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EXECUTIVE SUMMARY

Introduction

The adoption of a "rights-based approach" in legislation has come to constitute a core element being sought by groups representing people with disabilities and those working with them. This study seeks to contribute to this on-going debate by clarifying some key issues and informing the Irish discussion by a review of some relevant experience elsewhere.

Interpreting Economic and Social Rights

Current consideration of the rights-based approach to services for people with disabilities is taking place within a much broader debate about economic and social rights, in Ireland as elsewhere. This study brings out first that the assumption which often seems to underlie arguments from both proponents and opponents, that adopting a rights approach has a clear and transparent interpretation, is not in fact warranted. A variety of approaches to delivering services, framing entitlements and instituting enforcement mechanisms can legitimately be seen as arising from a rights perspective.

Constitution and Legal Protection of Economic and Social Rights

In Ireland, the status of economic and social rights has been debated particularly in the context of the Constitution. The Constitution Review Group's majority decision against incorporation of new economic and social rights was driven by the arguments that this would be an encroachment on democracy, transferring power from elected representatives to the judiciary, with unwarranted and/or unpredictable resource implications. On the other hand, the recognition of economic and social rights in the Constitution, or in law, is argued by some proponents not to confer absolute personal rights regardless of cost.

It seems commonly taken for granted in the Irish debate that there is an integral link between rights and justiciability. However, at the conceptual level rights need not necessarily be associated with the ability to have recourse to the courts, and in practice there may be alternative effective enforcement mechanisms.

Disability and Rights

The logic of the rights-based approach is widely argued to apply with particular force in the area of disability, with the Report of the Commission on the Status of People with Disabilities (1996) establishing the rights-based approach as the framework of reference. The perceived failure to base the Disability Bill presented

to the Oireachtas in 2001 on an explicit rights foundation was critical to the government's decision to undertake a further consultation process. The proposals for core elements of a revised Disability Bill published by the Disability Legislation Consultation Group (DLCG) in February 2003 see a rights-based approach as central.

Rights and Services

In terms of services, the DLCG propose that the individual's needs across the range of service areas are to be assessed independently, that the services identified as needed by that assessment should then be made available as a right, and that together with other rights to be set out in the legislation this should be justiciable. If the services one has been identified as needing are not made available, then one can – ultimately – go to court to enforce that right against the State. Under these proposals, decisions about service provision and consequently resource allocation would be made by professionals and the courts, without reference to the Oireachtas or the availability of resources. The framing of economic and social rights advanced by some proponents is more qualified, with an emphasis on "progressive realization" of these rights and on the State taking "reasonable steps to promote the general and progressive enjoyment" of economic and social rights "in view of actual conditions, resources and standards".

A Comparative Perspective

To inform the Irish debate, the study reviews structures and approaches in a number of other rich countries to the provision of services and advocacy to people with disabilities. The countries covered are the USA, Australia, New Zealand, Sweden and the UK, which share with Ireland a legal structure based on common law, so lessons of most direct relevance to Ireland can be learned. None of these countries has independent assessment of need carrying with it justiciable rights to services. In the USA people with disabilities may have a right to assessment by statutory and local government health care and social services providers, but only in relation to the services those agencies provide. Anti-discrimination legislation does not provide a generalised right to a particular health or support service or standard of service for those with disabilities. In Australia, classes of services to be provided to people with disabilities and standards to be met in the delivery of those services are set by the relevant Minister, in the light of available resources. New Zealand has a needs assessment and co-ordination system which assesses needs without reference to resource availability, but these assessments do not entitle people to the services identified as needed: the distinct Service Co-ordination function is responsible *inter alia* for rationing. In Sweden, social rights covering health and social services are enshrined in law, but in practice the services available differ substantially from one area to the next. In the UK, entitlement to services is based largely on eligibility criteria set at local level and assessment of need carried out by the relevant local authority setting

those criteria. Councils are obliged to assess everybody who presents as needing their services, regardless of resources. Councils thereafter have to meet the person's "reasonable needs", they must have transparent eligibility criteria that enable them to prioritise what needs it is reasonable to meet, and in establishing those criteria they can take resources available into account.

Transparency and Entitlement

It may be possible to make progress incrementally in this area in Ireland while leaving the most hotly contested issues, relating to justiciability and ultimate control of resources in particular, to one side.

It would be a significant advance if:

- the state, through the relevant authorities, set out clearly what level of service provision the current level of resources is intended to underpin;
- people with disabilities not only knew what this level of service provision was at individual level, but had an entitlement to those services with associated enforcement mechanisms;
- it was also set out in concrete terms how services are to be improved over time as more resources become available.

While this would have to overcome real practical difficulties, if achievable it could empower the individual, provide a lever to promote efficiency, greatly increase capacity to make long-term planning and resource allocation decisions, and lead to a much better informed public debate and political process in addressing those issues.

1. INTRODUCTION

Services for people with disabilities have come towards the forefront of public debate in Ireland in recent years. Not only the extent and nature of the services themselves but also the basis on which they are made available has become a central focus of attention. In particular, the adoption of a "rights-based approach" in legislation now constitutes a core element being sought by groups representing people with disabilities and those working with them. The perceived failure to base the Disability Bill presented to the Oireachtas in 2001 on an explicit rights foundation was critical to the government's decision to undertake a further consultation process, and new legislation in this area is expected shortly. What implications does adoption of a rights approach have, in particular for people's entitlements to services and how those are enforced?

While it is in the area of disability that these issues are first being addressed in very concrete terms, this is part of a much broader debate about economic and social rights in Ireland and elsewhere. The approach adopted in the disability services area may well have implications for many other areas of economic and social policy, reinforcing the importance of careful consideration of the principles involved at this stage.

This study seeks to contribute to this debate by clarifying some of the key issues and informing the Irish discussion by a review of some relevant experience elsewhere. Before coming specifically to the area of disability, we begin by setting out in Chapter 2 the broad thrust of the debate about economic and social rights and the international context in which it is taking place. We see that the language of rights is increasingly being applied in the economic, social and cultural spheres, but this still leaves open critical questions as to how these are to be interpreted and protected. In Ireland, the issue of incorporating economic and social rights has been extensively debated in the context of the Constitution. The related question of the legal status of economic and social rights, and in particular whether it should be possible to vindicate them in a court of law, has come to dominate the Irish debate.

Chapter 3 turns to the application of these arguments in the area of services for people with disabilities in Ireland. (Other significant issues in relation to disability, and disability legislation, such as employment or accessibility of transport and buildings are outside our scope.) We first describe the evolution of perspectives on disability away from the medical model towards seeing people with disabilities as having rights including the right to participate fully in society, a fundamental shift in thinking worldwide. We look at how

this has been reflected in international instruments, and at how it has filtered through to Ireland. The centrality of the rights approach in recent Irish debates about legislation in the disability area is then discussed. Most concretely, the rights approach plays a central role in proposals presented by the Disability Legislation Consultation Group (DLCG), made up of umbrella groups and organizations in the disability sector, as part of the consultation process undertaken in 2002. We discuss the implications of the way they envisage that approach being operationalised in relation to services.

In order to inform the Irish debate, we then turn in Chapter 4 to a review of structures and approaches in a number of other rich countries to the provision of services and advocacy to people with disabilities. The countries covered, namely the USA, Australia, New Zealand, Sweden and the UK, share with Ireland a legal structure based on common law. We look in particular at the way these countries approach assessment of needs, provision of services, appeals and enforcement, and advocacy.

Chapter 5 concludes by highlighting the key findings of the study and attempting to tease out their implications for applying a rights approach to improve services for people with disabilities in Ireland. It emphasises in particular the importance of clearly identifying the levels of service provision the current resources allocated are intended to underpin, and discusses framing these as entitlements. This could provide a basis for progressively improving services and entitlements over time as further resources become available.

2. ECONOMIC AND SOCIAL RIGHTS

2.1 Introduction

Current consideration of the rights-based approach to services for people with disabilities is taking place within a much broader debate about economic and social rights, in Ireland and elsewhere. Before coming specifically to the area of disability, it is necessary to first set out the broad thrust of this debate, and the international context in which it is taking place. We look first in this chapter at how the language of rights is increasingly being applied in the economic, social and cultural spheres as well as the more traditional application to civil and political spheres. We then sketch in key aspects of the development of the rights approach to economic, social and cultural issues at UN, Council of Europe and European Union level, and look at the recent criticisms by the UN Committee on Economic, Social and Cultural Rights that have focused on the legal status of economic and social rights in Ireland. We then describe the institutional context and setting in which these debates are taking place in Ireland, and the manner in which economic, social and cultural rights have been debated particularly in the context of the Constitution. We bring out how aspiring to recognise economic and social rights still leaves open critical questions as to how these are to be interpreted and protected, and focus on the relationship between rights, resources and justiciability.

2.2 Widening the Domain of Rights

The traditional divide between political and civil rights on the one hand, and economic, social and cultural rights on the other, has been increasingly called into question by those arguing for a broadly-based "rights approach" to economic and social issues. Civil and political rights relating to liberty of the person, property rights and the right to vote have been developing in many countries since the eighteenth century. These are now generally uncontested in principle in the countries of the European Union, though their application of course continues to raise complex issues and concerns at the margin in individual cases. By contrast it is only relatively recently – from around the middle of the 20th century –

that the terminology of economic and social rights has come into vogue, with the extension to cultural rights even more recent.[1]

In effect, it was the development of the welfare state that gave rise to the notion of economic and social rights. As health, education and welfare provision developed, the state came to be seen as having obligations to its citizens in these areas – or putting it another way, citizens came to be seen as having legitimate expectations, entitlements, or "rights" in that regard. Precisely what this means in practice of course varies a great deal across countries, depending on the extent and nature of the welfare state and on the legal system. Broadly speaking, though, when we say someone has a "right", we generally mean both that they have an entitlement and that there is a corresponding duty imposed on someone else or, most often, on the state to deliver on or uphold that entitlement. This means that, as Daly (2002) has put it,

> *Rights, then, are an expression of a public consensus on the entitlements and duties of different parties, but especially between individuals and the state* (p. 1).

Increasingly, the case is put for legal and constitutional protection to be extended from political and civil rights to include economic, social and cultural rights. Apart from the intrinsic importance of economic, social and cultural rights, this is argued on the basis that if they are not equally protected then the enjoyment of civil and political rights is not effective. (Homeless people will find it more difficult to vote, for example.) Civil and political rights are thus not independent of economic, social and cultural rights. Similarly the sharpness of the distinction between political and civil rights on the one hand and economic, social and cultural rights on the other has been questioned. Neither can be established and defended without incurring significant costs, for example, and defending civil and political rights is not necessarily neutral in distributional terms. It is the question of how rather than whether economic, social and cultural rights should be recognised, in particular via the types of constitutional and legal mechanisms employed to protect political and civil rights, that is most contentious, as we will see. First, though, it is worth sketching in the background in terms of the development of international instruments in this area.

2.3 The International Context

The international context in which the "rights approach" to economic, social and cultural issues is being debated in Ireland is important, and includes UN, Council of Europe and European Union dimensions. The principle of the universality, interdependence and inter-relation of all human rights has been accepted by the United Nations for many years. Economic, social and cultural rights have already been enumerated in a variety of

[1] It is of course not notions of core entitlements and obligations in the economic and social sphere, but rather framing them in rights terminology, that is this recent.

international conventions and other instruments to which Ireland subscribes. Supplementing the United Nations Declaration on Human Rights, the UN International Covenant on Economic, Social and Cultural Rights (UNCESCR) enumerates for example the right to work and to just working conditions, to social security, to freedom from hunger, to enjoyment of the highest attainable standard of physical and mental health; to an adequate standard of living, to adequate housing, to education, and to exercise of these rights without discrimination. At present, unlike many other UN human rights treaties, there is no individual or group complaints system under the UNCESR. The UN Committee on Economic, Social and Cultural Rights, a committee of appointed experts meeting in Geneva, regularly reviews developments in the countries which are parties to the Covenant, and its recent comments on Ireland have received a good deal of attention, as we discuss shortly. In addition, a draft Optional Protocol providing for individual and group complaints is currently being debated within the UN system.[2]

Turning to the Council of Europe, the European Convention on Human Rights (ECHR), which protects civil and political rights, was signed by Ireland in the 1950s but has only recently been incorporated into Irish law (following on the 1998 Belfast Agreement). The ECHR, which Ireland helped to draft, sometimes gives rise to positive state obligations, with cases based on it ruled on by the European Court requiring various forms of positive action which have had a resource cost for states, including Ireland (notably in the 1979 Airey case). This brings out that vindicating civil and political rights, as well as economic and social ones, may well have resources implications.

Supplementing the European Convention on Human Rights is the European Social Charter, adopted by the Council of Europe in 1961 and revised in 1996, aimed at protecting fundamental social and economic rights. The revised Charter, which came into force in 1999, recognises the right to for example social security, decent affordable housing, accessible and effective health care, free primary and secondary education, employment, protection against poverty and social exclusion, and the right of disabled persons to social integration, independence and participation in the life of the community. The Social Charter has been an influential point of reference both at national and European Union levels. There is a formal mechanism whereby the expert Committee of Social Rights, appointed by the Council of Europe Council of Ministers, monitors and reports on whether countries are honouring the undertakings set out in the charter, based on regular reports submitted by the country in question. There is also provision for a collective complaints procedure whereby recognised organisations including

[2] Ireland recently joined in a common EU position to agree to set up a Working Group within the EU to study the drafting of such a Protocol – which does not represent a commitment to adopt the Protocol if it is produced (see Irish Human Rights Commission 2003a).

employers' and unions' federations and certain non-governmental organisations may lodge complaints about specific features with the Committee.

At European Union level, the Amsterdam Treaty stresses respect for fundamental rights, especially those guaranteed by the European Convention on Human Rights (ECHR), but also defines social rights held to be fundamental, by reference in particular to the European Social Charter and the 1989 Community Charter of the Fundamental Social Rights of Workers. These fundamental social rights mainly concern employment, living and working conditions, social protection, social dialogue and the combating of exclusion. That Treaty incorporated the Social Chapter previously agreed by 14 Member States (excluding the UK), and Article 136 reaffirms that social policy is a competence which the European Community shares with the member states.

In June 1999, the European Council meeting in Cologne established a Convention tasked with drafting a Charter of Fundamental Rights for the European Union. It reported to the European Council in Nice in December 2000, when the Charter was promulgated as a political declaration.

The Charter draws together rights as they result, in particular, from the constitutional traditions and international obligations common to the Member States, the Treaty on European Union, the Community Treaties, the European Convention for the Protection of Human Rights and Fundamental Freedoms, the social charters adopted by the European Union and by the Council of Europe and the case-law of the EU Court of Justice and of the European Court of Human Rights.

The Charter includes chapters on: Dignity (including the right to life and the prohibition of torture); Freedoms (including respect for family life, freedom of religion and the right to education); Solidarity (including workers' rights to information and consultation and to fair and just working conditions); Citizens' Rights (including the right to vote and stand in European elections and the right to good administration); and Justice (including the right to an effective remedy and a fair trial and to the presumption of innocence). Its final chapter contains provisions of general application which define the extent of its scope and application. These make it clear that the Charter applies to the institutions of the European Union and to the Member States only when they are implementing EU law.

The European Council at Laeken in 2001 established a new Convention to bring forward recommendations for a Constitutional Treaty for the European Union. One of the questions it was asked to consider was whether the Charter should be incorporated in this new Treaty. The European Convention met from February 2002 until July 2003. It recommended that, if the Charter is to be included in the new Treaty, a number of important amendments should be made to its general provisions to ensure greater legal clarity and certainty as to its effect. In particular, the amendments it recommended would make it clear that the Charter respects the limits of the powers conferred on the Union by the Member States

and does not extend their scope. The Irish Government welcomed the important and positive work done by the Convention towards ensuring that agreement can be reached on its incorporation.

The draft Constitutional Treaty prepared by the European Convention included the Charter as an integral part of the new document. The draft as a whole is now being considered by an Intergovernmental Conference, drawing together representatives of the governments of Member States and of those countries that will shortly join the Union.

2.4 Ireland and the UN Covenant

We saw in the previous section that the UN Covenant on Economic, Social and Cultural Rights (UNCESCR) has a formal monitoring mechanism whereby the expert Committee on Economic, Social and Cultural Rights, meeting in Geneva, regularly reviews developments in the countries which are parties to the Covenant. This review is based on a report prepared and submitted by the relevant government, as well as inputs by non-governmental groups. In its most recent comment on Ireland, this Committee expressed concern that "a human rights based approach" had still not been adopted in the National Anti-Poverty Strategy. It argued that Ireland has an obligation to make the Covenant rights enforceable in domestic legislation, and a legal obligation to integrate economic, social and cultural rights into the Anti-Poverty Strategy (UNCESCR 2002a).

Before turning to the domestic debate about economic, social and cultural rights, it is worth putting this international commentary on Ireland into context by noting that the Committee regularly makes similar criticisms and recommendations in relation to a wide range of other countries, including some which in other respects are regarded by the Committee as performing particularly well in safeguarding the rights enshrined in the Covenant. In commenting on Australia at its most recent examination, for example, the Committee expressed concern that:

> *In spite of existing guarantees pertaining to economic, social and cultural rights in the State party's domestic legislation, the Covenant continues to have no legal status at the federal and state level, thereby impeding the full recognition of and applicability of its provisions. ...The Committee regrets that, because the Covenant has not been entrenched as law in the domestic legal order, its provisions cannot be invoked before a court of law. The Committee strongly recommends that the State party incorporate the Covenant in its legislation, in order to ensure the applicability of the provisions of the Covenant in the domestic courts.* (UNCESCR 2000.)

The Committee also urged Sweden, for example, "to take appropriate steps to give full effect to the Covenant in its legal system, so that the rights covered by it may be directly invoked before the courts." (UNCESCR 2001). In its observations on Canada, the Committee urged "the Federal Government to take concrete steps to ensure that the provinces and territories are made

aware of their legal obligations under the Covenant and that the Covenant rights are enforceable within the provinces and territories through legislation or policy measures and the establishment of independent and appropriate monitoring and adjudication mechanisms." (UNCESCR 1998a.)

The Committee's comments in relation to the UK are particularly relevant given the similarity between its legal structures and Ireland's. In its most recent report on the UK the Committee

> *...deeply regrets that, although the State party has adopted a certain number of laws in the area of economic, social and cultural rights, the Covenant has still not been incorporated in the domestic legal order and that there is no intention by the State party to do so in the near future. The Committee reiterates its concern about the State party's position that the provisions of the Covenant, with minor exceptions, constitute principles and programmatic objectives rather than legal obligations that are justiciable, and that consequently they cannot be given direct legislative effect. Affirming the principle of the interdependence and indivisibility of all human rights, and that all economic, social and cultural rights are justiciable, the Committee ... strongly recommends that the State party re-examine the matter of incorporation of the International Covenant on Economic, Social and Cultural Rights in domestic law. The Committee points out that, irrespective of the system through which international law is incorporated in the domestic legal order (monism or dualism), following ratification of an international instrument, the State party is under an obligation to comply with it and to give it full effect in the domestic legal order.* (UNCESCR 2002b.)

Issues relating to incorporation in domestic law are raised even in relation to Denmark, where the Committee noted "the high level of achievement by Denmark of its obligations in respect of the protection of the rights set forth in the Covenant". The Committee "commends the State party's long tradition of respect for human rights," but then "regrets that the Covenant has not been incorporated in domestic law". It notes that, although the provisions of the Covenant may be directly invoked before the courts or referred to by the courts, there is no case law as yet. In this respect, the Committee expresses concern that lawyers and judges "may not be sufficiently aware that the rights enshrined in the Covenant may be invoked before the courts." (UNCESCR 1999.)

The issue of the legal status of economic and social rights and of the UN Covenant itself is thus far from unique to Ireland. It is clear that many other countries, particularly ones in broadly the same legal tradition as Ireland, have taken a rather different attitude to these issues than the UN Committee. This is an evolving area, both in terms of the interpretation of states' international legal obligations and the response of different countries. There is no reason why Ireland should not aim to be in the forefront in this respect, but simply focusing on the Committee's remarks in relation to Ireland misses our comparative position entirely.

It is worth noting that the Irish Human Rights Commission, in recently-published Observations specifically in the area of disability

legislation to which we will be turning shortly, has addressed the implications of the CESCR. These spell out first that domestic constitutional or legal obstacles are not a defence (at least at the level of international law) with respect to non-performance of a state's treaty obligations. The conclusion is also reached that "there is a strong presumption in favour of legal remedies under the CESCR" (Human Rights Commission 2003a). It is noted that General Comment 9 of the CESCR (UNCESCR 1998b) leaves open the door to the possibility of equally effective administrative remedies, but these must be "accessible, affordable, timely and effective", and that an ultimate right of judicial appeal would also often be appropriate.

The focus on the purely legal aspects of the protection of economic and social rights is clearly a partial one, and the UN Committee in its reports does indeed pay considerable attention to the concrete situation of particular groups in specific countries (albeit in a rather variable way). The broader point to be emphasised is there may be little or no direct correlation between explicit constitutional or legal protection for such rights and the concrete situation of people living in the country. Countries which have attained a very high level of economic and social protection and provision for their citizens may have these rights less firmly enshrined in purely constitutional and/or legal terms than others attaining lower levels of protection in practice. As Daly (2002) has noted, access to social rights cannot be read off from the legal framing or status of the right. Furthermore, the direction of causation historically is important: the extent to which such rights are protected in constitutional and/or legal terms may as often reflect as lead the level of concrete protection and provision "on the ground". This does not mean that legal and constitutional status is unimportant or irrelevant, but they are important considerations to keep in mind as we turn to recent debates about enshrining economic and social rights in the Irish Constitution.

2.5 The Domestic Institutional Context

Certain economic and social rights are already recognised in the Irish Constitution. Specifically, the Constitution holds that all persons are to be held equal before the law, guarantees to protect the family, obliges the State to provide for free primary education, and recognises the right to private property in Articles 40, 41, 42 and 43 respectively. In addition, Article 45 sets out "Directive Principles of Social Policy", which are intended for the guidance of the Oireachtas and are not cognisable by the courts. These state for example that the State shall direct its policy towards securing that citizens "may through their occupations find the means of making reasonable provision for their domestic needs", and that "the State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged". The Constitutional obligation on the State to provide free primary education has been the subject of significant judicial activity

of late, particularly relevant to the area of disability. A number of findings based on this article have supported those seeking provision of services not hitherto made available to them by the State. This has, in all likelihood, contributed to the focus of the Irish debate on economic and social rights on the question of justiciability. However, most recently the Supreme Court has struck down decisions of lower courts which appeared to broaden the interpretation of this provision; has questioned the idea that implied socio-economic rights could be found in the Constitution; and has limited the role of the courts on the grounds of the separation of powers between the legislature and the judiciary.

Going beyond the Constitution, in Ireland as elsewhere a substantial range of socio-economic rights are protected by legislation, covering for example employment protection, health and safety at work, and gender equality. Most recently the Employment Equality Act, the Equal Status Act and the Education (Welfare) Act have been officially described in the Review of the National Anti-Poverty Strategy (2002) as "strengthening the rights available to the citizen", and the same could be said of the recently-introduced minimum wage. That Review goes on to say that "The Government is also committed to developing a strong infrastructure to promote and protect a range of rights", instancing the establishment of the Equality Authority, the National Disability Authority, Comhairle and the Human Rights Commission.

The Employment Equality Act (1998) outlaws discrimination in the workplace on nine stated grounds, including disability. The Equal Status Act (2000) complements it by giving protection against discrimination in non-workplace areas such as education, the provision of goods, services and accommodation and the disposal of property. The Equality Authority is an independent body set up in 1999 under the Employment Equality Act 1998, replacing the Employment Equality Agency with an expanded role and functions, to promote and defend the rights established in the equality legislation. A separate equality tribunal (ODEI, the Office of the Director for Equality Investigations) investigates or mediates complaints of unlawful discrimination under both employment equality and equal status legislation.

The National Disability Authority (NDA) was established as an independent statutory agency in 2000, to advise the Minister for Justice, Equality and Law Reform on disability issues, to engage in research and the development of standards and codes of practice for programmes and services for people with disabilities, and to monitor their implementation. Comhairle, a statutory agency set up in 2000 under the Department of Social and Family Affairs, is the national support agency responsible for the provision of information, advice and advocacy to members of the public on social services.

The Human Rights Commission was established in 2001 charged with the promotion, protection, and development of human rights not only in the Republic of Ireland but jointly with the Northern Ireland Human Rights Commission in the island of Ireland. Its

responsibilities include reviewing the adequacy and effectiveness of law and practice relating to the protection of human rights; making recommendations to Government on measures to strengthen, protect and uphold human rights; and taking legal proceedings to vindicate human rights or providing legal assistance to persons in that area. It has responsibility not only for examining law and practice with reference to human rights and fundamental freedoms contained in the Irish Constitution but also the European Convention on Human Rights, the UN Conventions on Civil and Political Rights and on Economic, Social and Cultural Rights, and a variety of other international conventions and agreements ratified by the state. In its recently adopted strategic plan the Human Rights Commission (2003b) announced that economic, social and cultural rights would constitute a key area of its work.

2.6 The Domestic Debate

At one level, depending on how one interprets "rights", the broadening of the rights agenda has already met with a significant degree of acceptance in Ireland as in other EU members. The National Economic and Social Council, for example, stated in 1999 that social inclusion is essentially about full participation in society and that such participation is dependent on access to "citizenship rights", going on to make clear that:

> *When we refer to citizenship rights and obligations we include not only widely taken-for-granted civil and political rights and obligations but also social, economic and cultural rights that guarantee equality of opportunity and access to education, employment, health, housing and social services.* (1999, p. 77).

In a similar vein the official government position as stated in the recent Review of the National Anti-Poverty Strategy (NAPS 2002) is that:

> *Citizenship rights encompass not only the core civil and political rights and obligations but also social, economic and cultural rights and obligations that underpin equality of opportunity and policies on access to education, employment, health, housing and social policies* (2002, p. 20).

The National Economic and Social Council's more recent report *An Investment in Quality: Services, Inclusion and Enterprise* (2003) reaffirms the importance of economic, social and cultural rights, and goes on to present some very useful reflections on the meaning and institutionalisation of rights. It notes for example that an air of "absolutism" can attend rights discourse, with the language of rights expressing claims in a way that seems to allow for no balancing or compromise, whereas the assertion of rights cannot provide an escape from scarcity, trade-offs, and conflicts between rights. It draws the distinction between moral versus legal rights: to say someone has a moral right to something does not necessarily mean that they should have a legal right to it, since there are many policy and institutional ways in which something may be secured for someone without them having a legal right to it. Socio-economic

rights often imply significant redistribution of resources, and their protection depends on widespread public support. Rights are thus continually being negotiated and renegotiated, interpreted and reinterpreted as part of the democratic process. The procedures and institutions that protect civil and political rights may or may not then be appropriate, effective or legitimate in securing economic, social and cultural rights.

So the crux of the matter that is currently contested, in Ireland as elsewhere, is not whether economic, social and cultural rights should be recognised but rather what these rights should comprise and how they should be underpinned. In particular, much of the debate in Ireland has been focused on the appropriateness of constitutional and legal recognition of economic, social and cultural rights. This was among the issues addressed by the Constitution Review Group set up by the government in 1995 to review the Constitution and establish areas where constitutional change was necessary or desirable.

The Report of the Constitution Review Group, published in 1996, devoted considerable attention to the question of incorporation of economic and social rights in the Irish Constitution. It addressed in particular "whether there should be a right to freedom from poverty and social exclusion" and "whether there should be provision for specific economic rights as a counterweight to economic inequality". A number of arguments for and against were set out, and these illustrate some central elements in the broader debate about these issues in Ireland (as elsewhere).

The arguments advanced in favour include

- because Ireland is a relatively wealthy society, it is appropriate to have a constitutional provision giving a right to freedom from poverty;
- that Ireland's commitment to the eradication of poverty 'as an ethical, social, political and economic imperative of humankind', as set out in the UN World Social Summit Declaration of 1995, should find constitutional expression;
- that constitutional recognition of rights such as adequate food, clothing, housing or income would signal a commitment by the State to ensuring basic material needs, enabling the judiciary to provide redress to anyone denied these minima;
- that such constitutional recognition would recognise the interdependence between people's resources and their access to justice and other aspects of equality;
- that such an assurance was needed as a counterweight to economic inequality;
- that greater economic equality would lead to greater political stability on which the effective functioning of democracy depends; and
- that economic inequality and poverty are socially and economically dysfunctional.

The arguments against, on the other hand, included

- the Constitution should not confer personal rights to freedom from poverty, or other specific economic or social entitlements, because these are essentially political matters which in a democracy should be the responsibility of the people's elected representatives rather than an unelected judiciary;
- it would not accord with democratic principles to confer absolute personal rights in the Constitution in relation to economic and social objectives and leave the Oireachtas with no option but to discharge the cost, whatever it might be, as determined by the judiciary;
- It is open to the Government and Oireachtas to reduce inequalities of wealth and income as desired;
- The Constitution already "appears to offer" ultimate protection from lack of food, shelter or clothing through judicial vindication of fundamental personal rights such as the right to life and the right to bodily integrity.

A majority of the Review Group agreed with the arguments as stated against the inclusion in the Constitution of a personal right to freedom from poverty or of specific personal economic rights. It is important in this context that the Group addressed these arguments after having stated that the inclusion of such a right in the Constitution would render it justiciable. The arguments against, which the majority supported, included the statement that "there could however be no objection to expressing the substance of these objectives as directive principles addressed to Government and Oireachtas but not justiciable in the courts" (p. 236).

The Review Group's stance was further demonstrated by its consideration of the right to education, the right to a primary education of course already being provided for in the Irish Constitution. The Group recommended that "The Oireachtas should also seriously consider extending this right to second level education". While some members favoured the extension of the right to education to all persons and argued that the right could be qualified so that it would not entail unrealistic financial demands on the State, the majority was against that amendment "because of its indefinite nature and unassessable implications" (p. 465).

The Review Group's conclusions have been challenged, notably by the Irish Commission for Justice and Peace (1998) and by Whyte (2001). These point *inter alia* to internal inconsistencies and critical unstated assumptions in the Review Group's reasoning – and indeed often do greater justice to the subtlety of the arguments involved. Even if (more) economic, social and cultural rights are not explicitly enshrined in the Constitution, Ireland has international legal obligations in that regard in any case, as already discussed. None the less, the constitutional discussion serves to highlight key issues in the broader debate about economic and social rights. Two central issues in relation to the "rights approach", which apply more broadly and urgently need clarification before the debate can progress fruitfully, are the relationship between rights and resources, and between rights and justiciability.

2.7 Rights and Resources

Two arguments against enshrining economic, social and cultural rights in the Constitution that played a key role in the Review Group's majority decision are also very often advanced in the broader debate. These are that is an encroachment on democracy, transferring power from elected representatives to the judiciary, and that the resource implications are unwarranted and/or unpredictable. These arguments are clearly inter-connected, since the "encroachment of democracy" argument assumes that there would indeed be a substantial shift to the judiciary of the power to determine how resources are allocated (see also McDowell 2002).

This is where the need for clarification is pressing. On the one hand, the "encroachment on democracy/separation of powers" argument takes no account of the fact that the courts are already involved in a wide range of issues with important resource implications. Indeed, it can be argued that legal protection of civil and political rights is also an encroachment on democracy, and that protection of economic, social and cultural rights can underpin rather than undermine democratic participation. On the other hand, there is significant divergence of views, including among proponents of legal/Constitutional recognition of economic and social rights, as to what such recognition would mean in practice. Some proponents argue strongly that it does not to confer absolute personal rights regardless of cost. As in other areas, they argue, the obligation on the State is not absolute, in that its obligation is only to defend and vindicate these rights as far as practicable. (The same applies to for example the citizen's personal rights and the right to access to the courts.) The Irish Commission for Justice and Peace (1998), for example, in arguing the case for Constitutional recognition of social and economic rights, note the Review Group's observation that property rights must yield to a wide range of countervailing interests, among them the redistribution of wealth, the protection of the environment, and the necessity for consumer protection. The Commission then state:

> *It is difficult to see why similar countervailing considerations would not or could not apply equally to other constitutionally enshrined socio-economic rights and permit their judicious regulation by the Oireachtas in the same way as property rights.* (1998, p. 12).

The Commission for Justice and Peace go on to argue that it is quite possible to state socio-economic rights in a form which will avoid the putative nightmare of leaving the Oireachtas with no option but to discharge the cost, whatever it might be, as determined by the judiciary. This is a common theme among some proponents of constitutional and legal recognition of economic, social and cultural rights: that those opposing such recognition misunderstand what is involved and do not appreciate that such rights could be framed, or would be interpreted, in a manner which met their concerns about the implications for resource allocation.

It is argued, for example, that this applies to the way international instruments are interpreted at present. The UN

Convention on Economic, Social and Cultural Rights commits states to ensure the satisfaction of minimum essential levels of various rights. The relevant UN Committee recognises that any assessment as to whether a state is satisfying this obligation must take account of resource constraints applying there. At national level, it is argued that rights can be worded in such a way that claims will be interpreted in due proportion to current standards and the resources currently available within the community. For example, they could be designed to protect people's ability to enjoy or exercise the right up to a defined minimum standard: the Oireachtas rather than the courts would then define what that minimum is (as in the case of Social Welfare entitlements). In addition, it is argued that explicit qualification in the way rights are framed by the use of terms such as "endeavour to ensure", "where reasonable", "where appropriate" can be used to ensure that the resource commitment is not open-ended. The emphasis is on the progressive realisation of economic, social and cultural rights, and this requires in the first place the effective use of the resources available rather than necessarily an increase in those resources.

A number of observations are relevant in this regard. The first is that this understanding of the "rights approach" seems to diverge significantly from that often featuring in recent Irish debates on both sides of the argument. On the one hand we have seen that the majority of the Constitution Review Group, effectively coming down against the approach, clearly did not share such an understanding. On the other side of the argument some proponents of the adoption of the rights approach regard the use of such qualifying terms as "where reasonable" as negating the value of explicit recognition of the right in the first place. It is one thing to assign the courts a role in assessing whether transparent and fair *systems* are in place for the use of resources currently being devoted to, for example, education or health care – which is seen by some of those arguing for the rights approach as a core benefit. It is very different if the courts are being asked to adjudicate on whether independent standards of adequacy are being met and by extension whether resources being devoted by the State are sufficient. As we shall see, this distinction has direct relevance in the context of disability and current Irish debates in that area.

The second and related observation relates to the way in which such rights – whether recognised in the Constitution or stated in legislation – would actually be interpreted by Irish courts. The advantages of the rights approach are often put forward at quite a high level of generality, and assumptions made about how this would operate in the Irish context without going into any depth. The Irish Commission for Justice and Peace, on the other hand, has made concrete proposals in a constitutional context for the way social and economic rights might best be framed. They state unambiguously that the right should be worded in such a way that claims made of it will be interpreted and discharged – by the community, the State, individual claimants and by the courts – in due proportion to current standards and to the resources currently

available within the community. The test of reasonableness should apply. Concretely, then, they suggest that the right might be framed to include something like the following wording:

> *As guardian of the common good the State shall take reasonable steps to promote the general and progressive enjoyment of this right in view of actual conditions, resources and standards. (p. 27).*

The question to be asked is how Irish courts would interpret such a formulation. This is something on which legal scholars and practitioners may differ, and about which there is an inherent uncertainty. While some indications may be gleaned from the way the current Constitutional right to primary education has been interpreted by the courts, that has itself not been static, and even predicting how that relatively specific right will evolve is not straightforward. It would certainly be very valuable if legal expertise were to be devoted to the question of how Irish courts might treat such concrete attempts to frame economic and social rights in a manner which explicitly recognised that such rights are qualified by *inter alia* resources. Quinn, for example, has argued that rights framed in such a manner would make it much more difficult for Irish courts to respond to particular cases by injunctive relief against Departments and Ministers than is the case with current Constitutional provisions. (The question then arising, from the point of view of some proponents of the rights approach, will be whether rights framed in that way are indeed of value; at this point though we are focusing on the prior issue of whether such qualification can be explicitly and effectively built into the way rights are framed.)

2.8 Justiciability and Rights

The second general issue to be highlighted before turning to the specific area of disability in the next chapter relates to justiciability and rights. As we have seen, the Constitution Review Group came down against enshrining new economic and social rights in the Constitution since these would be justiciable, but saw no objection to expressing the substance of these objectives as directive principles addressed to Government and Oireachtas but not justiciable in the courts. The Irish Commission for Justice and Peace, on the other hand, concluded that new economic and social rights should indeed be specified "in such a way as to be capable of being arbitrated, determined and enforced by the courts, i.e. they should be made justiciable". They saw this as essential on the basis that the experience of sixty years has made it clear that the relegation of certain matters to the non-justiciable scope of Article 45 of the Irish Constitution, setting out Directive Principles of Social Policy, has largely marginalised their constitutional impact.

The issue we would highlight here is not whether expressing such Directive Principles in the Constitution has value, but rather the broader one of whether rights necessarily entail justiciability, and in what form. It appears to often be commonly taken for granted in the Irish debate that there is an integral link between the two – because it is either being assumed that rights always entail

justiciability in principle, or that justiciability is in practice the only way in which rights can be effectively guaranteed. It is worth simply pointing out first of all that at the conceptual level, rights need not necessarily be associated with the ability to have recourse to the courts.

Secondly, in practice there may be alternative enforcement mechanisms which can allow rights to be supported. Thus the NESC, for example, was explicit in its 1999 report that:

> *The view of the Council is that social inclusion is not based on a set of specific rights understood in a justiciable sense.* (1999, p. 78.)

It did qualify this with a footnote stating that:

> *The Council recognises that developments at EU level and in Ireland in relation to the Human Rights Commission may at some stage in the future bring the issue of justiciability into consideration.* (1999, p. 78, footnote 21.)

In its recent 2003 Report the Council first restated its earlier view that social inclusion is not based on a set of specific rights understood in a justiciable sense. It went on to note that commitment to socio-economic rights does not necessarily entail commitment to judicial review, a Bill of Rights, or insertion of socio-economic rights in a constitution. Socio-economic rights can be secured by a variety of legal, policy and institutional methods, each having strengths, weaknesses and unintended consequences. This report's discussion also noted that where socio-economic rights are justiciable a number of tensions and complexities can arise. These include for example the tension between the legal pursuit of unique remedies or damages and the social policy need for enduring systemic remedies, and between the argument from principle or precedent that is the focus of judicial decision and considerations of aggregate welfare that resolve trade-offs and compromises inherent in complex policy issues.

We have already seen in this context that the Committee charged with assessing compliance with the UN Convention on Economic, Social and Cultural Rights has stated (in its General Comment 9) that "the right to an effective remedy need not be interpreted as always requiring a judicial remedy", though alternatives must be "accessible, affordable, timely and effective" (UNCESCR 1998b). It does go on to state that an ultimate right of judicial appeal would also often be appropriate. (The Irish Human Rights Commission (2003a) interprets the Committee's various Comments as meaning that "there is a strong presumption in favour of legal remedy under the CESCR".)

Even if judicial appeal is built in to administrative appeals systems, it is important to be clear that this might well apply to the decision-making processes involved rather than outcomes *per se.* (This is the case, for example, in the current Irish system of social welfare appeals).

The realisation of economic, social and cultural rights clearly depends on the creation of effective institutions and policies. As Daly's (2002) report for the Council of Europe notes, access to

social rights forms a chain whereby the declaration and framing of the right, the process whereby it is to be realised and the activities and resources necessary to realise it are all interconnected – or as the NESC report puts it, the link between rights, institutions and commitment is "a loop not a line" (p. 368). The NESC report emphasises in particular the connection between rights and standards, for example applying to State services. If social and economic rights are to be delivered it is necessary to develop specific, detailed norms in relation to these rights; establish how these norms or standards are to be monitored; clarify the role of the state; establish accessible, transparent and effective mechanisms of accountability; and ensure that all members of society are fully aware of the rights and standards that they are entitled to expect.

This is reflected in, for example, the Review of the National Anti-Poverty Strategy last year (NAPS 2002), where the government gave a commitment to *inter alia* move towards a more formal expression of entitlements across the range of public services and to setting standards and guidelines regarding the standard of service delivery which can be expected by the customer; to monitor, by means of indicators, access to services of a given standard; and to work to improve performance over time; and to focus on effective outcomes and indicators to monitor outcomes. The Review also stated that the principles set out in the International Covenant on Economic, Social and Cultural Rights and other international human rights instruments adopted by Ireland "will inform the future development of social inclusion policy" (p. 21).

Before one arrives at the judgement that in particular circumstances justiciability is required to fully and effectively support economic and social rights, that case has to be argued on its merits rather than taken for granted *a priori*. Furthermore, justiciability itself may take rather different forms, and may focus on processes rather than outcomes. The relevance of these considerations in the context of services for people with disabilities will become clear as we turn to that specific area in the next chapter.

3. DISABILITY AND RIGHTS IN IRELAND

3.1 Introduction

Having filled in the broader context and made some relevant general observations in relation to economic and social rights, we now turn to the application of these arguments in the area of services for people with disabilities in Ireland. The logic of the rights-based approach is widely argued to apply with particular force in the area of disability. Starting from a position where people with disabilities have often in effect been regarded as a problem, the central themes in current discourse relate to people with disabilities as having rights, rejecting the medical model of disability. We therefore start this chapter with a discussion of the evolution of perspectives on disability away from the medical model, which has been a fundamental shift in thinking world-wide. We then look at how this has been reflected in international instruments, and then at how it has filtered through to Ireland. We then come to the centrality of the rights approach in recent Irish debates about legislation and disability.

3.2 The Rights Perspective and Disability

The way issues relating to disability are approached in a particular society at a particular point in time, by legislation and by institutional structures as well as individuals, depends on how disability is thought of – which model, as it were, people generally have in their minds about the nature of disability. Recent years have seen a major shift in thinking in this regard, away from what has been termed the medical model of disability towards what has been termed a social model. Arguably, the social model is now itself evolving towards a model based firmly and explicitly on human rights (see for example Quinn 2002). It is worth briefly sketching out that evolution in thinking, since it provides the backdrop to recent Irish debates on the rights of people with disabilities.

The medical model of disability, which focuses on people's specific impairments and implicitly sees the problem as located only there, was for many years the dominant model internationally. The underlying assumptions of that model are that people with a disability are different from the norm, and that they need to be helped and if possible cured so that they might conform to that norm. They are sick, unfortunate, and will not be able to have autonomy or full participation in society. The power to address the "problem" of disability is then located with the medical profession

and the aim is to cure the impairment. The focus of State activity is on rehabilitation, vocational training, and sheltered employment, as well as dedicated income support. The emphasis is on the individual and their inability, and the result is very often segregation of people with disabilities into separate institutions, in a manner which may deprive them of basic human rights.

Starting from the early 1970s, this way of thinking about disability was increasingly challenged and rejected by people with a disability, in favour of what has been termed the social model of disability. The central shift in thinking was that disablement arose from the environment and the organisation of society rather than from the individual and their impairment. Disability is seen as a consequence of social, attitudinal and environmental barriers that prevent people from participating in society: disability is a social construct. The focus is then on the need to change societal conditions to accommodate the needs of the person with a disability, rather than on curing the impairment. Failure to adjust to the needs of the person with a disability can be viewed as a form of discrimination. Those with disabilities should be able to participate in such activities as education, employment, and leisure along with everyone else.

Rather than the medical profession, from the perspective of the social model the power and responsibility to address barriers to participation lies with the state. This sea-change in thinking about disability has been reflected in a wide range of institutional changes, notably a move away from segregated education and institutionalisation for people with a disability, and also in anti-discrimination legislation to promote access of people with disabilities to employment, transport and services. A duty is placed on employers and on suppliers of goods and services to "reasonably accommodate" the needs of the person with a disability, to use the term at the heart of disability discrimination laws in many countries. Where possible, services for people with disabilities should also be delivered through the mainstream rather than separately. The emphasis is on the ability rather than inability of the person, and on changing attitudes and structures in society.

While the social model has been enormously influential, it has continued to evolve and in particular since the 1980s disability is increasingly being seen within a rights-based discourse or model (see for example Quinn 2002). The human rights perspective on disability continues to locate the main problem outside the person, in society and in its lack of responsiveness to difference, but emphasises that persons with a disability should have autonomy and enjoy the same economic, social and cultural rights as others. Persons with a disability should have power over their own lives, and should be admitted into the mainstream of society on an equal basis with everyone else. The human rights model is not just concerned with restructuring society to meet the economic, social and cultural rights of persons with a disability, it insists on their right to independence and self-determination and on full participation in all aspects of life.

The disability rights movement can thus be seen as a particularly powerful current in a broader human rights agenda. Promoting autonomy, valuing difference, and the need for economic and social supports to underpin civil and political rights are common themes in that broader human rights agenda which resonate particularly deeply in the disability context. The area of disability is thus seen as highlighting the inter-dependence of civil and political rights on the one hand and economic, social and cultural rights on the other. People with disability are entitled to the support required to allow them to participate fully in the life of their society, to liberate them in their own lives.

3.3 The Rights Perspective on Disability in International Instruments

This human rights approach to disability is increasingly reflected in and underpinned by international covenants and instruments (see for example Quinn, Degener *et al* 2002). There are at present no United Nations human rights treaties which apply solely to persons with disabilities, but their anti-discrimination clauses guarantee that the rights recognised will be exercised without distinction of any kind, "such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status". Although disability is not expressly included it is widely accepted that it falls under the heading "other status" and is thus treated as a ground in respect of which discrimination is prohibited. In addition the UN General Assembly, in a Declaration on the Rights of Disabled Persons in 1975, proclaimed the right of persons with a disability to *inter alia* respect for their human dignity, to measures designed to enable them to become as self-reliant as possible, and to treatment and rehabilitation to enable them to develop their capabilities and skills to the maximum and hasten the processes of their social integration or reintegration.

With its emphasis on rehabilitation this Declaration still reflected a notion of disability that falls within the medical model. Over the following years a much greater emphasis on equalisation of opportunities was seen, with the 1982 World Programme of Action on disability emphasising that the environment largely determines the effect of an impairment on a person's daily life. States were urged in particular to develop and follow a national plan of action for people with disabilities, and to draft national rights based legislation dealing with disability. In 1993, the General Assembly adopted the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities", the purpose of which is to ensure that all persons with disabilities "may exercise the same rights and obligations as others". The Standard Rules emphasise the principle of equal rights, and urges states to create the legal basis to allow persons with disabilities to achieve full participation in all aspects of life. They are not binding on member states, being monitored by a United Nations Special Rapporteur who reports to the Commission for Social Development.

As far as the UN Covenant on Economic, Social and Cultural Rights is concerned, the relevant UN Committee issued a General

Comment in 1994 making explicit that persons with disabilities should enjoy all the rights it sets out on an equal basis with the rest of society. Thus the right to education is violated whenever children with disabilities are denied access to public educational institutions (e.g. because buildings are not accessible) or when their special educational needs are not taken into account in developing national educational programmes. According to the article on the right to health, persons with disabilities must be provided with the same level of medical care as other members of society, and have the right to have access to, and to benefit from, medical and social services which enable them to become independent, prevent further disabilities and support their social integration. Similarly the right to work may be violated when the State fails to adopt adequate regulations and policies to make the workplace accessible to disabled persons, to provide persons with disabilities with adequate technical and vocational guidance to improve their capabilities and skills or to support the integration of the disabled in mainstream employment.

There remains a concern that the rights of persons with a disability are not adequately captured and protected in this manner, with the lack of binding human rights law for persons with disabilities leading to a demand for adoption of a new convention specifically to protect and promote the rights and dignity of persons with disabilities.[3] In December 2001, the UN General Assembly established an Ad Hoc Committee to consider such proposals. This Committee held its first session in mid-2002, and both States and experts attending expressed the view that a convention would improve the quality of life of persons with disabilities by including in a single, comprehensive and legally binding instrument, all the norms that are currently dispersed in the existing human rights instruments. A number of options for how to proceed were proposed, such as elaborating a comprehensive human rights treaty tailored to the needs of persons with disabilities versus focusing on human rights principles particularly relevant in the context of disability. These were considered at the second session of the Ad Hoc Committee in June 2003, where it was informally agreed to proceed with the drafting of a convention on the rights of persons with disabilities, with a further meeting of the Committee planned for May/June 2004.

The recent revision of the European Social Charter in itself provides an illustration of changing perspectives on disability. The Revised Charter refers to the right of persons with disabilities to independence, social integration and participation in the life of the community, and commits states to not only providing education and vocational training and promoting access to employment, but also to promoting the full social integration and participation of persons

[3] For a number of years a resolution calling for such a convention to be considered was tabled at the UN Human Rights Commission sessions, with Ireland among the countries tabling such a resolution.

with disabilities, specifically mentioning overcoming barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure. This is in contrast to the original formulation in the 1961 Charter, which referred to vocational training and rehabilitation, including "where necessary specialised institutions", and to "specialized placing services, facilities for sheltered employment and measures to encourage employers to admit disabled persons to employment". As Quinn (2003) points out, at that time granting access to welfare and rehabilitation was seen as exhausting the human rights entitlements of persons with disabilities, whereas the Revised Charter reflects the paradigm shift from a welfare to a rights approach taking place around the world.

At the Malaga Ministerial Conference convened by the Council of Europe in May 2003, a Political Declaration was adopted. In that Declaration states undertook inter alia to promote the provision of quality services, responding to the needs of individuals with disabilities which are accessed via published eligibility criteria, based on thorough and equitable assessment, shaped by the disabled person's own choices, autonomy, welfare and representation, with proper safeguards, regulation and access to independent adjudication of complaints. This Declaration is to guide the elaboration of a decade-long Action Plan on disability for Europe.

3.4 The Rights Perspective on Disability in an Irish Context

In an Irish context, the Commission on the Status of People with Disabilities represented a major watershed in terms of the articulation of a rights approach to disability. The Commission expressed this in the following terms in their Report (1996), based on the submissions and listening meetings which formed a major part of their work:

> *People with disabilities and their families made it clear that they want equality, that they want to move from a reliance on charity towards establishing basic rights. They want, and are entitled to, equality and full participation as citizens.* (1996, para 1.2).

Reflecting international trends but also firmly based in the expressed views of people with disabilities in Ireland, this was enormously influential in establishing the rights-based approach as the frame of reference.

The shift to a rights-based approach is reflected in the way disability has now been mainstreamed in the State's main legislative weapons against discrimination. In the Employment Equality Act (1998) and the Equal Status Act (2000), disability is one of the nine stated grounds on which discrimination is outlawed. It is worth noting that the protection originally provided in the case of disability had to be weakened following a Supreme Court judgement that the original formulation was unconstitutional, because it required employers and service providers to make such special provisions as would facilitate people with disabilities who could not otherwise access the employment or service. This was held to be a breach of property rights unless only nominal costs were involved,

so employers and service providers now *may* be required to provide special arrangements to persons with a disability who could not otherwise access the employment or service, and then only if there is only nominal cost involved. The Equality Authority is required to promote and defend the rights established in the equality legislation, including for people with disabilities, and the complaints of unlawful discrimination investigated or mediated by ODEI, the equality tribunal, include ones based on disability.

The aim of mainstreaming services for persons with a disability, consistent with the philosophy of the equal status approach, led to the dissolution of the National Rehabilitation Board in 2000. The newly-established Comhairle was assigned responsibility for information, advice and advocacy functions previously carried out in relation to disability by the NRB, with functions of the NRB in the training and rehabilitation areas taken over by FAS. At the same time the National Disability Authority (NDA) was established, a dedicated agency to develop and monitor the implementation of standards in services for people with disabilities. The Authority presents its core role as striving "to ensure that the rights and entitlements of people with disabilities are protected", and its Strategic Plan for 2001 – 2003 is entitled "A Matter of Rights". In operational terms, it states, this approach is seen in the mainstreaming of a range of programmes and services, including training and employment, information and advocacy and in the establishment of new institutional structures – including the NDA itself.

3.5 The Rights Approach and Disability Legislation in Ireland

The rights approach has also come to play a central role in current debates about legislation in the disability area in Ireland. The enactment of rights based legislation has come to represent a core demand of many in the disability sector. This was articulated clearly and emphatically at a conference held in December 2001 and entitled "Get Your Act Together", immediately prior to publication of the Disability Bill, 2001. This was attended by over 400 people, individuals with disabilities, families of people with disabilities and organisations of and for people with disabilities. There was what was described as "a resounding consensus among the participants that the Disability Bill must be rights based and person centred" (Conference Report 2002 p. 26). The Conference Report highlighted the need for the Disability Bill to reflect "real disability rights legislation", and called for it to *inter alia*

- Be comprehensive and mandatory, clearly establishing the rights of people with disabilities to participate in the mainstream of society, clarifying how those rights are to be given effect.
- Focus on the rights of individuals to disability support services, including a range of advocacy services and assessments of needs.
- Provide for an independent, comprehensive and holistic assessment of need.

- Provide for a mandatory obligation to meet the needs identified in accordance with an individual's Assessment of Need.
- Provide for an independent and effective appeals/mediation process.

The Disability Bill presented to the Oireachtas in December 2001 was criticised by many in the disability sector as failing to reflect this rights focus. Particular criticism was levelled at a clause which stated that, "without prejudice to any right of action existing apart from the Bill", it did not "confer a right of action in any civil proceedings by reason only of a failure by a public body to comply with any duty imposed on it under this Act" (Disability Bill 2001, Section 47). After the general election of June 2002, the Agreed Programme for Government between Fianna Fail and the Progressive Democrats stated in that regard that:

> *We will complete consultations on the Disabilities Bill and will bring the amended Bill through the Oireachtas and include provisions for rights of assessment, appeals, provision and enforcement.* (2002, p. 27).

In this consultation process the Department of Justice, Equality and Law Reform was assisted by an Expert Consultation Team (of which the author was a member). The NDA was invited to facilitate dialogue within the disability sector and this led to the formation of the Disability Legislation Consultation Group (DLCG), made up of umbrella groups and organizations in the disability sector. A rights-based approach underpins *Equal Citizens: Proposals for Core Elements of Disability Legislation* produced by the DLCG (and published on the NDA's web site) in early 2003 as a key input into the consultation process. Following the completion of the consultation process, the preparation of a revised Disability Bill is in progress with publication expected before the end of the year. Since the rights approach plays such a central role in the debate around Irish disability legislation and in the DLCG's proposals, it is worth teasing out here some implications of the way these proposals envisage that approach being operationalised in relation to services. (Our focus here is strictly on the relationship between the rights approach and the provision of services, and other aspects of the proposals on a range of important issues such as accessibility, mainstreaming and disability proofing, public service employment, will not be discussed here.)

The DLCG believe that new legislation on disability in Ireland represents an important shift in thinking about how services can be provided more effectively and efficiently in order to meet the expectations and rights of people with disabilities. They believe that rights of people with disabilities need to be further elaborated beyond those found in anti-discrimination legislation to ensure that appropriate economic and social supports are available to enable people with disabilities to exercise those rights in practice. The proposals identify the positioning of the individual with disabilities at the centre of service provision as a key component of the rights-based approach. Through needs assessment and service

coordination, resources are attached to the person him/herself. The purpose of new legislation should include the establishment of enforceable rights to enable people with disabilities to achieve equal access, participation and outcomes in all areas of service provision and employment and to exercise the same rights and obligations as others to fully participate in Irish society, including independent needs assessment, services, advocacy and redress.

The DLCG is of the view that there should be a statutory right to an independent assessment of need leading to a Statement of Need for the individual. The proposals go on to state that:

> *The DLCG consider that the right to independent needs assessment should result in services that are made available as a right for people with disabilities. These services should be identified to meet the needs set out in the Statement of Need. In the event of services not being available a programme of measures should be put in place in order to realize these services within an established timeframe.* (2003, p. 9.)

It goes on to say that provision should be made for legal redress, complaints and appeals. Effective and accessible complaints systems should cover all service provision. These should include service providers own internal systems for handling complaints and complaints mechanisms of public bodies funding services, and an independent complaints process through the Ombudsman's Office with enhanced powers. The rights stated in the legislation should also be justiciable, with people having access to the courts to enforce these rights. These rights should also include advocacy, to be provided through an independent advocacy agency.

The situation envisaged in the DLCG's proposals, in terms of services, could be baldly summarised as follows. The individual's needs across the range of service areas are to be assessed independently – that is, independent of service providers and of current availability of services. The services identified by that assessment should then be made available as a right. Together with other rights to be set out in the legislation, this right should be justiciable. If the services one has been identified as needing are not made available, then one can – ultimately – go to court to enforce that right against the State. Implicitly but self-evidently, the clear understanding is that the legislation would be framed in such a way as to ensure that the courts would indeed vindicate the right to those services.

At first blush, there seems to be a substantial divergence between such an implementation of the rights-based approach and the more qualified framing of economic and social rights favoured by some proponents and discussed in the previous section, with its emphasis on the State taking "reasonable steps to promote the general and progressive enjoyment" of economic and social rights "in view of actual conditions, resources and standards". The DLCG proposals do however nuance the bald outline presented in the previous paragraph in (at least) two important respects.

First, in the event of services not being available "a programme of measures should be put in place in order to realise these services

within an established timeframe". This is open to different interpretations, and could perhaps be seen as providing some scope for the "progressive realization of rights" seen as central by some proponents of the rights approach. However, generally this is discussed in terms of rights being progressively realised over time as *inter alia* the society becomes more prosperous and more resources become available. The time-scale involved could then be quite long, whereas the more obvious interpretation of "within an established time-frame" is that delivery within a relatively short space of time is envisaged. More fundamentally, a State fully committed to a progressive realisation of rights might still find the pace at which that could be achieved in terms of services across a very broad range indeterminate looking forward, whereas a guarantee that specific services will be made available within a specified time-frame is clearly envisaged here.

Secondly, the basis on which the independent assessment of needs is itself carried out is clearly of central importance. The DLCG proposals explicitly state that needs assessment should provide for a professional service and accurate identification of needs "that are not influenced by existing service levels or cost/economic considerations". The proposals do state that "detailed guidelines on effective systems, structures and processes for independent needs assessment should be made through Ministerial regulations which are supported by NDA Standards and Codes of Practice". This seems to relate to the manner in which the assessment is carried out, however, rather than to the basis or standards against which needs will be judged – although the text as quoted is not entirely unambiguous.

We saw earlier that some proponents of explicit recognition of economic and social rights see these as (at least in some instances) being designed to protect people's ability to enjoy or exercise the right up to a defined minimum standard: the Oireachtas rather than the courts would then define what that the minimum is, as in the case of Social Welfare entitlements. What seems to be envisaged here (again subject to some ambiguity in interpretation) is quite different: professionals are to base their assessment of needs on standards that have not been set down or endorsed by the Oireachtas. It hardly needs to be said that this is likely to prove unpalatable to those who argue against justiciability of economic and social rights on the basis of the primacy of the legislature.

The Human Rights Commission has published its observations on the DLCG's proposals (2003a), focusing on the recommendation that "provision should be made for legal redress, complaints and appeals" in the context of the provision of services to meet independently assessed needs. The primary purpose of these observations is to explore whether, or to what extent, international law supports this proposal. The conclusion reached, on the basis of an examination of the General Comments of the UNCESCR Committee already discussed in earlier chapters, is that "the International Covenant on Economic, Social and Cultural Rights is indeed supportive of the kind of proposal made by the

DLCG" (2003a). It does however acknowledge that these Comments leave open the door to equally effective administrative remedies, as mentioned earlier. In addition, while there may indeed be a strong presumption in favour of legal remedies under the CESCR, this does not necessarily imply a judicial appeals procedure designed to ensure that an individual receives all the services an independent assessment process has determined they need. Again, the way the DLCG's proposals are interpreted is critically important.

We will return to these issues in our concluding chapter. First, though, it is helpful to put them in comparative perspective by examining how some other countries approach the provision of services and advocacy to people with disabilities. From this examination, presented in the next chapter, some important lessons emerge which may be helpful in thinking about how best to proceed in the Irish case.

4. A Comparative Perspective on Rights-Based Services for People With Disabilities

4.1 Introduction

In order to inform the Irish debate, we now turn to a review of structures and approaches in a number of other rich countries to the provision of services and advocacy to people with disabilities. The countries covered all share with Ireland a legal structure based on common law, so lessons of most direct relevance to Ireland can be learned. The countries covered are the USA, Australia, New Zealand, Sweden and the UK, and we first describe the way the review was framed before presenting the results.

4.2 Scope of the Review

As noted in the introductory chapter, our focus in this study is strictly on services – health, education, personal social services – and advocacy rather than on access to public or private buildings, transport, or employment. Within this, the approaches adopted in different countries can usefully be studied in terms of four distinct areas:

- Assessment
- Provision of services
- Appeals/enforcement
- Advocacy.

To provide a framework for the comparative review, a number of key questions have been identified in each of these areas: it has not always been possible to answer them definitively, but they serve to structure both the investigation of country approaches and the presentation of the material here. These questions are as follows:

1/ ASSESSMENT:

(a) Is there an entitlement or right to an assessment of needs?
(b) If so, what form does this assessment take?

(c) Are there established (national?) standards for service levels and quality against which the assessment is made?
(d) Can the resources available to the provider affect the assessment?
(e) Is the assessment carried out by the service provider or by an independent entity?
(f) Is the assessment a unified one or are there different assessments for different areas of need (e.g. health vs. education)?

2/ PROVISION OF SERVICES:

(a) (In what sense) Is there an entitlement/right to services?
(b) Does this cover the services indicated by an assessment of need?
(c) What do the services provided generally cover?

3/ APPEALS/ENFORCEMENT:

(a) Is there a right to appeal against an assessment?
(b) If so, is the adjudicating body independent of the service provider?
(c) If services indicated by an assessment of need are not being delivered, is there a right to appeal to a third party?
(d) If so, is this body independent of the service provider?
(e) How can this appeals body seek to enforce a favourable judgement?
(f) Can resource constraint be used by the provider/State to justify non-delivery of services?
(g) When can someone not receiving what they regard as appropriate services succeed in enforcing entitlements/rights through the civil courts?

4/ ADVOCACY:

(a) In addition to provision of information, is there available a State-supported service to help people understand and claim their entitlements to services?
(b) Can this service represent people in seeking to claim these entitlements/get better services?
(c) Is this advocacy service independent of the service provider?

With these questions to the forefront, we now look in turn at the approaches adopted in the USA, Australia, New Zealand, Sweden and the UK in these areas.

4.3 Provision of Health and Social Services to People With Disabilities in the USA

In the USA, there are two separate types of laws relevant to services for people with disabilities. One set of laws prohibit discrimination against individuals with disabilities. The most prominent of these is the Americans with Disabilities Act (ADA) of 1990. This prohibits discrimination on the basis of disability in the areas of employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. Title II of the ADA requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programmes, services, and activities, including health care and social services. (This involves in particular access to their buildings and communicating effectively with people who have hearing, vision, or speech disabilities.) Title III of the ADA prohibits discrimination by private businesses, including, among others, health and social service providers, educational institutions, and shops rendering consumer services (e.g., dry cleaners and beauty salons). Title IV of the ADA requires phone service providers to establish a relay service for customers with speech and hearing impairments. Section 504 of the Rehabilitation Act also places a nondiscrimination requirement on services provided by recipients of federal grants.

These laws do not in themselves require the provision of health and personal services, nor assessments of the need for services. They simply require that any goods, services, accommodations, etc., provided by an entity subject to the laws must be made available on a non-discriminatory basis to people with disabilities. (One might categorise certain requirements of the non-discrimination laws, such as the duty to make reasonable accommodations and to provide auxiliary aids, as a requirement to provide a service, but this is regarded not as a special service but as an element of not discriminating.) As far as health and associated services are concerned, the Department of Health and Human Services (DHHS) seeks to ensure that people have equal access to and opportunity to receive services in all health and associated programmes without facing unlawful discrimination.

People with disabilities may have a right to assessment of their personal health and medical needs by statutory and local government health care and social service providers, as well as need for auxiliary aids or services. However, this assessment will relate to the service area involved and generally be carried out by the service provider – e.g. by a care centre, to assess whether they can meet the needs of the person involved. There is no unified assessment of need across different areas, nor is there generally a right to an assessment independent of the service provider. Developmental Disabilities legislation requires various kinds of services to be provided for habilitation, training, and residential services for persons with disabilities meeting the statutory eligibility standards. The federal Medicaid programme provides funding for various kinds of health-related services and establishes standards and procedures for such services and for establishing eligibility for them.

Each of these and similar statutes contains its own criteria for eligibility, specifications of types of services authorised and required, assessment requirements, and procedures for review and appeal of unfavourable determinations.

People who believe they have experienced discrimination because of their disability (or race, age, sex etc.) by a health care or human services provider receiving funds from the DHHS may file a complaint with the Office for Civil Rights (OCR). (Such providers include hospitals, nursing homes, community mental health centres, alcohol and drug treatment centres, family health centres and clinics, physicians, day care and senior citizen centres.) The OCR is independent of service providers and of the Department of Health and Human Services, operating under the Department of Justice. Discussion and mediation must be tried first, and resolves most complaints. If agreement is not reached the case enters the litigation stage and can end up in the Supreme Court. Penalties can include injunctive relief, damages and civil penalties for the discrimination involved.

The ADA, does not provide a generalised right to a particular health or therapeutic service/support or standard of service for those with disabilities. Nonetheless, this anti-discrimination legislation, with its focus on the treatment of those with disabilities versus those without, can have a significant impact on service provision. This was illustrated in 1999, in the Supreme Court ruling on the "Olmstead case". Title II of the ADA and its implementing regulation require public entities to administer their programmes "in the most integrated setting appropriate to the needs of qualified individuals with disabilities," that is, a setting which "enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." The Supreme Court ruled that under certain circumstances, this requires states to provide community-based treatment for persons with disabilities. The Court said that institutionalizing a person with a disability who can benefit from living in the community and wishes to do so constitutes discrimination because it severely diminishes the individual's ability to interact with family and friends, work and make a life for him or herself.

The decision also makes clear that the right of people with disabilities to receive services in the "most integrated setting" is not absolute. Title II does not require measures that would "fundamentally alter" the nature of a public entity's programmes, and costs may bear on that determination. In the Olmstead ruling, the Supreme Court indicated that, in evaluating a state's "fundamental alteration" defence, courts are to consider not only the cost of providing community-based care to individuals, but also the range of services the state provides to others with disabilities and the state's obligation to mete out those services in an equitable manner. A state may demonstrate compliance with the ADA by adopting a plan to provide services in the "most integrated setting" that is comprehensive and effective and by ensuring that any waiting list for community-based services moves at a reasonable pace. This

ruling is having a major impact on the approach to provision of services in institutions versus the community, and is requiring very substantial additional expenditure. Partly in response, the Federal government introduced the New Freedom Initiative for Americans with Disabilities in 2001 aimed at providing greater opportunity for work and integrated community living. An Executive Order from President Bush called for a broad review of federal laws, programmes and policies that may interfere with community based living for those with disabilities.

As far as advocacy is concerned, various divisions and agencies under the Department of HHS provide information, help people understand their entitlements, and give advice on how to submit claims and complaints. In addition, the Department of Justice can represent people pursuing ADA cases.

The comparison with education is instructive. The Individuals with Disabilities Education Act requires public schools to make available to all children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. People with disabilities have a right to evaluation of their education needs. Each public school child who receives special education must have an Individualised Education Programme, devised by his or her teachers, parents, and where appropriate the student. This sets goals and specifies what additional supports etc. are required, with re-evaluation at least every three years, in accord with nationally-established standards and procedures. Parents who disagree with an assessment can take their child for an independent educational evaluation, and ask the school system to pay. If they agree with the assessment but not the programme, they can appeal to a State-level board, which is independent of the service providers. If still dissatisfied, they can file a complaint with the OCR. The Office of Special Education Programmes monitors State compliance and the results achieved for students with disabilities.

Despite this, education services for students with disabilities still vary substantially from state to state, with the level of funding playing an important role – although the federal government has injected significant resources since 1999 to try to reduce gross disparities between states in terms of levels of financial provision. Lack of resources may not in principle justify non-delivery of services, but in practice the onus may be cast back on the disabled individual and/or parents to challenge that failure through the courts Entitlement to an independent assessment and to the provision of services assessed as required are still clearly much more firmly based under the Individuals with Disabilities Education Act than in the area of health and related services.

4.4 Provision of Services to People With Disabilities in Australia

In Australia the Disability Services Act (1986) provides the basis on which services are to be provided to people with disabilities – including rehabilitation therapies, advocacy and information services, respite care, employment training and supported employment services, as well as assistance with modification of accommodation and meeting special transport needs. The relevant Minister has the power to approve classes of services to be resourced by the federal government, and to set standards which must be met in the delivery of these services. The aims include assisting people with disabilities to receive services necessary to enable them to work towards full participation as members of the community. The Act states explicitly that "in construing the objects and in administering this Act, due regard must be had to the limited resources available to provide services and programmes under this Act".

The decision as to which services to support and what standards to set in the provision of these services thus appears to rest fully with the Minister. The monitoring of service standards covers both government and non-government service providers. In the majority of cases this combines provider self-assessment with a level of independent monitoring. Service agreements between the government and the disability service provider dictate the quality expected and these agreements are reviewed regularly.

There is a federal agency which undertakes assessment of needs, the Commonwealth Rehabilitation Service (CRS). When the CRS takes on a case it tailors an individual programme to suit the client's needs, but the client is not directly involved in their assessment. Specific agencies or networks of agencies in the different states also carry out assessments with public funding – in South Australia, for example, there is a state-wide network of five agencies. These have differing procedures, and generally cover only health and personal services, with distinct assessments required for different areas of need such as education. There is no national standard for assessments, in terms of what services will be deemed necessary in particular circumstances. The Department of Health and Family Services is currently considering an independent assessment and referral mechanism for people with disabilities.

The Disability Services Act requires that services for people with disabilities be provided in a manner consistent with their rights as Australian citizens and as human beings – including the right to dignity, privacy, choice and the fulfilment of their capacity to contribute fully to community life. The Disability Discrimination Act (1992) and the Equal Opportunity Act (1994), as well as state-level equal opportunities legislation, specify that people with disabilities have the same rights as other members of the Australian community to the assistance and support that will enable them to exercise their rights, discharge their responsibilities and attain a reasonable quality of life. This anti-discrimination legislation defines disability-based discrimination and clearly prohibits it, with the stated overall aim being complete social equality and integration for people with disabilities. The DDA prohibits discrimination in the

areas of work, housing, education, access to premises, and provision of goods and services. The key term employed is 'reasonable accommodation' or reasonable adjustments that have to be undertaken by the employer, service provider, government or other entity. The Disability Discrimination Act does not establish entitlement to services, it establishes a complaints-based process in relation to discrimination.

An overall planning framework for Commonwealth (federal) agencies to ensure access to all Commonwealth programmes, services and functions for people with a disability was set out in the Commonwealth Disability Strategy (1994). This, together with the Disability Discrimination Act, is presented as reflecting a change in focus from a welfare approach to a rights-based approach to meeting the needs of people with a disability. Quotations from the Strategy help to convey this emphasis:

> *This Strategy takes us further toward our goal of being a progressive, fair and inclusive society in which all citizens have equal rights.*
>
> *The Strategy is based on a belief that people with a disability have the same fundamental rights as other Australians, and should have equal opportunities to participate in community life.*
>
> *The Commonwealth government recognises that each person with a disability has a right to:*

- *be recognised as a valuable citizen;*
- *have equal access to the systems of society, the environment and community life;*
- *the opportunity to contribute to the economic, social, political and cultural life of the community;*
- *have their needs recognised in the planning and administration of public services and infrastructures;*
- *maximise opportunities for their independence;*
- *participate in decisions which affect their lives and the communities in which they live; and form and maintain relationships of their choice.*

The Strategy is also seen as providing a framework to meet Australia's obligations under the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.

The Strategy seeks to address access by people with a disability to the services which are available to the rest of the community. It takes as given the continuing need for a range of specialist services to support people with a disability, where necessary, to gain access to the systems and facilities of community life, and does not deal with those services: it concentrates on activities by agencies to reduce or eliminate barriers within mainstream Commonwealth programmes. "*It does not relate to proposals for increased outlays on disability services* (italics added)." A Commonwealth Office of Disability undertakes a range of functions in connection with the Strategy including assisting Departments and Agencies to identify and fulfil their responsibilities.

Advocacy and appeals mechanisms are available under the anti-discrimination and equal opportunities legislation. Complaints can be made to independent state-level legal or advocacy agencies,

which will mediate with service providers. They can also forward complaints to the Human Rights and Equal Opportunities Commission (HREOC). However, this focuses primarily on discrimination in employment, and HREOC itself states that "The Commission is not a major source of information or expertise on disability specific programmes including those under the Disability Services Act". Issues relating to service provision are channelled through administrative complaints procedures. While HREOC can require organisations to develop action plans towards compliance with the DDA, it has no power to enforce action plans. The government's principal response in this context is to fund third party, non-judicial, advocacy support for people with a disability.

4.5 Provision of Services to People With Disabilities in New Zealand

New Zealand has recently embarked on a fundamental restructuring of its health services, which has major implications for services to people with disabilities which have not yet fully worked their way through. The NZ Public Health and Disability Act (2000) now provides the basis on which health and support services are to be provided to people with disabilities. The main focus of that Act is to set up a structure of (21) District Health Boards throughout the country, and in time these will become responsible for disability support services, which as yet remain centrally administered by the Ministry of Health. Among the stated objectives of the Public Health and Disability Act is "the promotion of the inclusion and participation in society and independence of people with disabilities" and "the best care or support for those in need of services". However, it also states explicitly that "these objectives are to be pursued to the extent that they are reasonably achieved within the funding provided" (3 (2)).

The District Health Boards, already responsible for e.g. hospital services, are in time to become responsible for determining health and disability strategies, and providing or arranging for both health and disability support services. Their core function is "to ensure the provision of services". This will be within the framework of national health and national disability strategies. The development and application of national standards, quality assurance and monitoring for health services is explicitly legislated for; disability support services are not mentioned explicitly in that context. The act imposes obligations on the District Health boards to provide services and to promote the inclusion and participation of people with disabilities – it is not framed in terms of rights or entitlements of individuals in relation to services. The Minister of Health may require the District Health Board to provide, or arrange for the provision of, specified services, having regard to the health strategy and the disability strategy. It is worth noting that at least some organizations representing people with disabilities oppose the devolution of responsibility to District Health Boards for disability support services, on the grounds that it would "re-medicalise" disability since these boards are dominated by health professionals

who will tend towards a biomedical perspective rather than seeing disability in social and environmental terms.

The NZ Disability Strategy, drawn up by the Ministry of Health in 2001, has among its objectives to "ensure rights for disabled people". Its Introduction states that:

> *The desire to break down the barriers that cause disability is also closely linked to ideas about the human rights of people with impairments. Without human rights we cannot live as full human beings. Human rights include political, civil, social, cultural and economic rights. Human rights are described by international instruments... In New Zealand we have legislation such as the Bill of Rights Act, the Human Rights Act and the Privacy Act.* (2001, p. 9)

The Strategy does not however specify any rights for disabled people (its preferred term) in relation to services, over and above the general provisions included in the Bill of Rights and the Human Rights Act,[4] and rights of service users under the Code of Health and Disability Services Consumers' Rights (see below). Instead, it aims to "uphold and promote the rights of disabled people", committing the government to, *inter alia*,

- Review Human Rights legislation to ensure the ongoing enhancement and strengthening of the rights of disabled people.
- Investigate, and if appropriate, support, development of a United Nations convention on the rights of disabled people.
- Investigate the level of access that disabled people have to independent advocacy, and address any shortfall in service provision.
- Evaluate New Zealand's performance on the rights of disabled people.
- Consider disabled people whenever New Zealand's performance is being evaluated against international human rights obligations.

As far as service provision is concerned, the Strategy includes a commitment to "create a quality assessment and service delivery system that is centred on disabled people, ensures their participation in assessment and service delivery, has invisible borders and is easy to access". It also includes commitments to "investigate the development of a holistic approach to assessment and service provision, that applies across agencies and funding sources", and to "identify unmet need and develop affordable solutions to fill these gaps".

In another significant recent structural change, disability support services are now assessed and awarded through a Needs Assessment & Service Coordination system. This was set up in response to the widely held belief by disabled people that needs assessment was budget driven. Needs Assessment is in principle now separate from

[4] The Human Rights Act was amended in 2000 to explicitly include disability.

Service Coordination, so that needs are assessed without any reference to resource availability.[5] However, these assessments are then passed on to the Service Coordination function which does the rationing. (Some disability groups see recent changes, although developed and framed in terms of empowerment of disabled people, as, in practice, a move away from the previous situation where people had entitlements to services towards what are in effect capped budgets without entitlements.) It is not entirely clear that disabled people have a *right* to a needs assessment, this is not explicitly stated in law or regulation; however, since an assessment is necessary to qualify for state provision of services, it is felt that such a right might indeed be upheld in court.

A set of rights for users of health and disability services are set out in the Code of Health and Disability Services Consumers Rights. This covers hospitals, doctors, special needs assessors, and other providers, whether public or private, and entitles consumers to *inter alia* non-discrimination and proper standards. An independent Director of Advocacy has been established to purchase, administer and promote advocacy services. Advocates and the Health and Disability Commissioner can assist in progressing a complaint, but providers are obliged to do only "what they reasonably can under the circumstances". In practice the Health and Disability Commissioner Act is used little by disabled people so far, and its emphasis is not on enforcing rights. Like the Human Rights Act, it has focused on mediation, low-level dispute resolution rather than case law determination of rights. Over 85 per cent of the complaints to the Health and Disability Commissioner are referred by the investigation service to the advocacy service, which so far appears to have functioned primarily as a complaints service.

This complaints mechanism is open only to those already getting health and disability services, not those who are unable to access services in the first place. Human rights-related legislation could perhaps be employed in such a situation, though this remains to be clarified. Availability of disability support services at present is seen as constrained in particular by workforce, training and remuneration issues.

4.6 Provision of Health and Social Services to People With Disabilities in Sweden

Social, economic and cultural rights are mentioned in the Swedish Constitution, but this does not give them the status of Constitutional rights that the individual can use in legal actions. The stated aim of policy is that people with disabilities have the same chance as others of participating in community life. Responsibility for achieving this objective is borne by society as a whole, but ultimately by the state, local authorities and county councils.

Social rights covering social services, health, and education are enshrined in law, and apply to people with disabilities in the same

[5] In practice, it appears the separation of needs assessment and service coordination may often be ignored in many districts.

way as everyone else. The ambition is for financial security and social rights to be guaranteed to all citizens – not by being focused on certain hard-pressed groups in society, but by being given to everyone. Each person who resides in a municipality has "a right to assistance from the social welfare board for his support and way of life in general"; this covers both cash assistance and care and other services. However, the right to assistance is not defined with any great precision in the (1980) Social Services Act, and the application of this right varies greatly from one municipality to another. The National Board of Health and Welfare issues general advice and guidelines to the municipalities, but these need not follow them. Appeals are processed by a system of administrative courts, but these decide every case on its merits without establishing precedents that would apply more generally. The county council is also responsible for public health and medical services, with supervision by the National Board of Health and Welfare. The (1982) Public Health and Medical Services Act leaves county councils with a good deal of freedom to organise these services according to local conditions.

Over and above these general provisions, there are a number of rights and financial benefits that supplement and augment welfare, notably for people with functional impairments. This is set out in special legislation, initially for "developmentally disabled persons", i.e. those with an intellectual impairment (1986) and then a broader codifying reform in 1994, the LSS (Support for Persons with Certain Functional Impairments). This is stated to be based on an environmental view of disability (a handicap is not viewed as a characteristic of a person, but as something that arises when a person with a functional impairment is confronted by an inaccessible environment) and on the principle of universal human equality of dignity and rights, so persons with functional impairment must be given the opportunity of taking part in the life of the community on the same terms as others. Social welfare services must endeavour to ensure that persons who for various reasons encounter considerable difficulties in their everyday life are enabled to participate in the life of the community and live on the same terms as others.

Division of responsibility is critically important in the Swedish case. The state is responsible for legislation, social insurance, planning, and setting out the objectives of policy. However the local authorities have basic responsibility for education, housing, child care and social services, and the county councils have primary responsibility for health care. Local authorities and county councils enjoy great freedom to decide on the quality and nature of the measures actually undertaken, and they themselves levy taxes to finance their work. It is the local authorities' social services that have ultimate responsibility for ensuring that all those who are resident in the area obtain the support and help they need.

In terms of responsibility for different types of benefits and services, the National Social Insurance Board provides full financial assistance for the hiring of personal assistants; financial assistance to

families for home care of a child with disabilities; and financial assistance for modifications to vehicles for disabled drivers. County councils provide free or subsidised travel; orthopaedic and technical aids and equipment (such as wheelchairs, lifts); rehabilitation services (including occupational therapy, physiotherapy and speech therapy); and extension education. Municipalities provide special housing; adaptations to housing; short-stay respite homes; support families; dedicated recreational facilities; and special schools.

A central element in the legislation is the appeal procedure. Those entitled under the legislation can appeal to county administrative courts if they are not receiving the services they believe they are entitled to, and about two-thirds of appeals are decided in favour of the individual. Refusals to provide the services is generally justified by lack of money (and there is no state subsidy to counties). For example, in refusing people applying for places in group homes, municipalities typically do not deny that the service was needed, but state no places are available. The administrative courts, including the Administrative Supreme Court, do not accept financial arguments where the need appears pressing (e.g. an individual with disability and living with elderly parents) but can do so when it is less urgent (e.g. an individual in an institution, where the policy of de-institutionalisation is being implemented over time). Further, the court judgments may not then be implemented: a significant proportion of positive judgments are ignored by the local authorities, and the national government and the courts have no power to force them to follow the law, there are no binding sanctions. Fines on such authorities were however introduced in 2000 by the National Board of Health and Welfare and are becoming increasingly common.

There is also a Disability Ombudsman appointed by the government to monitor the rights and interests of people with disability, so that people with various kinds of disability can participate fully in the life of the community and live on the same terms as others. This is based on the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly of the UN in 1993, which lay down what is required of a state to ensure that people with disability have the same opportunities as other citizens. Sweden has approved the Standard Rules and undertaken to comply with them. The Disability Ombudsman was established in 1994 among other things to monitor how the Standard Rules are observed in Sweden. (The UN Committee on Economic, Social and Cultural Rights has however criticised Sweden on the basis that the Covenant on Economic, Social and Cultural Rights is not fully incorporated into its legal system, so that the rights covered by it may not be directly invoked before the courts.)

The Disability Ombudsman investigates complaints from individuals who consider that they have been excluded or discriminated against owing to their disability. The investigation may be concluded by the Ombudsman issuing a formal opinion. The Ombudsman may also contact local authorities, businesses or other

organisations in order to achieve an improvement for people with disability. If the matter involves inadequacies in current legislation, the Disability Ombudsman can draw the attention of the Government to this. Lawyers in the Ombudsman's office also provide advice on rights, laws and rules, relating to, for example, employment, education or health care. A person who is dissatisfied with the decision made by an authority in those areas can, for example, get advice from the Ombudsman on how to appeal against it. As regards discrimination in employment only, staff of the Ombudsman may represent an individual in her/his action in the Labour Court.

The Ombudsman and disability rights organisations meet regularly to exchange information and develop collaboration, and the Ombudsman also collaborates with other authorities working within the disability sector, for example, the National Board of Health and Welfare, the National Board of Housing, Building and Planning, and the National Road Administration. The Disability Ombudsman also monitors work in the area within the EU, the Council of Europe and the UN, and together with Sweden's other Ombudsman organizations – including the Ombudsman for Equal Opportunities (focused on gender), the Ombudsman against Discrimination because of Sexual Orientation, and the Ombudsman against Ethnic Discrimination – participates in various international fora on human rights.

4.7 Provision of Health and Social Services to People With Disabilities in the UK

In the UK, the Disability Discrimination Act (DDA) (1995) gives disabled people rights in the areas of employment, access to goods, facilities and services, and buying or renting land or property. Part III of the DDA gives disabled people rights of access to everyday services that others take for granted. It is unlawful for a provider of goods, facilities or services to discriminate against disabled people by:

- refusing to provide a service without justification;
- providing a service to a lesser standard without justification;
- providing a service on worse terms without justification;
- failing to make reasonable adjustments to the way services are provided for disabled people;
- and, from the year 2004, failing to make reasonable adjustments to the physical features of service premises, to overcome physical barriers to access.

Those affected include, central and local government services, courts, hospitals and doctors' and dentists' clinics, and bus and railway stations. Cases where individuals feel the DDA has been breached can be brought to the Disability Rights Commission (DRC) and the county courts. The DRC is an independent body set up by the Government to help secure civil rights for disabled people.

However, health and social services per se are covered by the DDA only in the sense that a disabled person must not receive less favourable treatment in receipt of those services as compared to a

non-disabled person, as with any other service provided to a member of the public. There is no right to a specified level of services set nationally. The officially-stated aim is to ensure that there is no discrimination on the grounds of disability in delivering health and social services. Under health and social services legislation, entitlement to services is based largely on the assessment of need. In practice there is substantial variation in the delivery of services across the UK because eligibility criteria are set locally, by the relevant local authorities responsible for health and social services. It is however becoming clear that, once an individual is assessed as eligible, entitlement to services may be vindicated through the courts.

Statutory guidance on "Fair Access to Care Services" (Department of Health, 2002) has recently been developed and circulated to councils with social services responsibilities throughout England and Wales. This sets out a framework for determining eligibility for adult social care, covering how councils should carry out assessments and reviews of needs and support individuals through these processes. The aim is to have a more consistent approach to eligibility and fairer access to care services across the country. None the less, it is explicit that in setting their eligibility criteria local councils should take account of their resources, local expectations, and local costs. It is not intended that individuals with similar needs receive similar services up and down the country, and because of different budgetary decisions some councils will be able to provide services to proportionately more people seeking help than others. Case-law up to the House of Lords has made clear that councils are obliged to assess everybody who presents as needing their services, regardless of resources. Councils thereafter have to meet the person's "reasonable needs", they must have transparent eligibility criteria that enable them to prioritise what needs it is reasonable to meet, and in establishing those criteria they can take resources available into account.

As far as advocacy and support to ensure that people with disabilities get proper service or treatment from health and social services is concerned, Sections 1 to 3 of the Disabled Persons (Service, Consultation and Representation) Act 1986 provide for "authorised representatives"; this has not been implemented, but a recent government-appointed task force recommended that doing so could strengthen access for those people who would benefit from this type of representation. In terms of assessments for social care, the 2002 "Fair Access" guidelines set out that councils should promote the development of services that provide interpreters, translators, advocates, and supporters to help individuals access and make the best use of the assessment process. There should be one assessment, it should be rounded and person-centred, and where appropriate should take account of health and housing needs as well as social care. Councils should recognise that individuals are the experts on their own situations and encourage a partnership approach to assessment.

The Special Educational Needs and Disability Act (2001) seeks to improve the standard of education for children with Special Educational Needs and brings access to education within the remit of the Disability Discrimination Act. This makes it unlawful for education providers to discriminate against disabled pupils, students and adult learners. In addition, local education authorities and schools are now under a duty to plan to increase progressively the accessibility of schools to disabled pupils.

4.8 Key Findings from the Comparative Review

To conclude this chapter, we highlight the main findings from its review of approaches to provision of services to people with disabilities in some other countries,

In the USA, people with disabilities may have a right to assessment by statutory and local government health care and social services providers, but only in relation to the services those agencies provide. Anti-discrimination legislation does not provide a generalised right to a particular health or support service or standard of service for those with disabilities. It can nonetheless have a significant impact on service provision, as illustrated by the impact of the recent "Olmstead" Supreme Court ruling in promoting a shift from institutional to community-based care.

In Australia, classes of services to be provided to people with disabilities and standards to be met in the delivery of those services are set by the relevant Minister; the Disability Services Act makes explicit reference to resource constraints: "due regard must be had to the limited resources available to provide services and programmes under this Act".

New Zealand has set up a needs assessment and co-ordination system, which assesses needs without reference to resource availability, but these assessments do not entitle people to the services identified as needed: the distinct Service Co-ordination function is responsible *inter alia* for rationing.

In Sweden, social, economic and cultural rights are mentioned in the Constitution, but this does not give them the status of Constitutional rights which can be used in legal actions. Social rights covering health and social services are enshrined in law, but in practice the services available differ substantially from one area to the next.

In the UK, health and social services are not covered by the Disability Discrimination Act, and there is no right to a specified level of services determined nationally. Under health and social services legislation, entitlement to services is based largely on eligibility criteria set at local level and assessment of need carried out by the relevant local authority setting those criteria. Councils are obliged to assess everybody who presents as needing their services, regardless of resources. Councils thereafter have to meet the person's "reasonable needs", they must have transparent eligibility criteria that enable them to prioritise what needs it is reasonable to meet, and in establishing those criteria they can take resources available into account.

5. CONCLUSIONS AND IMPLICATIONS

5.1 Introduction

The adoption of a "rights-based approach" in legislation has come to constitute a core element being sought by groups representing people with disabilities and those working with them. This provides the rationale for the present study, which seeks to contribute to the on-going debate about how best to proceed legislatively in addressing services for people with disabilities in Ireland. In this concluding chapter, our aim is to highlight the key findings of the study and try to tease out their implications in a constructive fashion.

5.2 Economic and Social Rights

We have seen that current consideration of the rights-based approach to services for people with disabilities is taking place within a much broader debate about economic and social rights in Ireland as elsewhere. It is in the area of disability that these broader issues are first being addressed in very concrete terms, so the direction taken there may have implications for many other areas of economic and social policy. The present study makes clear that the assumption which often seems to underlie arguments from both proponents and opponents, that adopting a rights approach has a clear and transparent interpretation, is not in fact warranted. This means that a variety of approaches to delivering services, framing entitlements and instituting enforcement mechanisms can legitimately be seen as arising from a rights perspective.

In Ireland, the status of economic and social rights has been debated particularly in the context of the Constitution. The Constitution Review Group's majority decision against incorporation of new economic and social rights was driven by the arguments also most frequently advanced in the broader debate: that enshrining economic, social and cultural rights is an encroachment on democracy, transferring power from elected representatives to the judiciary, and that the resource implications are unwarranted and/or unpredictable. On the other hand, the recognition of economic and social rights in the Constitution, or in law, is argued by some proponents not to confer absolute personal rights regardless of cost. A common theme among those proponents is that those opposing such recognition do not appreciate that such rights could be framed or would be interpreted

in a manner that met their concerns about the implications for resource allocation.

It appears to be commonly taken for granted in the Irish debate that there is an integral link between the rights and justiciability – because it is either being assumed that rights always entail justiciability in principle, or that justiciability is in practice the only way in which rights can be effectively guaranteed. It is important to be clear that at the conceptual level rights need not necessarily be associated with the ability to have recourse to the courts, and in practice there may be alternative enforcement mechanisms which can allow rights to be effectively supported.

5.3 Disability and Rights

The logic of the rights-based approach is widely argued to apply with particular force in the area of disability. The Report of the Commission on the Status of People with Disabilities (1996) is widely seen as a watershed in Irish disability policy, setting the rights-based approach as the framework of reference. The perceived failure to base the Disability Bill presented to the Oireachtas in 2001 on an explicit rights foundation was critical to the government's decision to undertake a further consultation process. The proposals for core elements of a revised Disability Bill prepared by the Disability Legislation Consultation Group (DLCG) see a rights-based approach as central, and detail what they see that entailing.

The recent proposals produced by the DLCG in terms of services can be baldly summarised as follows. The individual's needs across the range of service areas are to be assessed independently, the services identified as needed by that assessment should then be made available as a right, and together with other rights to be set out in the legislation this should be justiciable. If the services one has been identified as needing are not made available, then one can – ultimately – go to court to enforce that right against the State.

At first blush, there seems to be a substantial divergence between such an implementation of the rights-based approach and the more qualified framing of economic and social rights advanced by some proponents. Those proponents emphasise for example the "progressive realization" of these rights and the State taking for example "reasonable steps to promote the general and progressive enjoyment" of economic and social rights "in view of actual conditions, resources and standards". The DLCG proposals do nuance the bald summary presented in the previous paragraph,[6] and these elaborations are open to different interpretations. However, on the face of it the import of the proposals still seems to be that

[6] The most important qualifications or elaborations in this respect are that in the event of services not being available "a programme of measures should be put in place in order to realize these services within an established timeframe", and that "detailed guidelines on effective systems, structures and processes for independent needs assessment should be made through Ministerial regulations which are supported by NDA Standards and Codes of Practice".

decisions about service provision and consequently resource allocation would be made by professionals and the courts, without reference to the Oireachtas and unconstrained by the availability of resources.

Without repeating the detailed findings of our review, the approaches adopted to provision of health and other support services in the other countries reviewed in Chapter 4 – the USA, Australia, New Zealand, Sweden and the UK – could not be characterised, and do not operate, in that way. In the USA people with disabilities may have a right to assessment by statutory and local government health care and social services providers, but only in relation to the services those agencies provide. Anti-discrimination legislation does not provide a generalised right to a particular health or support service or standard of service for those with disabilities. In Australia, classes of services to be provided to people with disabilities and standards to be met in the delivery of those services are set by the relevant Minister, and the Disability Services Act makes explicit reference to resource constraints. New Zealand has a needs assessment and co-ordination system which assesses needs without reference to resource availability, but these assessments do not entitle people to the services identified as needed: the distinct Service Co-ordination function is responsible *inter alia* for rationing. In Sweden, social rights covering health and social services are enshrined in law, but in practice the services available differ substantially from one area to the next. In the UK, entitlement to services is based largely on eligibility criteria set at local level and assessment of need carried out by the relevant local authority setting those criteria. Councils are obliged to assess everybody who presents as needing their services, regardless of resources. Councils thereafter have to meet the person's "reasonable needs", they must have transparent eligibility criteria that enable them to prioritise what needs it is reasonable to meet, and in establishing those criteria they can take resources available into account.

5.4 Transparency and Entitlement

We have argued that adoption of a "rights approach" to the provision of disability-related services would not necessarily involve acceptance that independent assessment of need carry with it justiciable rights to services. Such a combination, though seen by people with disabilities as desirable or indeed essential, might be expected to be anathema to those arguing that economic and social rights differ fundamentally from civil and political rights, and that the separation of powers is the best guarantor of not only civil and political liberty but also economic and social progress. The position currently adopted by many people with disabilities no doubt reflects their long-running experience of services that do not meet their needs and their disappointment with alternative approaches, but if carried to the extreme it runs the risk that "the best may be the enemy of the good": an impasse would be to no-one's advantage.

Without in any way pre-judging how the political process is likely to address current legislative issues, it may be worth seeing if there are ways to make progress incrementally while leaving the most hotly contested issues, relating to justiciability and to ultimate control of resources in particular, to one side.

With this in mind it may be useful to distinguish two different aspects of service provision: what people actually receive, and what they are entitled to and know they can access. At present, people with disabilities face not only what they clearly regard as seriously inadequate levels of service provision. They also face the frustration of not (generally) having an entitlement to those services, and very often having to work hard to find out and access what is available. (Much of this also applies to users of for example the health services generally.) There is little transparency in the way the resources made available nationally are allocated, and at local level there may be substantial variation in the services available from area to area or Health Board to Health Board. Those seeking to access services are to a large extent disempowered, at the mercy of what they may well see as arbitrary or capricious decisions by various organs of the state.

For those with long memories this has echoes of the system whereby, up to the early 1970s, those in need but not meeting the qualifying conditions for the various social welfare schemes could apply for safety-net income support through "Home Assistance". The scope for local discretion and lack of formalised entitlement meant that there was substantial variation across areas in the amounts actually paid out, and the scheme was replaced in 1973 by Supplementary Welfare Allowance, with nationally-set qualifying criteria and payment rates.

In the same vein, it is worth tentatively suggesting that it would be a significant advance if:

- the state, through the relevant authorities, set out clearly what level of service provision the current level of resource is intended to underpin;
- people with disabilities not only knew what this level of service provision was at individual level, but had an entitlement to those services with associated enforcement mechanisms;
- It was also set out in concrete terms how services are to be improved over time as more resources become available.

Once again this obviously has parallels with the current situation with respect to social welfare payments. The Oireachtas votes each year on the level of payment for each social welfare scheme, but people then have an entitlement to that level of support if they meet the qualifying conditions, with a formal appeals procedure. A system of entitlements is thus entirely consistent with the primacy of the legislature. The actual level of expenditure in a given year on social welfare may well be different to that budgeted for, because the numbers claiming on different schemes may differ from that anticipated in framing the budget. The granting of entitlements does in that way dilute the most direct form of control over resources,

but adjustments can be made to those entitlements in subsequent years, if necessary, to fit within the resources the political process decides to make available.

It may be objected, with some force, that the parallel is unhelpful because service provision cannot be seen in the same light as social welfare payments. The contingencies being dealt with are much more varied, and the decision is not simply whether someone is or is not to benefit, but rather which services and to what level they should receive. In addition, the case for discretion and judgement in the allocation of the available resources to maximise the benefits may well be stronger in the case of services. However, it hardly seems conducive to either efficiency or equity if the state is not in a position to set out clearly the level of services that it aims to make available with a given quantum of resources. Indeed, if it cannot say that, how can rational decisions about either the size of the overall resource bundle for those services or its allocation across different uses be made?

Having arrived at a position where the state was able to specify the level of services it intends to make available, attributing that as an entitlement to individuals would be possible. As well as working to empower the individual, this could provide another lever to promote efficiency in the production of services. It may once again be objected that services are different to cash transfers and that it is much more difficult to define entitlement in an operational way. It may also be asked why there should be entitlements to services for people with disabilities when there is no generalised entitlement to, for example, health services for the population as a whole. While it is certainly true that framing a system of entitlements to services is challenging, the Health Strategy *Quality and Fairness: A Health System for You* has in fact already set out a commitment to preparing new legislation "to move away from the rather theoretical model of 'eligibility' to a system of entitlement to services within a reasonable timeframe" (p. 74).

Furthermore, in thinking about service provision there is an increasing emphasis on "attaching the money to the person", as reflected, for example, in the DLCG's proposals emphasis that funding should be attached to the person, so that where possible people with disabilities are responsible for organising their own provision. It may then be possible to define areas and degrees of need and identify the base level of resources to be devoted to each, in the form of cash transfers or direct provision. Anyone meeting the criteria would be entitled to that level of support, with resources for additional needs adjudicated on through a transparent process.

It may also be objected that key service provision decisions are often made at local rather than national level, at the level of the Health Board for example, and that the discretion this provides is an essential element in current structures. Once again this is an issue that will have to be faced in the health services context as well. The best balance between (local) discretion and (national) rules is always a difficult one to find. A system of entitlements could clearly allow for some scope for discretion at local level but specify a minimum

set of services applying throughout the country. Any meaningful system of entitlements also has to have a credible appeals and enforcement mechanism, and international experience suggests a range of approaches are possible in that regard.

Having spelt out the level of services it sees as underpinned by current resources, the state would also be in a position to set out in concrete terms how it intends to progressively improve the services made available over time as resources become available. A system of independent assessment of needs for people with disabilities could then play a key role. While this assessment would not automatically mandate access to the full range of services seen as needed by the assessors, a clear picture of the gap between actual and desired services would be seen, and that could be a critical input into the planning process. It would also serve to inform the public debate and political process in addressing the issue of resource allocation.

The discussion here has been at a high level of generality and the practical difficulties to be faced in developing a transparent system of service provision and entitlements are not to be underestimated. Success is not guaranteed and certainly could not be arrived at overnight, but, if set out as a priority objective, could be worked towards over a period. Many of the challenges involved will have to be dealt with anyway if the Strategic Management Initiative is to be fully implemented in the public service and the capacity to make long-term planning and resource allocation decisions is to be properly developed. From the perspective of those advocating a rights approach, the framing of entitlements would be a crucial step forward and the gap between what is currently provided and what is independently assessed as required would become visible. From the perspective of those arguing for the primacy of the political process, that transparency would be a key ingredient in promoting informed public debate and the making of resource allocation and redistributive choices through that process.

REFERENCES

COMMISSION ON THE STATUS OF PEOPLE WITH DISABILITIES, 1996. *A Strategy for Equality: Report of the Commission on the Status of People with Disabilities*, Dublin: Stationery Office.

COMMONWEALTH DEPARTMENT OF HEALTH AND FAMILY SERVICES, 1994. Disability Strategy: A ten year framework for Commonwealth departments and agencies, Commonwealth of Australia, Canberra.

AN AGREED PROGRAMME FOR GOVERNMENT BETWEEN FIANNA FAIL AND THE PROGRESSIVE DEMOCRATS, 2002. Dublin: Stationery Office.

DALY, M., 2002. *Access to Social Rights in Europe*, Strasbourg: Council of Europe.

DEPARTMENT OF HEALTH (UK), 2002. *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*, Local Authority Circular LAC(2002)13, London: Department of Health.

DEPARTMENT OF HEALTH AND CHILDREN, 2001. *Quality and Fairness: A Health System for You, Health Strategy*, Dublin: Stationery Office.

DEPARTMENT OF THE TAOISEACH, 2003. Ireland and the European Union: Identifying Priorities and Pursuing Goals, Dublin: Department of the Taoiseach.

DISABILITY LEGISLATION CONSULTATION GROUP, 2003. *Equal Citizens: Proposals for Core Elements of Disability Legislation*, Dublin: National Disability Authority.

FORUM OF PEOPLE WITH DISABILITIES, 2001. *Advocacy: A Rights Issue*, Dublin.

GET YOUR ACT TOGETHER: CONFERENCE REPORT, 2002. Dublin: Forum of People with Disabilities, People with Disabilities in Ireland, Disability Federation of Ireland, National Association for the Mentally Handicapped in Ireland. Email: info @disability-federation.ie

HUMAN RIGHTS COMMISSION, 2003a. *Observations on the Proposals Paper of the Disability Legislation Consultation Group (DLCG) From the Perspective of the International Covenant on Economic, Social and Cultural Rights*, Dublin.

HUMAN RIGHTS COMMISSION, 2003b. *Promoting and Protecting Human Rights in Irish Society – A Plan for 2003-2006*, Dublin.

HUNT, P., 2001. *Narrowing the Gap Between Rich and Poor*, Dublin: Presentation to Combat Poverty Agency Conference, May.

IRISH COMMISSION FOR JUSTICE AND PEACE, 1998. *Re-Righting the Constitution: The Case for New Social and Economic Rights: Housing, Health, Nutrition, Adequate Standard of Living.* Dublin: Irish Commission for Justice and Peace.

McDOWELL, M., 2002. Speech to Annual Conference of the Irish Social Policy Association, Dublin: Dublin City University, September.

MINISTRY FOR DISABILITY ISSUES. 2001. *The New Zealand Disability Strategy Making a World of Difference Whakanui Oranga*, New Zealand: Wellington.

NATIONAL ANTI-POVERTY STRATEGY, 2002. *Building an Inclusive Society; Review of the National Anti-Poverty Strategy under the Programme for Prosperity and Fairness*, Dublin: Department of Social, Community and Family Affairs.

NATIONAL ECONOMIC AND SOCIAL COUNCIL, 1999. *Opportunities, Challenges and Capacities for Choice*, Report No. 105, Dublin: National Economic and Social Council.

NATIONAL ECONOMIC AND SOCIAL COUNCIL, 2003. *An Investment in Quality: Services, Inclusion and Enterprise*, Report No. 111, Dublin: National Economic and Social Council.

QUINN, G., 2001. "Rethinking the Nature of Economic, Social and Cultural Rights in the Irish Legal Order" in C. Costello (ed.), *Fundamental Social Rights: Current European Legal Protection and the Challenge of the EU Charter of Fundamental Rights*, Dublin: Irish Centre for European Law.

QUINN, G., 2002. "Ireland and International and Comparative Disability Law Reform", mimeo.

QUINN, G., 2003. "The European Social Charter and Its Significance in Ireland," Paper to Conference on The European Social Charter, Dublin Castle, Dublin, March.

QUINN, G., T. DEGENER, *et al.*, 2002. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, New York and Geneva: United Nations.

REPORT OF THE CONSTITUTION REVIEW GROUP, 1996. Dublin: Stationery Office.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 1994. *General Comment No. 5, Persons with Disabilities*, December, Geneva: UNHCR.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 1998a. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Canada*, E/C.12/1/Add.31. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 1998b. *General Comment No. 9, The Domestic Application of the Covenant*, E/C.12/1998/24. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 1999. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Denmark*, E/C.12/1/Add.34. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 2000. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Australia*, E/C.12/1/Add.50. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 2001. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Sweden*, E/C.12/1/Add.70. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 2002a. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Ireland*, E/C.12/1/Add.77. UNHCR, Geneva.

UN COMMITTEE ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS, 2002b. *Concluding Observations of the Committee on Economic, Social and Cultural Rights: UK*, E/C.12/1/Add.79. UNHCR, Geneva.

WHYTE, G., 2001. *Social Inclusion and the Legal System: Public Interest Law in Ireland*, Dublin: Institute of Public Administration.

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23. *A Report on the Impact of Agricultural Schemes and Payments on Aspects of Ireland's Heritage*, The Heritage Council, Kilkenny (1999, D. Hickie, E. Smyth, U. Bohnsack, S. Scott, D. Baldock, €12.70). Full text available on internet at http://www.heritagecouncil.ie/publications/agriherit/index.htm.
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