:

- (i) keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights (section 8(a) of the Act);
- (ii) the making of such recommendations to the Government as the Commission deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights in the State (section 8(d) of the Act).

The terms of reference of the enquiry are:

- to enquire into whether the State fully respected the human rights of the residents of the centre the subject of the enquiry, including through reference to whether the State provided adequate facilities and/ or services for persons with intellectual disabilities;
- to enquire into the extent to which persons with intellectual disabilities are entitled to and receive the necessary services to meet their human needs and human rights;
- to enquire into the extent to which the State's service provision to persons with intellectual disabilities has impacted on the residents of the centre the subject of the enquiry;
- to enquire into the legal bases, rationales and justifications advanced for decisions to grant or to refuse certain services to the residents of the centre;
- to consider what recommendations, if any, may be made to improve the human rights of the residents concerned.

## Important Note

It is very important to emphasise that the enquiry function of the Commission is *not* free-standing, but is linked to the performance of the specified Commission functions, in this case the functions set out in sections 8(a) and 8(d) of the Act above. As such, the enquiry will consider *only* whether the State has fully respected the human rights of the persons concerned. However, during the course of the enquiry, the Commission will not act as an adjudicatory body – it will not investigate a specific complaint against an individual which would reflect in any material way on a person’s good name or reputation. Accordingly, no evidence may be tendered during the course of the enquiry which would reflect in any material way on any particular person or discreet class of persons’ good name or reputation.

Dated \_\_\_\_\_

Signed \_\_\_\_\_  
Éamonn MacAodha  
Chief Executive

### Appendix III: Enquiry Procedure (Revised)

Pursuant to section 9(12), (13), (14) and (15) of the Human Rights Commission Act, 2000 ("the Act"), the following procedure will be followed in the course of the enquiry (subject to the need to maintain a degree of flexibility in responding to matters which may arise, as considered appropriate by the Commission):

- 1) The enquiry will be conducted in private.
- 2) The enquiry will be inquisitorial and not adversarial in nature. It will be directed towards keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights and the making of such recommendations to the Government as the Commission deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights in the State.
- 3) The enquiry will not investigate or consider a specific complaint against an individual which would reflect in any material way on a person's good name or reputation. Accordingly, no evidence may be tendered during the course of the enquiry which would reflect in any material way on any individual person or discreet class of persons' good name or reputation. As such, the enquiry will not be directed towards attributing wrong-doing to any person. Nor will the enquiry make any such findings or attribute wrong-doing to any named person.
- 4) The Commission shall discontinue the enquiry if it is of opinion, or, as the case may be, it becomes, during the course of the enquiry, of the opinion, that -
  - (a) the matter to which the request relates ("the matter concerned") is trivial or vexatious or any alleged violation of human rights concerned is manifestly unfounded, or
  - (b) the person making the request has an insufficient interest in the matter concerned.
- 5) Every effort will be made to ensure fairness of procedure, including allowing any relevant person<sup>866</sup> the opportunity to make their views known to the Commission on a matter raised in the course of the enquiry.
- 6) Upon request from the Commission, any evidence required of a person under section 9(6) of the Act will be verified in the form outlined in section 9(8)(b) of the Act; i.e. by signature of a declaration of the truth of his or her answers to any question or questions put to him or her by the Commission (other than a question or questions the answer to which may incriminate the person).

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<sup>866</sup> A relevant person includes a person who is named in the course of the enquiry and can include a Government Department, a Statutory Body, a non-Statutory Body, an official of a Statutory Body or an employee of a non-Statutory Body.

- 7) Given the private nature of the enquiry, all communications in connection with this enquiry, including the contents of any document, evidence or information produced to the Commission in the course of the enquiry, shall be regarded as confidential and shall not be disclosed to any person unless otherwise authorised by the Commission or required in accordance with law
- 8) Every effort will be made to complete the enquiry as expeditiously as possible.
- 9) The findings of the enquiry will be published.
- 10) Prior to publication, relevant sections of the enquiry's draft findings may be forwarded, on a confidential basis, to persons to whom the enquiry directly relates, for any comments they may care to make. The persons contacted will be afforded 28 days, from receipt of the relevant sections of the enquiry's draft findings, to communicate any such comments to the Commission and any such comments will be taken into account before the findings of the enquiry are finalised and published. A strict timeline will be exercised in relation to the receipt of any such comments from such persons. A strict timeline will be exercised in relation to the receipt of any such comments from such persons.
- 11) This procedure is subject to any further procedure which may be made in the course of the enquiry pursuant to section 9(12), (13), (14) and (15) of the Act and any person wishing to clarify the application of the procedure to them, should in the first instance raise the matter with the Commission's Enquiry and Legal Officer.

Dated \_\_\_\_\_

Signed \_\_\_\_\_  
Éamonn MacAodha  
Chief Executive

# SERVICE AGREEMENT

Form of Service Agreement between Health Services Executive and designated Voluntary Bodies providing services to persons with a Disability.

**THIS AGREEMENT APPLIES FROM THE 1st DAY OF JANUARY 2009**

**BETWEEN THE HEALTH SERVICES EXECUTIVE**

**-and-**

**BROTHERS OF CHARITY SERVICES GALWAY LTD.**

## **PREAMBLE**

**Whereas** the Health Services Executive (hereinafter called the "HSE") has statutory responsibility to ensure the provision of services to persons with a Disability in its functional area,

**Whereas** the Brothers of Charity Services, Galway Ltd. a designated Voluntary Body (hereinafter call the "Body") has as its purpose the provision of services to persons with an Intellectual Disability, Autism and Dual Disability.

**Whereas** the Health Acts empower the HSE to enter into arrangements with voluntary bodies to provide services, similar or ancillary to services which the HSE may provide and require the HSE to have regard to the need for co-operation with voluntary bodies providing such services,

**Now therefore the HSE and the body enter into this agreement for the provision of certain services by the body to persons with Disabilities in the functional area of the HSE for a period of one year from 1<sup>st</sup> January 2009 to 31<sup>st</sup> December 2009 or until such time as other arrangements are entered into.**

## PRELIMINARY

### **The Body and the HSE recognise and accept:**

- The right of persons with a Disability to quality services, within the limits of available resources, which respect their dignity, are provided within the least restrictive environment and aim at the greatest possible inclusion of persons with a Disability in society;
- The role of a strong and vibrant voluntary sector in the field of Intellectual Disability, Autism and Dual Disability;
- The principles underpinning the United Nations Standard Rules on the Equalisation of Opportunities for Persons with a Disability, 1993;
- The principles of equity, quality of services and accountability and the concept of health and social gain which underpin the Health Strategy *"Shaping a Healthier Future"*, 1994, the recommendations contained in the report *"Enhancing the Partnership"*, submitted to the Minister for Health & Children in December 1996.
- *Work conjointly with the HSE in meeting the legislative requirements as set out in the Health Act 2004, Education for Persons with Special Educational Needs (EPSEN) Act 2004 and the Disability Act 2005*

### **The Body hereby agrees with the HSE that:**

- It will provide certain services to persons with a Disability in the functional area of the HSE in accordance with the terms of this agreement;
- It will respect the individuality of each person with a Disability availing of its services and will promote their physical, spiritual and emotional development;
- It will provide the HSE with a confirmation of its legal status;
- The service shall be conducted in accordance with the agreed policies and objectives for Disability services in the functional area of the HSE and relevant policies and objectives of the Minister for Health & Children or the Government;
- Access to services will be determined by actual need for services and those requiring services will have them made available as soon as possible, within the terms of this agreement and subject to the availability of resources;
- It recognises the statutory role, regulatory and public accountability responsibilities of the HSE and will continue to co-operate fully with the HSE in this regard;
- It will co-operate with the HSE in the monitoring of this agreement in accordance with *"Enhancing the Partnership"*, 1996. It will develop policies and protocols, to ensure the protection of all the service users. The providers of children's services should ensure that local procedures are in line with Children First, the National Guidelines for the Protection and Welfare of Children and the Disability Act 2005.

- It will keep correct and accurate data on each client who consents to be registered on the National Intellectual Disability Database in line with the nationally agreed policies and procedures and to provide data to the HSE on all clients in receipt of services for the purposes of monitoring and tracking as and when requested.
- It will provide the HSE with a report on expenditure against budget on a monthly and quarterly basis and will alert the HSE to any serious financial difficulties that may arise between reports; as per Chapter 5, appendix 6 of *"Enhancing the Partnership"*, 1996;
- It will provide the HSE with a monthly and quarterly staff census report in line with Chapter 6 - Enhancing the Partnership, Monthly Employment Control System.
- It will maintain systems, procedures and controls which mirror the best practices of accountability in expending public funds. In this regard, the Body will develop an appropriate internal audit/service evaluation function;
- It will comply with all relevant statutory and legal obligations;
- It will provide appropriate levels of insurance cover, the details of which will be set out in the Annual Plan for Service;
- It will arrange for an annual audit of expenditure funded from the statutory sources and will supply copies of the audited accounts to the HSE by an agreed date and, on request, to the Comptroller and Auditor General;
- The Body wishing to make application for a Capital Grant, in respect of any Capital Project, undertakes to ensure that the Capital Grant will be used solely for the purpose intended and agreed. The Body agrees with the HSE to make appropriate arrangements to secure the State's interest in any project in respect of which a Capital Grant has been made available.

**The HSE agrees with the Body that:**

- It will respect the independent identity, operational autonomy and ethos of the Body;
- It will respect the Body's functions of innovation, advocacy, representation and research;
- It will recognise the Body's continuing role in service provision;
- It will agree an annual budget with the Body within a reasonable time scale in respect of the delivery of the agreed quantum of services, having regard to the level of funding made available by the HSE;
- An agreed payments arrangement will be concluded with the Body in accordance with *"Enhancing the Partnership"*, 1996;

- Funding will be by electronic transfer on a monthly basis on a day to be agreed with the Body and will represent 95% of the allocation. The remaining balance will be transferred following satisfactory review of the annual audited financial statements.
- Communication between the HSE and the Body will be as per the Communication Framework as outlined in Appendix F.

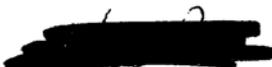
**Procedure for Resolving Problems**

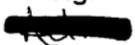
The HSE and the Body agree that any differences of interpretation of this service agreement will be resolved in accordance with the procedures outlined in Chapter 7, paragraphs 7.12 – 7.15 of *“Enhancing the Partnership”*, 1996.

**Detailed Provisions To Be Agreed Following Consultation Between The HSE and The Body.**

It is agreed that details of the matters set out hereunder will be agreed locally on an annual basis, following consultation between the HSE and the Body, and will then form part of this agreement.

1. The Quantum of Services to be provided by the Brothers of Charity Services, Galway Ltd.
2. The nature of the disability of persons with a disability for whom the Brothers of Charity Services, Galway Ltd. will provide services.
3. Policy in relation to referral, admission and discharge of clients.
4. The catchment area or areas for which the Brothers of Charity Services, Galway Ltd., will provide services.
5. The number of and category of staff employed in WTE's or to be employed by the Service.
6. Level of funding to be provided by the HSE to the Service.
7. Arrangements for an Annual Review of the Quantum of Services to be provided by the Brothers of Charity Services, Galway Ltd. and related issues, including the level of funding to be provided by the HSE in respect thereof.
8. Arrangements for the making of any modification that may be required to this Agreement.
9. A Programme of activities to be carried out by the Body in relation to enhancement of information systems, research, service evaluation, quality systems and assurance processes.

Signed:  Date: 23 - 02 - '09  
Chairman of the Board, Brothers of Charity Services Galway Ltd.

Signed:  Date: 23.2.09.  
 Chief Executive, Brothers of Charity Services Galway Ltd.

Signed:  Date: 22.12.08  
AND, on behalf of HSE

**1. The Quantum of Service To Be Provided By The Brothers of Charity Services, Galway Ltd.**

**Year: 2009.**

**1.1** Woodlands Centre is the administrative centre for all the Disability Services provided by the Brothers of Charity Services, Galway Ltd. in the HSE West, Galway PCCC.

The Brothers of Charity Services, Galway Ltd. in the HSE West Area provides services for both children and adults, males and females. The Service extends over a broad range of activities which include:

- Early Assessment Intervention, Development and Pre-School Service
- Health related Support Services for Educational Services
- Residential Care and Day Activation for Adults and Children
- Vocational Preparation, Personal Development and Independent Living
- Training
- Supported Employment Services
- Crisis Intervention and Respite Care Service
- Adult Counselling and After Care Service
- Service for Children and Adults with Autism (with/without Learning Disability)
- Care of Elderly Persons with Intellectual Disability
- Staff Training and Development Service
- Pastoral Care and Chaplaincy Service
- Family and Sibling Support
- Kilcornan Transformation Programme

The list of services referred to above is not exhaustive as persons with Intellectual Disability, Autism and Dual Disability will not always have needs identical with their peers. Nor does the above list include the whole area of disability prevention, health education and genetic counseling. However, these services are components of services which support persons with Intellectual Disability, Autism and Dual Disability their parents, guardians, siblings and carers.

**1.2** It is recognised that services for persons with a Disability are also provided by the HSE and by other voluntary bodies within the Galway PCCC Area. It is the object of the Brothers of Charity Services, Galway Ltd. to develop and promote the enhancement of the quality of life and the dignity of persons with Intellectual Disability in co-operation with the Co-ordinating Committees. It is equally recognised that the parent, families, and guardians of persons with a Disability, together with carers and the wider community in which they live, have a major part to play in ensuring that persons with a Disability can share equally in the benefits that membership of the community brings to each individual.

It is important that the services for which the Brothers of Charity Services, Galway Ltd. has a responsibility are provided in a comprehensive, effective and an efficient manner and that those who are now without a service, receive a service appropriate to their needs and that areas of weakness in the current service provision are

identified and systematically improved subject to availability of resources.

The service provided by the Brothers of Charity Services, Galway Ltd. is based on the original principles which were established at the setting up of the service, namely:

- working for inclusion with people who are marginalised;
- striving for the highest possible human dignity in our services;
- developing caring relationships and inclusive community;
- integrating the best of current trends in service provision;
- valuing a high standard of expertise;
- a progressive approach to the organisation and structure of services;
- a willingness to function within a social framework and to work in partnership with statutory bodies;
- finding final motivation in the Gospel.

It is in the context of these principles that the service has been developed and will continue to be developed.

Appendix A – Quantum of Service

Signed: \_\_\_\_\_ Date: \_\_\_\_\_  
Chairman of the Board, Brothers of Charity Services Galway Ltd.

Signed: \_\_\_\_\_ Date: 23.2.09  
Chief Executive, Brothers of Charity Services Galway Ltd.

Signed: \_\_\_\_\_ Date: 22.12.2008  
AND, on behalf of HSE

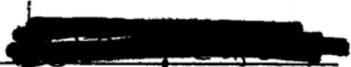
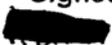
2. The Nature Of The Disability Of Persons With a Disability For Whom The Brothers of Charity Services, Galway Ltd. will Provide Services.

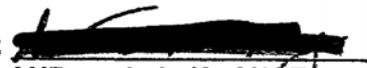
2.1 This shall be in accordance with the data held on the NIDD by the HRB on behalf of the HSE and in addition any clients not registered on the NIDD to whom services are being provided by the Body.

2.2 This is the most comprehensive source of information on service users and those awaiting a change of service or who have no service within our defined geographic catchment area in that it accurately reflects all the factors that have resource implications which are not just related to the degree of intellectual disability.

Appendix B – Client Profile

Signed:  Date: 23-02-'09  
Chairman of the Board, Brothers of Charity Services Galway Ltd.

Signed:  Date: 23.2.09  
 Chief Executive, Brothers of Charity Services Galway Ltd.

Signed:  Date: 22-12-2008  
AND, on behalf of HSE

4. The Catchment Area Or Areas For Which The Brothers of Charity Services, Galway Ltd., Will Provide Services.

4.1 Since the establishment of the Brothers of Charity Services, Galway Ltd. many other services providers have undertaken the care of persons with a Disability and many of these are either providing a limited range of services or are providing comprehensive service for discrete geographic areas. Recognising the trend towards the concentration of service provision within the defined HSE Galway PCCC Area the Brothers of Charity Services, Galway Ltd. has in the recent past, concentrated on meeting the service needs of persons from the specific PCCC Area in which their services are located.

4.2 In the HSE West Area a specific geographic sub-area of responsibility has been agreed upon, and therefore, the principal concentration is on the needs of persons from the Galway PCCC Area within the agreed geographic area assigned to the Service as outlined in the map as appropriate.

4.3 It is recognised that there are people from outside the catchment area in our service, mainly residential, for whom repatriation to their places of origin is not a realistic option at this stage.

4.4 The Administration, Discharges and Transfers Policy Document deals with the issue of referrals from outside our defined geographic catchment area and how such referrals should be handled.

Appendix C – Map and agreed catchment area

Signed:  Date: 23-02-'09  
Chairman of the Board, Brothers of Charity Services Galway Ltd.

Signed:  Date: 03.2.09  
 Chief Executive, Brothers of Charity Services Galway Ltd.

Signed:  Date: 22.12.2008  
AND, on behalf of HSE

3. Policy in Relation to Referral, Admission and Discharge of Clients:  
Policy on Admissions, Discharges and Transfers (A.D.T.)

This is a list of headings that, *inter alia*, the Admissions, Discharges and Transfers Policy should cover:

- Referrals
- Catchment Areas
- Criteria for determining admissions to the Brothers of Charity Services, Galway Ltd. (Residential or Day)
- General Criteria applicable to all aspects of the service:
- Specific Criteria applicable to individual services
- Assessment and Guidance Services
- Child Development, Early Services, Pre-School and School
- Respite Services
  - Planned:
  - Unplanned / Emergency:
  - Community Respite
- Part-time Residential Services
- Crisis Intervention
- Challenging Behaviour
- Discharge Criteria
- Mechanism for Securing and Channeling Reports on Individual Applicants
- Mechanism for Securing and Channeling Transfers between Residential Settings and/or Day Services
- ADT Team Membership
- General Administrative Procedures.
- Management of Waiting Lists
- Terms of Reference for the ADT Team

**General Policy and Procedures**

- Client Protection Procedures

Signed: \_\_\_\_\_ Date: 23-02-09  
Chairman of the Board, Brothers of Charity Services Galway Ltd.

Signed: \_\_\_\_\_ Date: 03.2.09.  
Chief Executive, Brothers of Charity Services Galway Ltd.

Signed: \_\_\_\_\_ Date: 22-12-2008  
AND, on behalf of HSE

## Appendix V: Employment Trends in the Public Health Service

Date	Medical/ Doctor	Nursing	Health and Social Care Professional	Management/ Admin	General Support Staff and Other Patient & Client Care	Total
31/12/1997	4,976	27,332	5,969	8,815	20,705	67,797
31/21/1998	5,123	26,611	6,422	9,478	21,973	69,638
31/12/1999	5,385	27,044	6,831	10,555	22,928	72,744
31/12/2000	5,698	29,177	7,613	12,366	25,216	80,070
31/12/2001	6,285	31,429	9,228	14,714	28,645	90,302
31/12/2002	6,775	33,395	12,557	15,690	27,242	95,679
31/12/2003	6,792	33,766	12,692	15,766	27,485	96,501
31/12/2004	7,013	34,313	12,830	16,157	28,410	68,723
31/12/2005	7,266	35,248	13,952	16,699	28,812	101,978
31/12/2006	7,712	36,737	14,913	17,262	29,648	106,273
31/12/2007	8,005	39,006	15,705	18,043	30,746	111,505
31/12/2008	8,109	38,108	15,980	17,967	30,861	111,025
<b>% change</b>	<b>63%</b>	<b>39%</b>	<b>168%</b>	<b>104%</b>	<b>49%</b>	<b>64%</b>

Source: Letter from the Department of Health to the Commission dated 14 December 2009

Notes: (1) Excludes Homes Helps. (2) Student nurses are included in the 2007 and 2008 employment ceilings on the basis of 3.5 students equating to 1 whole time equivalent. The employment levels adjusted for student nurses on the above basis are 110,664 WTEs (Dec 07) and 111,001 WTEs (Dec 08). (3) The categories of General Support Staff and Other Patient & Client Care have been combined to enable comparison.





**FUTURE SERVICE REQUIREMENTS**

**REQUIRED DAY SERVICES**

- 70. Type of day service (1) required |\_\_|
- 71. Level of support required in day service (1) 0. 1. 2. 3. 4. 5.
- 72. Year in which day service (1) is required |\_\_|\_\_|\_\_|
- 73. Primary reason for duplication on current and future day service (1) |\_\_|
- 74. Type of day service (2) required |\_\_|
- 75. Level of support required in day service (2) 0. 1. 2. 3. 4. 5.
- 76. Year in which day service (2) is required |\_\_|\_\_|\_\_|
- 77. Primary reason for duplication on current and future day service (2) |\_\_|

**CONTINGENCY DAY SERVICES**

- 81. Type of day service required - contingency plan |\_\_|
- 82. Level of contingency plan day support required 0. 1. 2. 3. 4. 5.
- 83. Primary reason for duplication on current and contingency day service |\_\_|
- 84. Primary reason for duplication on future and contingency day service |\_\_|

**RESIDENTIAL SERVICES**

- 85. Type of residential service (1) required |\_\_|\_\_|
- 86. Level of support required in residential service (1) A. B. C. D. Z.
- 87. Year in which residential service (1) is required |\_\_|\_\_|\_\_|
- 88. Primary reason for duplication on current and future residential service (1) |\_\_|
- 89. Type of residential service (2) required |\_\_|\_\_|
- 90. Level of support required in residential service (2) A. B. C. D. Z.
- 91. Year in which residential service (2) is required |\_\_|\_\_|\_\_|
- 92. Primary reason for duplication on current and future residential service (2) |\_\_|

**CONTINGENCY RESIDENTIAL SERVICES**

- 93. Type of residential service required - contingency plan |\_\_|\_\_|
- 94. Level of contingency plan residential support required A. B. C. D. Z.
- 95. Primary reason for duplication on current and contingency residential service |\_\_|
- 96. Primary reason for duplication on future and contingency residential service |\_\_|

97. HSE area responsible for funding future services |\_\_|\_\_|

**DAY SUPPORT LEVEL CODES**

Coding for variables 42, 46, 50, 71, 75 & 82

- 0: NOT APPLICABLE
- 1: MINIMUM (staff to client ratio is 1 to 10+)
- 2: LOW (between 1 to 6 and 1 to 9)
- 3: MODERATE (between 1 to 4 and 1 to 5)
- 4: HIGH (between 1 to 2 and 1 to 3)
- 5: INTENSIVE (1 to 1 or above)

**RESIDENTIAL SUPPORT LEVEL CODES**

Coding for variables 56, 59, 86, 90 & 94

- A: MINIMUM (no sleep-in)
- B: LOW (staff on duty most of the time plus sleep-in)
- C: MODERATE (two staff on duty plus sleep-in)
- D: HIGH (two staff on duty plus on-duty night staff)
- Z: NOT APPLICABLE

**ADDITIONAL INFORMATION**

100. Date of completion/review |\_\_|\_|-|\_\_|\_|-|\_\_|\_|\_|\_|\_|

101. Person responsible for update of form \_\_\_\_\_ |\_\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

102. Unit/Centre of person responsible \_\_\_\_\_ |\_\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

103. Agency returning record |\_\_|\_|\_|\_|\_|\_|\_|\_|\_|

104. HSE area returning record |\_\_|\_|

105. Local Health Office returning record |\_\_|\_|

106. Date consent received |\_\_|\_|-|\_\_|\_|\_|-|\_\_|\_|\_|\_|\_|

106a. Consent Reason Awaiting  Consent Received  Refused

107. Reason for removal |\_\_|\_|

If transferred (1) please indicate: to HSE |\_\_|\_| to LHO |\_\_|\_| to Agency |\_\_|\_|\_|\_|\_|\_|\_|\_|\_|

If deleted (3) please indicate:

<input type="radio"/> Emigrated	<input type="radio"/> Parents' request
<input type="radio"/> Service no longer required	<input type="radio"/> Client's request
<input type="radio"/> To NPSDD	<input type="radio"/> Duplication between HSE areas
<input type="radio"/> Other reason	<input type="radio"/> Duplication within HSE area

108. Date of removal |\_\_|\_|-|\_\_|\_|\_|-|\_\_|\_|\_|\_|\_|

**NATIONAL PERFORMANCE INDICATOR (NPI)**  
To be completed for all people in full-time residential services (codes 115 to 172)

200. **NPI:** Does this person have a written Person-Centred Plan? |\_\_|\_| 1=yes 2=no

**SERVICES CODED AS "OTHER"**

If a day service or residential service is coded as "Other" please provide the question number and a text description of each "Other" service below.

**Question number/Text description**

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## Appendix VII

## Residential Services at the Centre

**Table 1: On campus residential services provided at St. Stephen's and the Maples (St. Michael's and Agnes's)**

	St. Stephen's	St Michael's	St. Agnes's
Total number of service users	10 (2 Sh)*	6+1	7
Male	7	2	2
Female	3	5	5
Number of bedrooms	8	7	7
Number of service users sharing bedrooms	2	1	2
Number of bathrooms	3	2	2

\* Sharing

**Table 2: On campus residential service provide at Radharc na Mara (St. Teresa's, St Aiden's, St. Francis' and St. John's) and the Meadowview apartment.**

	St. Teresa's	St. Aiden's	St. Francis'	St. John's	M Apt*
Date built	1979	1979	1979	1979	2002
Total number of service users	4 (1 Pt)**	1	4	3	1
Male	3		4	3	1
Female	1	1			
Number of bedroom	5	3	4	5	1
Number of service users sharing a bedroom	0	0	0	0	0

\* Meadowview Apartment

\*\* Part time

**Table 3: Respite services provided at the Centre**

	Eden House
Total	16
Male	8
Female	8
Number of persons staying in Eden House at any one time	5-6
Number of persons receiving respite, who are on residential waiting list	12
Number of years each persons above has been on the permanent residential waiting list	1-12
Number of bedrooms	7
Number of persons sharing bedroom at any one time	0
Number of bathrooms	3