

# **NEW DIRECTIONS**

**REVIEW OF HSE DAY SERVICES AND IMPLEMENTATION PLAN 2012 - 2016**

**PERSONAL SUPPORT SERVICES FOR ADULTS WITH DISABILITIES**

## **Working Group Report**

**February 2012**



**Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive**

This document was produced in consultation with the National Adult Literacy's Plain English Service.

## Foreword

The proposed new approach to adult day services charts new territory and has been titled ***New Directions***. It envisages that all the supports available in communities will be mobilised so that people have the widest possible choices and options about how they live their lives and how they spend their time. It places a premium on making sure that being part of one's local community is a real option. It recognises that people with severe and profound disabilities may need specialised support throughout their lives. The guiding principle for the future is that supports will be tailored to individual need and will be flexible, responsive and person-centred.

Having choices, doing interesting and useful things with one's time, learning new skills, meeting people and enjoying their company – these are things that most people take for granted. These are the ordinary experiences that people with disabilities tell us they want. The way in which adult day services has evolved over the years has tended to get in the way of these reasonable expectations. Our adult day services have, for the most part, been organised as segregated services, separate from local communities and offering limited options, experiences and choices. This report is making radical proposals and recommendations to change that.

***New Directions*** calls for a blurring of the boundaries between 'special' and 'mainstream' services so that people can access the support most suited to helping them put their personal plans into action. It challenges people with disabilities to have high expectations for themselves and of their community. It also challenges families and services to adopt an attitude of positive risk-taking. It encourages providers to provide greater outcomes from their current service.

The Health Service Executive (HSE) must introduce new and innovative ways of funding services that support choice, person-centeredness, accountability and best value.

In the course of the work of our group, it became clear that there is already a commitment to change in day services. Many providers have moved ahead, with new kinds of services and better ways of doing things. There is knowledge, skill and experience among service providers and advocacy organisations which will help to embed cultural and system change.

An ambitious change management process and systems to deliver quality and strengthen long-term planning will need to be mobilised and progressed.

Implementation must take place within the framework of the existing resources allocated to the Health Service Executive. I am confident that through a continuation of the sustained collaborative effort that was such a positive feature of our work that considerable progress can be made. The measures to consider first are those that can be achieved on a cost-neutral basis.

People with disabilities, families, service providers and funders want to see real change in adult day services. This report details the best way forward towards meeting these expectations. I am confident it will be a welcome contribution to the ongoing development of policy in relation to the organisation and delivery of all disability services in the future.



---

Leo Kinsella  
Area Manager HSE Cavan & Monaghan  
Chairman National Working Group

## Contents

1	Introduction.....	8
1.1	Purpose of the Review .....	8
1.2	Programme of Work .....	8
1.3	Public Consultation.....	9
1.4	Research Programme .....	9
1.5	Census .....	10
1.6	Priority Issues of Concern .....	10
1.7	The Report.....	11
2	Executive Summary.....	13
3	<i>New Directions: Vision for Future Service Provision</i> .....	20
3.1	Introducing <i>New Directions</i> .....	20
3.2	<i>New Directions: Making it Happen</i> .....	22
4	The Principles, Laws and Policies that Guide <i>New Directions</i> .....	26
4.1	Legal and Policy Framework for <i>New Directions</i> .....	26
4.2	Guiding Principles .....	26
4.3	Legislative and Policy Developments Shaping <i>New Directions</i> .....	27
4.4	Impact and Significance of these Laws and Policies .....	32
5	Current Day Services.....	34
5.1	How Day Services have Evolved.....	34
5.2	Current Day Services.....	35
5.3	Number of Service Providers and Service Locations .....	39
5.4	Disabilities and Age Range of Service Participants .....	41
5.5	Programmes, Activities and Service Models in which Adults with Disabilities Participate .....	42
5.6	Hours of Attendance.....	44
5.7	Individual Planning.....	45
5.8	Range and Number of Staff Employed in Day Service Provision.....	46
5.9	Funding for Day Services .....	47
6	The Consultation: What We Learned From Service Users, Families and Service Providers .....	48
6.1	Messages from the Consultation .....	48
6.2	People’s Day-to-Day Experience of Services .....	48
6.3	How Services are Planned, Funded and Monitored .....	55
6.4	Summary.....	60
7	What We Learned from the International Research .....	62
7.1	The Shift in Thinking about Disability.....	62
7.2	Challenges in Moving to a Social Model that Offers Individualised Supports .....	63
7.3	The Concept of Person-Centeredness.....	64
7.4	Moving to a Responsive Person-Centred Approach .....	67
8	<i>New Directions: Personal Support Services for Adults with Disabilities</i> .....	70
8.1	An Overview of <i>New Directions</i> .....	70
8.2	Core Values of <i>New Directions</i> .....	71
8.3	Introducing the Personal Supports .....	74

9	Making it Happen: the Changes Needed to Implement <i>New Directions</i>	108
9.1	Supporting the Change Management Process	109
9.2	Policy into Action – Using the National Disability Strategy to support the delivery of <i>New Directions</i>	114
9.3	Strengthening Capacity for Person-Centeredness	117
9.4	Clarifying the Future Role of the HSE in Employment, Training and Work Opportunities	123
9.5	Strengthening HSE Systems for Planning, Monitoring and Quality-Assuring Service Provision	133
9.6	Aligning Funding Systems with the New Service Approach	137
10	Addressing the Priority Issues	141
10.1	Overview	141
10.2	The Approach to Addressing the Priority Issues	141
10.3	Clarifying the future role of the HSE in Employment, Training and Work Opportunities	142
10.4	Strengthening the HSE Systems for Planning, Monitoring & Quality-Assuring Service Provision	151
10.5	Strengthening Capacity for Person-Centeredness	154
10.6	Day Services provided through a Residential Funding Stream	159
11	Implementation Plan	162
	Acknowledgements	177
12	Appendices	179
12.1	<i>New Directions</i> Appendices	179
	Appendix 1 – Terms of Reference for the Review	179
	Appendix 2	185
	Membership of the National Working Group and National Disability Steering Group	185
	Appendix 3	187
	Review Methodology	187
	Appendix 4	197
	Public Consultation	197
	Appendix 5	205
	Census Methodology	205
	Appendix 6	207
	A Summary of Departmental Sectoral Plans	207
12.2	Priority Issues of Concern Appendices	209
	Appendix 7	209
	Membership of the Priority Issues of Concern Project	209
	Appendix 8 - Overview of PIOC Project Methodology	211
	Appendix 9	214
	Case Management Data, Work and Employment Activities – Methodology	214
	Appendix 10	216
	Person Centred Exploration Process - Methodology	216
	Appendix 11	218
	Qualitative Research	218

## **List of Tables**

Table 5-1 Programme Descriptors .....	36
Table 5-2 Service Locations Providing Day Services catering for categories of Disabilities .....	40
Table 5-3 Hours of Attendance at Day Service Programmes .....	44
Table 5-4 Range of Planning Processes in Use.....	46
Table 5-5 Staff Groups Involved in Delivery of Day Services.....	46
Table 10-1 Number of Service Users engaged in Sheltered Work Activities in 2010 .....	145
Table 12-1 People and Organisations who Made a Formal Submission.....	198
Table 12-2 Attendance at Public Consultation Meetings .....	202

## **List of Diagrams**

Figure 5-1 Disability of Service Users.....	41
Figure 8-1 Personal Supports Services for Adults with Disabilities.....	75
Figure 12-1 Management and Governance Arrangements: Project Organisation Structure.....	187
Figure 12-2 People and Organisations who made a Formal Submission .....	199
Figure 12-3 Submissions by Type of Disability .....	200
Figure 12-4 Geographic Source of Submissions.....	201
Figure 12-5 Management and Governance Arrangements: Project Organisation Structure.....	211

# **1 Introduction**

## **1.1 Purpose of the Review**

The purpose of the review of HSE funded adult day services, which began in August 2007, is to reconfigure and modernise HSE funded day services to embrace the principles of person-centeredness, access, accountability and quality.

The terms of reference for the review state that the new approach should deliver better outcomes for service users, provide good value for money and be in line with relevant legislation, national standards and best practice<sup>1</sup>.

## **1.2 Programme of Work**

The Primary Community and Continuing Care Directorate initiated the National Review of HSE Funded Adult Day Services based on a recommendation from the National Review of Sheltered Services which had been completed in 2007. A National Working Group<sup>2</sup> (NWG) was set up in August 2007 to conduct the National Review of HSE Funded Adult Day Services. The membership represented advocacy groups, service providers, policy makers and the research community. It also reflected the three strands of disability – intellectual disability, mental health difficulties, and physical and sensory disability. The NWG undertook a major programme of work to help it to make recommendations for a modern, person-centred day service<sup>3</sup>.

---

<sup>1</sup> The detailed Terms of Reference of the review are contained in Appendix 1 – Terms of Reference for the Review.

<sup>2</sup> See Appendix 2 for Membership of the National Working Group.

<sup>3</sup> A description of the methodology used for each element of the work programme is set out in Appendix 3.



The NWG commissioned an extensive independent national public consultation<sup>4</sup>, a programme of research and a census of current day service provision. The work programme also included a demonstration phase, where day service innovations being applied by providers were demonstrated in partnership with them.

### **1.3 Public Consultation**

The objective of the public consultation was to gather the views of those with an interest in adult day services.

The consultation comprised three elements:

1. People with disabilities, service providers and other interested parties were invited to make a formal submission.
2. People in need of a day service, service participants, families and carers participated in focus group meetings.
3. Four open public consultation meetings were held around the country.

### **1.4 Research Programme**

The objectives of the research programme were to:

- review the literature, documentation and practice in adult day services from both national and international perspectives;
- identify and document the issues that are shaping the development of adult day services nationally and internationally;
- describe and critically evaluate models of modern person-centred adult day services for all disability groups that can be drawn upon for future HSE funded adult day service provision.

---

<sup>4</sup>The methodology used in conducting the consultation is described in Appendix 4.

## **1.5 Census**

The objective of the census was to gather information about all aspects of adult day services. The work involved developing a questionnaire to capture relevant information about service provision, arranging data collection and analysis, and identifying from the data analysis key issues to be addressed in a reconfigured, modernised service<sup>5</sup>.

The census included questions on innovative practice that gave service providers an opportunity to describe new developments and the challenges they experienced in introducing innovation into their services.

## **1.6 Priority Issues of Concern**

Following completion of *New Directions*, the report was considered by HSE at national level and by the Office of the Minister for Disability and Mental Health (ODMH). It was jointly agreed that a number of areas of recommendation in *New Directions* required immediate action. The Priority Issues of Concern Project (PIOC) was established to address these issues concurrently with the consideration of the main report by HSE and ODMH. The work of the PIOC has been incorporated into the final report of *New Directions*.

The work of the Priority Issues of Concern project was undertaken through a series of work modules that addressed each of the issues on which work was undertaken.

---

<sup>5</sup> The census methodology is described in detail in Appendix 5.

## 1.7 The Report

Chapter 2 *Executive Summary* summarises the rationale for the review, the programme of work undertaken, the review outcomes and the ambitious change agenda required to implement the new vision for day services.

Chapter 3 ***New Directions: Vision for Future Service Provision*** describes the vision for adult day services in the future and the changes and developments that will be needed to bring about the new approach.

Chapter 4 *The Principles, Laws and Policies that Guide **New Directions*** describes the legislative and policy framework within which adult day services work.

Chapter 5 *Current Day Services* describes how current day services evolved and sets out the current service information obtained from the census of day services.

Chapter 6 *The Consultation: What We Learned from Service Users, Families and Service Providers* describes what people with disabilities, families, services providers and the public think is working well, what is not working so well, and what people would like to see in future day service provision.

Chapter 7 *What We Learned from the International Research* describes the key findings from the research commissioned to inform the review.

Chapter 8 sets out the detailed proposals for ***New Directions: Personal Support Services for Adults with Disabilities*** and describes what ***New Directions*** will mean for service users. The key modernisation and reconfiguration issues to deliver ***New Directions*** are also included.

Chapter 9 *Making it Happen - the Changes Needed to Implement **New Directions*** sets out the recommendations for the programme of change, reconfiguration and development needed to deliver ***New Directions***.

Chapter 10 *Addressing the Priority Issues* - describes the work of the Priority Issues of Concern Project on those issues identified for immediate action, and outlines the proposals made by the Project Team for addressing these priority issues.

Chapter 11 The *Implementation Plan* details the planned implementation of the actions needed to make ***New Directions*** happen and the proposed timeframe for these actions.

**Note:** As noted earlier in the Introduction, the HSE, in consultation with the Office for Disability and Mental Health prioritised a number of areas of recommendation in *New Directions* for immediate action, and work was commenced on these. These areas concerned the need to act to minimize any vulnerability for some key population groups, the need to expedite legal clarity for certain groups in sheltered work situations, and the need to make urgent progress on the development of a quality system for *New Directions*. The report on the work done to progress these issues has been incorporated into the final *New Directions* report.

## **2 Executive Summary**

Day services for adults with disabilities provide a vital network of support for over 25,000 people. The people who use these services have a widely diverse set of interests, aspirations and personal circumstances. They are people with physical and sensory disabilities, with learning disabilities and with mental health difficulties. They include young people, people who have been in day services for many years and older people of retirement age. They live in small communities, in isolated rural areas and in cities and towns. The challenge for the review of HSE funded adult day services was to make proposals for a modern service that can respond to these unique and diverse individual needs.

The work programme undertaken by the National Working Group included:

- a census of current day service provision;
- a wide consultation with all stakeholders;
- a programme of international and Irish research; and
- a demonstration phase highlighting innovations being tried by providers.

This work programme was designed to guide, and provide an evidence base for, a modern, reconfigured service.

The census highlights the diversity of current day services and the absence of nationally agreed or clear definitions about what constitutes a day service. It describes a diversity of programmes and activities that have developed without the benefit of a coherent national guidance framework. There is a wide variability in the use of essential tools such as individualised planning and quality assurance systems.

The census identifies the numbers of people over the age of 65 in day services and points to the lack of opportunities for progression, as a result of which many people remain in services that do not address their changing needs as they move through

the life cycle. The need for appropriate services for the ageing population has been highlighted. Funding systems are also diverse and inconsistent.

The census provides data on the time spent by service users in work-related activity of various kinds, using a set of descriptors developed for the census. This data shows the numbers of service users who may be engaged in work-related activities to a degree that their status may border the legal definition of an employee. It pinpoints the need to take steps to clarify and regularise their position. The report on innovative practice that was conducted as part of the census shows the extent to which service providers have been taking initiatives to modernise services and, in particular, to give service users choices about how they live their lives.

The consultation gave an opportunity for people with disabilities, families, carers, service providers and the general public to make submissions and to attend public meetings where they gave their views about current day services and how they should be improved. Over 1,500 people contributed to the consultation.

The consultation highlighted the striking differences in people's experiences of services, underlining the need for quality assurance systems and support for providers to help them to achieve common standards. The absence of choice and the time spent doing nothing, or doing repetitive activities of little use or value to the individual, was a common theme in the consultation, alongside stories of good experiences and worthwhile activity.

People with disabilities were clear that they want to do worthwhile things that fit with their interests and aspirations for their lives. Training and work are very important to them. They want to do ordinary things in ordinary places and to be part of their community. They want support to be independent and they want to be able to make choices and plans for their lives. They also want to have the support they need to do that. People want to have a say about what happens in the service they attend, to help shape policy and to influence how services are run.

People with disabilities want a 'joined-up service' that enables them to move easily between HSE services and the services provided by other government agencies. They want to know how to access services and to have the information and guidance to make good choices about which service to attend.

Providers want appropriate funding, transparent funding systems and adequate staffing levels to meet the diversity of needs and to provide for people on waiting lists or with very limited access to a day service. They argue for quality standards based on person-centred principles, along with systems for monitoring services and support to provide services that meet these standards.

The research programme conducted as part of the review looked at policy and practice in relation to day service provision to identify best current thinking from both a national and international perspective. The research findings highlight the fundamental shift that has resulted from the social model of disability and the commitment to person-centeredness, which builds on that social model.

Person-centeredness challenges organisations to move away from segregated service practices that limit people's social roles. It places a premium on community inclusion, on supporting people to build their capacities and competencies, and on helping people to discover and make use of their unique abilities so that they can make a valued contribution to their community.

The research describes the change processes needed to embed a person-centred approach to service provision. These change processes require a strong national vision, cultural change among providers and funders, support for innovation, funding systems that facilitate individual choice, and an expanded array of demand-led, individualised services that let service users exercise choice and control over decision-making about their service.

These strands of the work programme provided clear direction to the National Working Group (NWG). Based on the findings, the NWG proposes that day services

in the future take the form of a menu of 12 individualised, outcome-focused supports which will allow adults in day services to live a life of their choosing in accordance with their own wishes, aspirations and needs.

This new approach to adult day services will be known as ***New Directions***. The range of supports to which individuals will have access should equip them to:

- make choices and plans to support personal goals;
- have influence over the decisions which affect their lives;
- achieve personal goals and aspirations; and
- be active, independent members of their community and society.

The nature of the supports offered to an individual will depend on the particular needs and abilities of that individual. It will be the responsibility of the service provider to work with each individual to tailor the programme of supports to their individual needs, according to their person-centred plan. The focus of ***New Directions*** in any service delivery setting should take account of the capacities of service users and the diversity of their needs.

The programmes offered by the service provider should deliver the 12 supports that make up ***New Directions***. In line with the principles of person-centred planning, the individual's participation in any programme or skill development module offered by the service provider should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen.

The process of reconfiguring and modernising adult day services to deliver ***New Directions*** will mean significant change for many service providers, depending on the gap between their current approach to provision and the needs of an individualised, person-centred approach. Providers may need to make changes to programme design and content or to individual planning processes. They may need to adjust staff roles and introduce greater flexibility to respond in a holistic way to people's needs. Organisational culture may need to change. All service providers will have to work with the HSE to prepare their plans for delivering ***New***



**Directions** within the quality assurance framework that the HSE will develop. Through the Priority Issues of Concern Project described in the Introduction, work begun by the National Working Group on the development of a quality assurance system to underpin the delivery of *New Directions* has been advanced.

The work programme identified the need for action by the HSE to address the needs of some key population groups. The HSE should work with service providers to make sure that older people in current day services have access to a continuum of care that respects their rights, dignity and choices and that is provided within the relevant older person's policy and legislation.

The HSE, together with the Office for Disability and Mental Health, should also engage with providers of day services to children under the age of 18 (both HSE and non-statutory providers) and with the Department of Education and Skills to make sure that those children can access suitable support services and that all support services comply with approved childcare guidelines and legislation.

Work was begun to progress the report's recommendations in relation to people over 65 and children under 18 in day services, immediately on presentation of *New Directions* to the HSE and the Office for Disability and Mental Health in order to take person-centered action in relation to any vulnerabilities for these groups.

The review examines the role of the HSE in relation to employment, training and work opportunities and makes proposals for the future role of HSE funded services in these areas. The 'drivers' for the future role of the HSE in relation to employment, training and work opportunities are:

- the need for HSE funded services to fit within the HSE's remit for provision of health and personal social services;
- the need to conform to government policy on the transfer of responsibility for employment programmes and supports to the Department of Jobs, Enterprise and Innovation (DJEI) and FÁS;

- the need to make sure there is legal clarity about the employment status of people currently in HSE supports or programmes and to minimise any legal risk for the HSE or providers, while making person-centred provision for participants who may transition to ***New Directions***;
- the need to engage with DJEI to make sure that in future there are seamless links between HSE funded supports and mainstream employment supports.

The HSE should no longer be involved in providing sheltered or supported employment and should engage with the Department of Jobs, Enterprise and Innovation about transferring responsibility for these services to DJEI.

For those adults whom the census found to be in various forms of sheltered work, as distinct from sheltered employment, it is essential to review their status in the light of modern culture and legislation. The HSE cannot allow the situation to continue where there is ambiguity for these adults about their employment and entitlements, and where there is potential legal risk for providers. The people involved should be offered a person-centred planning process where they can explore options and choices and be offered alternative options within the scope of the HSE support services.

The outcome of this process may indicate a requirement for policy-makers to examine the need for a developed sheltered work or 'like work' programme that bridges therapeutic work and formal sheltered employment.

Structured work began immediately on resolving the situation of service users in a range of sheltered work settings where there was an identified need for legal clarity about their employment status, a need to minimise any legal risk for the HSE or providers, and in order to examine person-centered provision for this group in the context of *New Directions*. The person-centered exploration process undertaken with this group underline the value they place on work.

The ambitious change envisaged in ***New Directions*** is strongly linked to the implementation of the policy of mainstreaming that is a core part of the National Disability Strategy. Support and engagement from all the stakeholders who can advance the Strategy will be key to the success of ***New Directions***.

The scale of change involved in ***New Directions*** requires the support of a large-scale change management plan. The NWG proposes that the HSE should put in place a national change management plan in partnership with representatives of service participants, service providers, Government departments, local authorities and key mainstream agencies.

### **3 New Directions: Vision for Future Service Provision**

#### **3.1 Introducing *New Directions***

The new approach to adult day services will be known as ***New Directions: Personal Support Services for Adults with Disabilities***. ***New Directions*** will involve a radical shift from provider-led programmes to individualised, user-led supports. In the new approach, each adult will have access to flexible and outcome-driven supports to enable them to live a life of their choosing that meets their own wishes, aspirations and needs. The core purpose of the supports will be to enable people to participate as equal citizens in their community and to contribute to that community.

The range of supports to which the individual has access should equip them to achieve the following outcomes and goals:

- to make choices and plans to support personal goals;
- to have influence over the decisions which affect their lives;
- to achieve personal goals and aspirations;
- to be active, independent members of their community and society.

The nature of the support will depend on the particular needs and abilities of each individual. It is the responsibility of the service provider to work with each individual to tailor the provision to the individual's needs.

The **personal supports** that should in future be available to an adult with disability are:

1. support for making choices and plans;
2. support for making transitions and progression;
3. support for inclusion in one's local community;
4. support for accessing education and formal learning;
5. support for maximising independence;

6. support for personal and social development;
7. support for health and wellbeing;
8. support for accessing bridging programmes to vocational training;
9. support for accessing vocational training and work opportunities;
10. support for personal expression and creativity;
11. support for having meaningful social roles;
12. support for influencing service policy and practice.

***New Directions*** should accommodate the wide diversity of individual need among service users. This spectrum of need ranges from those with severe and profound learning disability, challenging behaviour and high support needs who are likely to need long-term, specialist service provision to people with lower support needs and greater potential for community participation and inclusion.

***New Directions*** will be based on the core values of person-centeredness, community inclusion, active citizenship and high-quality service provision. It will be underpinned by good governance, monitoring and guidance for providers.

### **3.1.1 Person-Centeredness**

When services are person-centred, the service provider truly listens to and respects the choices that the individual makes and tailors services and supports around these choices. The service provider uses creativity and flexibility to support the person to achieve his or her chosen goals. They also look beyond the options that can be offered within the boundaries of their own service. Staff help the individual and his or her family to manage risk and challenge and to have high expectations for the individual. As a result, the individual grows in relationships in natural community settings and experiences the benefits of holding valued social roles.

### **3.1.2 Community Inclusion and Active Citizenship**

When services are directed to supporting community inclusion and active citizenship, individuals will be empowered to be part of their local community and to

play an active part in that community. They will have the support they need to get to know people in their community, to live and work in ordinary places, to access local services and facilities, and to contribute to community life and community associations.

### **3.1.3 A Quality Service**

The commitment to quality will be expressed in service standards and in the arrangements made for monitoring and evaluating services. This commitment will guide the policies and procedures that govern the work of every service.

## **3.2 *New Directions*: Making it Happen**

***New Directions*** will mean a radical reconfiguration of adult day services. Service provision will need to adjust in order to deliver a real shift from the traditional delivery of provider-led programmes in segregated settings to individualised, person-centred supports directed to community inclusion and active citizenship.

### **3.2.1 What *New Directions* will mean for Service Providers**

In ***New Directions***, service providers will have to make sure that person-centredness is embedded in their culture and reflected in governance, policies, programmes and practices. ***New Directions*** will mean a significant change in service culture, work practices, programme content, staff roles and service user roles. This change is already under way in many services. The extent of the change in any service will depend on the gap between current practice and what is needed to deliver a modern, person-centred service. The main areas of change will be:

- developing a person-centred culture and approach, together with person-centred planning processes;
- developing and maintaining a core service focus on community inclusion;
- adopting a flexible and seamless approach to the provision of supports that is not constrained by traditional 9am - 5pm service boundaries;

- providing ways for service users and families to influence service policy, planning and evaluation;
- using and complying with the Quality Assurance Framework and Guidelines for adult services which will be developed by the HSE to reflect ***New Directions***;
- participating in local forums for collaboration and shared learning;
- working within the new HSE service arrangements that will govern the contractual relationship between service providers and the HSE as funder of services and which will underpin the arrangements for the delivery of ***New Directions***;
- facilitating a move to shared services by exploring ways of making the best use of resources currently invested in the sector in areas such as staff training and human resource management.

### **3.2.2 *New Directions* and the National Disability Strategy**

The ambitious change envisaged in ***New Directions*** will depend on and benefit from an acceleration of the policy of mainstreaming that is a core part of the National Disability Strategy.

Improved access to mainstream services will be essential to let adults with disabilities participate fully as members of communities. Without affordable, accessible transport, people cannot readily be part of their local community. Income support arrangements and housing shape the extent to which people can aspire to live independent lives. Access to further education is key to enabling people to continue to learn throughout their lives. The National Disability Strategy can advance social inclusion for people with disabilities in these and other areas and can facilitate links between mainstream and specialist services so that people with disabilities can access a seamless set of options and opportunities.

The implementation of ***New Directions*** will require joint planning between the HSE and key government departments to get maximum benefit from the National Disability Strategy.

### **3.2.3 What *New Directions* will mean for the HSE**

#### **A National Change Management Plan**

***New Directions*** represents a process of large-scale national change. Change of this magnitude does not happen without a major change management support programme. A comprehensive HSE led change management programme will be essential to implement ***New Directions*** quickly and effectively. The approach to change should be a partnership approach in which the HSE takes account of the differing capacities of providers.

The national change management plan should involve collaboration with representatives of service participants, service providers, Government departments, local authorities and key mainstream agencies. The plan should include strategies for:

- a communications and promotional strategy for ***New Directions***;
- a national demonstration programme to test and promote innovation;
- dissemination of the Quality Assurance Framework and Guidance;
- a workforce skills audit to identify champions for change;
- management development programmes;
- a centre for innovation and change to support shared learning and dissemination of good practice;
- an agreed national strategy for evaluating progress in implementing ***New Directions***.



## **Strengthening Person-Centeredness**

The HSE will need to strengthen the scope for person-centeredness by developing strategies for specific groups and by maximising access to public health services.

The priority initiatives needed include:

- development of a strategy to offer continuity of service for adults over 65 years in a way that respects their rights, dignity and choices; and
- making sure that adults with disabilities have access to primary care teams and multidisciplinary team specialist services.

## **HSE Infrastructure for *New Directions***

The modernisation of adult day services in line with ***New Directions*** will depend on a number of essential developments within the HSE. These include:

- completion of the quality assurance system (which began during the National Review of Adult Day Services) and a national roll-out of this system;
- design and implementation of a national funding framework for allocating and managing resources in a way that supports the delivery of ***New Directions***;
- development of new standardised data gathering and data management systems for planning services, identifying needs, monitoring provision and case management;
- provision of a national guidance service for all adults with disabilities, linked to mainstream guidance services.

## **Essential Reconfiguration Actions**

The HSE must urgently reconfigure its role in relation to training and employment in line with government policy and equality legislation by:

- making arrangements, in collaboration with the Department of Jobs, Enterprise and Innovation, for the transfer of sheltered and supported employment to DJEI; and
- planning alternative provision for and with adults in HSE funded day service programmes that risk contravening employment legislation.

## **4 The Principles, Laws and Policies that Guide *New Directions***

### **4.1 Legal and Policy Framework for *New Directions***

In making its proposals for modernising and reconfiguring adult day services, the National Working Group has been guided by a range of laws and policies that have an important bearing on the future of services for people with disabilities.

In particular, the National Disability Strategy, health legislation and policy, equality legislation and employment legislation provide an important context for ***New Directions***.

The clear direction that is emerging from this body of law and policy is towards a focus on person-centeredness. It provides the impetus to make sure that people with disabilities can do ordinary things in ordinary places and a strong focus on their right to access public services alongside all other members of communities.

### **4.2 Guiding Principles**

The report of the Commission on the Status of People with Disabilities, *A Strategy for Equality* (1996), set out the key principles to underpin the provision of services to people with disabilities as *equality, maximising participation, and enabling choice and independence*. The health strategy, *Quality and Fairness (2001)*, adopted broadly similar principles and introduced the concept of person-centeredness as one of its key principles. More recently, the national mental health policy, *A Vision for Change*, which was adopted in 2006 sets out service delivery principles and values that include citizenship, partnership, quality and inclusion. All of these principles have guided the work of this review and underpin the proposals for ***New Directions***.

## **4.3 Legislative and Policy Developments Shaping *New Directions***

### **4.3.1 The National Disability Strategy**

Until relatively recently, disability was treated in law and policy as a health issue, with the provision of services to people with disabilities being the statutory responsibility of the health authorities.

The National Disability Strategy (NDS), which was launched by Government in 2004, represents a fundamental shift towards social inclusion and full citizenship for people with disabilities, and makes specific legal provision for the mainstreaming of access to public services. The main objective of the National Disability Strategy is that people with disabilities should be supported to be active and contributing members of society.

The Disability Act 2005, which is a core element of the NDS places a duty on six key Government departments to prepare and publish sectoral plans. The plans are detailed statements of the actions that these departments will take to strengthen the provision of their services to people with disabilities.

The sectoral plans deal with access to health services, employment and training, transport, income support, telecommunications, housing, and access to the built environment. The effectiveness of ***New Directions*** in empowering people to live with their families and as part of their local communities will be influenced by the progress of the sectoral plans.

One of the main goals of the sectoral plans is to make sure that government departments work closely together to deliver services to people with disabilities in a co-ordinated way. For this reason, formal structures for cross-departmental co-operation have been put in place. These structures can be used to build links between specialist services and mainstream services, so that individuals can have the benefit of the seamless continuum of service to which ***New Directions*** aspires.

The Education for Persons with Special Educational Needs Act 2004 (EPSEN Act) also forms part of the National Disability Strategy. Of particular importance for ***New Directions*** is the fact that EPSEN deals with the arrangements for the transition from school to further education or training of school leavers with special educational needs.

It is the responsibility of the school and the Special Educational Needs Organiser (SENO) to find out what the young person wants to do and to help them to progress to the education or training programme that meets their wishes or those of their parents. Seamless pathways and effective linkages between the educational services and HSE funded support services will be needed to make sure that young people can make easy transitions between these services, if they need to.

Many people will need access to advocacy so that they can make their own choices and plans and have their voices heard in decision-making about services. For this reason, the **Citizens Information Act 2007**, which is also part of the National Disability Strategy, is important for the future of adult day services. This Act charges the Citizens Information Board (CIB) with providing certain advocacy services to people with disabilities. The advancement of the provision of advocacy services under the Act can make an important contribution to making sure that people benefit from the supports that will be offered as part of ***New Directions***.

### **4.3.2 Health Legislation**

Under the Health Act (2004), the Health Service Executive (HSE) is responsible for managing and delivering health and personal social services, or arranging to have these delivered on its behalf. The HSE's statutory role in providing supports to adults with disabilities arises from this legislation.

The Health Information and Quality Authority (HIQA) is the body with statutory responsibility (under the Health Act 2007) for quality in health and personal social services. HIQA will be responsible for developing standards for ***New Directions***.

The Mental Health Act 2001 allowed for several new civil liberty checks and balances for people in approved centres offering treatment for mental illness.

A key element of the Mental Health Act 2001 is the responsibility assigned to the Mental Health Commission for assuring the quality of mental health services. The Commission has published the Quality Framework for Mental Health Services in Ireland.

This framework gives guidance to service users, families and advocates, providers and the public on what to expect from a mental health service. The framework applies to services being delivered in the home, community or residential setting, or in in-patient settings. This framework will apply to mental health supports provided to adults as part of ***New Directions*** in addition to the requirements of the HSE Quality Assurance System that will underpin ***New Directions***.

*A Vision for Change* is the national policy framework for mental health services. Its emphasis is on community-based mental health teams, the recovery model and the role that work plays in the recovery model. The concept of 'recovery' reflects the belief that people with mental health difficulties can achieve control over their lives, recover their self-esteem and move towards building a life where they experience a sense of belonging and participation. The person-centred focus of *A Vision for Change* is strongly reflected in ***New Directions***.

#### **4.3.3 Legislation and Policy related to the Employment of People with Disabilities**

Until relatively recently, policy relating to the employment of people with disabilities and the provision of formal supports to assist them in finding jobs or training rested with the health authorities. The sectoral plan of the Department of Health (2006) envisaged a phased transfer of funding and responsibility for supported employment to the Department of Jobs, Enterprise and Innovation by 2010, in line with the 1998 government decision that this transfer of responsibility should take place.

The Department of Health's sectoral plan states that an action plan for this transfer will form part of an agreed protocol with the Department of Jobs, Enterprise and Innovation.

A key challenge for ***New Directions*** is to propose ways in which the HSE, the Department of Health and the Department of Jobs, Enterprise and Innovation can collaborate to make sure that, in the short term, the transition follows the principles of person-centeredness and that, in the longer term, there are clear pathways to facilitate seamless transfer between HSE funded supports and the services of the Department of Jobs, Enterprise and Innovation. Employment legislation and equality legislation also have important implications for people with disabilities.

The Employment Equality Acts 1998 and 2004 prohibit discrimination on nine grounds including disability and provide for equal pay for like work. The 1998 Act prohibits discrimination in a number of aspects of employment including access to employment, conditions of employment, and training or experience in relation to employment or promotion.

Arising from these legislative and policy provisions, the HSE must make sure that the employee status of people in HSE funded services does not run the risk of contravening employment equality legislation or create a risk for the HSE or service providers.

#### **4.3.4 European and International Influences**

International developments such as the UN Convention on Human Rights have played an important part in shaping the agenda on disability and have helped to bring about major changes in thinking, attitudes and policy.

The **UN Standard Rules** on the Equalisation of Opportunity for People with Disability in 1993 signaled a major shift in thinking about disability policy. In Ireland, it had a major influence on the Commission on the Status of People with Disabilities. The rules aim to make sure that all people with disabilities can exercise

the same rights and obligations as other citizens and set out what needs to happen to make social inclusion a reality, such as access to information, transport, education, employment and income support.

Adopted by the Council of Europe in April 2006, the Disability Action Plan 2006-2015 contains a number of specific actions including participation in political, public and cultural life, education, information and communication, employment, accessibility of the built environment, and transport.

The key commitments are:

- to make sure that support measures, such as sheltered or supported employment are in place for those people whose needs cannot be met without personal support in the open labour market; and
- to support people with disabilities to progress from sheltered and supported employment to open employment.

### **The United Nations Convention on Individuals with Disabilities**

There are seven landmark United Nations human rights treaties that protect the rights of women, children, migrant workers and others. However, until the Convention on the Rights of Persons with Disabilities in May 2008, there was no specific global treaty addressing the needs of people with disabilities.

The Convention marks a major shift in attitudes and approaches to people with disabilities. It embeds the social model of disability, viewing people with disabilities as 'subjects' with rights who are capable of claiming those rights, making decisions for their lives based on their free and informed consent, and being active members of society.

The provisions that are of particular importance for ***New Directions*** are as follows:

- *States Parties recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law (Article 5);*

- *States Parties ... recognize the equal right of all persons with disabilities to live in the community, with choices equal to others (Article 19);*
- *... Persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice (Article 21);*
- *... Enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life (Article 26);*
- *... Enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society (Article 30).*

While it is too early to determine the impact of the effectiveness of putting this global disability rights instrument in place, its a significant step towards moving forwards on the full participation of people with disabilities into work and community life.

#### **4.4 Impact and Significance of these Laws and Policies**

This body of law and policy creates a strong momentum for ***New Directions*** and a positive climate for its implementation.

The impetus for community inclusion and active citizenship that is a core part of ***New Directions*** is strongly in tune with the intent of the National Disability Strategy. It will be supported by the actions that government departments take, separately and together, to advance the goals of the Strategy. Planning for the reconfiguration of training and employment responsibilities provided for in the National Disability Strategy is an important focus for ***New Directions***.

The Mental Health Act 2001 and *A Vision for Change* together create a climate of support for enabling people with mental health difficulties to have control over their



lives and experience a sense of belonging and participation. People will have the benefit of the quality assurance systems and the oversight and monitoring that goes with such systems. These features of mental health services are fully in harmony with the goals and purpose of ***New Directions***.

The United Nations Convention on Individuals with Disabilities adds a further strong support to the direction of the supports programme contained in ***New Directions***, with its focus on community participation, creativity, and opportunities for independence, learning and having the chance to take up valued social roles.

***New Directions*** also takes account of the need to make sure that supports and programmes offered through HSE funded services must respect the equality and employment rights of every citizen, including every adult with a disability.

## **5 Current Day Services**

### **5.1 How Day Services have Evolved**

Day services for adults with disabilities in Ireland can be traced back to the late 19th century and the institutional care mainly provided under the Poor Laws. These institutions were characterised by a culture of containment and separation where people with disabilities were hidden from the public eye and kept away from social contacts and community life.

Most institutional care was provided by philanthropic and religious organisations with a limited involvement by some parents and friends associations. Residential services were the main services provided and 'day services' developed as very basic care programmes to occupy those living in residential institutions during the day.

The 1953 Health Act and the subsequent 1970 Health Act gave the Department of Health powers to support voluntary organisations in providing services 'similar or ancillary to their own' to people with disabilities. Grants were at the discretion of the individual health board and there were no nationally agreed criteria for such grants or no clear prioritisation of development needs. Not surprisingly, the development of services has been haphazard, fragmented and episodic, influenced by type of disability and inconsistent funding programmes.

From the mid-1970s, community workshops operated by the health boards under the auspices of the Department of Health were the main mechanism for providing activities, vocational training and sheltered work for people with disabilities.

In 1984, the *Green Paper on Services for Disabled People* began to draw a tentative new vision of integrated, inclusive services for people with disabilities. This shift was supported and to some extent started by leaders in the disability movement who advocated for people with disabilities to be treated equally with other citizens and challenged prevailing attitudes towards institutional care in inappropriate settings for people with intellectual disability.

The emerging independent living movement in the United States encouraged the leadership of the movement in Ireland to campaign for basic services like personal assistants and accessible transport.

Access to funding from the European Social Fund (ESF) for training people with disabilities developed during the 1970s and continued until mid-1994 when a reduction in funding was experienced. This funding was supplemented by Horizon funding for innovative projects and European Regional Development Fund (ERDF) funding for capital projects. This access to ESF funding led to the development of a specialist infrastructure focused on the delivery of training in vocational skills.

The Commission on the Status of People with Disabilities and the recommendations contained in its 1996 report *A Strategy for Equality* marked a watershed in Irish disability policy.

The acceptance by government of the recommendations of the Commission led, in turn, to groundbreaking decisions by government in 2000 that services for people with disabilities should be mainstreamed and to the preparation of the National Disability Strategy which now provides a comprehensive framework for the mainstreaming agenda.

## **5.2 Current Day Services**

Current day services were influenced by the developments that took place over the past 15-20 years and, in particular, by the investment of European Social Fund monies and the decision to mainstream responsibility for vocational training and employment. Although ESF funding was directed to vocational training, the injection of this funding brought with it a new and more structured orientation in the design and development of programmes. A wider range of programmes and modules was developed for all disability groups and there was an increased focus on service accreditation and on outcomes for people with disabilities. This increasing

professionalism in service provision spread throughout the sector and had an impact beyond the vocational training services.

Following on from these developments, there is now a diverse array of day service programmes for people with physical and sensory disability, intellectual disability and mental health difficulties.

The diversity of current services presented a significant challenge for the census of day services conducted as part of this review. With the exception of rehabilitative training, there are no nationally agreed or clear definitions of service activity.

This has resulted in a lack of clarity and consistency in how service providers and funders define programme activity. With the benefit of a good working knowledge of services on the ground, a set of programme descriptors were developed and piloted for the census (see Table 5-1 Programme Descriptors). The census information based on these descriptors is the main source of data used in describing aspects of current services.

**Table 5-1 Programme Descriptors**

<b>Programme Description</b>	<b>Explanation</b>
Day Care Programme	High support services primarily focused on providing a health care service to meet the specific needs of individuals.
Day Activation/Activity	A day programme which is essentially a support and therapeutic service designed to meet the needs of people through individual plans. The environment is designed to maximise the functional levels of service users. Day programmes provide a range of skills and activities such as independent living skills, personal development, education classes, social and recreational activities, and health-related and therapy supports. Day activation is

	essentially a programme that does not include work activity.
Active Community Participation/ Inclusion	<p>Programmes and supports specifically targeted towards the inclusion and active participation of service users in mainstream community programmes and activities. This includes participation in educational opportunities, sport and recreation involvement, social events, local partnership projects and advocacy initiatives.</p> <p>A range of supports that promote and facilitate inclusion are provided to individuals and groups, such as accessing services, liaison, planning, co-ordinating and supporting attendance and active participation by service users.</p>
Sheltered Work Therapeutic	<p>A centre-based programme designed to provide constructive occupation for an individual or group where work activity is a key element of the programme. The work is carried out in a centre or location designed for that purpose but there is no third party involvement, that is, no contract work and not open to public. Examples of this could be a day service that focuses on cooking and baking or arts and crafts. The product is consumed within the service. They may also hold coffee mornings to showcase the work and sell some of the products at nominal cost to encourage service users and prevent a build-up of stock. Service users may or may not receive allowances or discretionary top-up payments.</p>
Sheltered Work Commercial	<p>A day programme which consists of work activity. In these situations, the public has access to the product or service and contract work is carried out for a third party. Money is exchanged for goods or services. Service users may or may not receive allowances or discretionary top-up payments.</p>
Sheltered Work - 'Like Work'	<p>A day programme which involves service users working within HSE or service provider organisations in what could be described as 'like work' situations. This includes service users working in</p>

	<p>kitchens, maintenance work, landscaping, office, administration, post room, catering, hospital shops, canteens, and so on. Service users receive a discretionary top-up payment. The purpose of this discretionary payment is to give the service user a sense of worth and reward and encourage him or her to continue with the activity. This payment could be argued to be an important part of the therapeutic aspect of the work done.</p>
<p>External Work 'Like Work' – (less than minimum wage)</p>	<p>A day programme which involves service users working in external 'like work' situations. In most cases, the service provider sources the placement in an open employment setting as part of the individual's day programme. Minimum wage or Disability Allowance (DA) plus rules do not apply but the employer normally makes a discretionary top-up payment, either directly to the individual or to the service provider to allocate at its discretion. Examples include service users working in supermarkets, fast food chains, and so on. Short-term work placements that are part of a recognised training programme are not included.</p>
<p>Open Employment (no supports)</p>	<p>This is employment in the open labour market without additional supports. In some instances, a service user may be in open employment with no supports for only part of his or her week. The service provider may have helped the individual to get their job but has now withdrawn all support.</p>
<p>Supported Employment</p>	<p>Supported Employment is paid employment in the open labour market with ongoing supports. The minimum wage and full employee status applies. Service users may be participating in the FÁS-funded Supported Employment Programme or in initiatives run by service providers.</p>
<p>Sheltered Employment</p>	<p>Employment in an enterprise set up specifically to employ people with disabilities and which receives designated funding from the</p>

	HSE. It refers to employment under sheltered conditions where workers have a contract of employment and are in receipt of the minimum wage.
Rehabilitative Training	Rehabilitative Training programmes are designed to equip participants with basic personal, social and work-related skills that will enable them to progress to greater levels of independence and integration in the community. These are approved programmes with 'Whole Time Equivalent' (WTE) places allocated by the national Occupational Guidance Service structure.
Education Programme	Programmes funded by the Department of Education and Skills to enhance day services.
Voluntary Work	The volunteer works in the community or for the benefit of the natural environment primarily because he or she chooses to do so. A volunteer worker does not get paid or receive compensation for services rendered. Each person's motivation will be unique but will often be a combination of: - <b>altruism</b> (volunteering for the benefit of others), - <b>quality of life</b> (serving the community because doing service makes one's own life better, for example from being with other people, staying active and having a sense of the value of themselves that may not be as clear in other areas of life), and - <b>giving back, a sense of duty or religious conviction.</b>

### 5.3 Number of Service Providers and Service Locations

Adult day services are provided by a large number of voluntary organisations and by the HSE. In 2008, 81 organisations provided services to 25,302 service users in 817 locations. Voluntary organisations were the main providers, offering services in 573 locations. The HSE provides services in 244 locations. The voluntary sector

provides about 90% of services to people with intellectual disabilities, reflecting its long history and engagement in pioneering and running these services.

The number of service locations reflects the growing trend towards smaller, community-based services and a strong move away from large centre-based services catering for lots of people in one setting.

The distribution of services by disability category is shown in Table 5-2.

**Table 5-2 Service Locations Providing Day Services catering for categories of Disabilities**

<b>Primary Disability</b>	<b>Locations</b>	<b>Locations catering for single disability</b>	<b>Locations catering for primary disability and other disability</b>			
			<b>Intellectual Disability</b>	<b>Mental Health</b>	<b>Physical and Sensory</b>	<b>Autism</b>
<b>Intellectual Disability</b>	530	359	-	111	98	82
<b>Mental Health</b>	281	164	111	-	80	39
<b>Physical and Sensory</b>	196	93	98	80	-	39
<b>Autism</b>	108	24	39	39	82	-
<b>Total</b>	817	640				

Of the 817 locations, 177 provide day services for multiple disability groups and 640 to single disability groups.

A total of 530 locations indicated that they provide services to people with an intellectual disability, 281 locations provide services to people with mental health difficulties, 196 to people with a physical and sensory disability, and 108 to people with autism. Altogether, 359 locations provide services exclusively to people with an intellectual disability, 164 to people with a mental health difficulty, 93 to people with a physical and sensory disability, and 24 to people with autism.

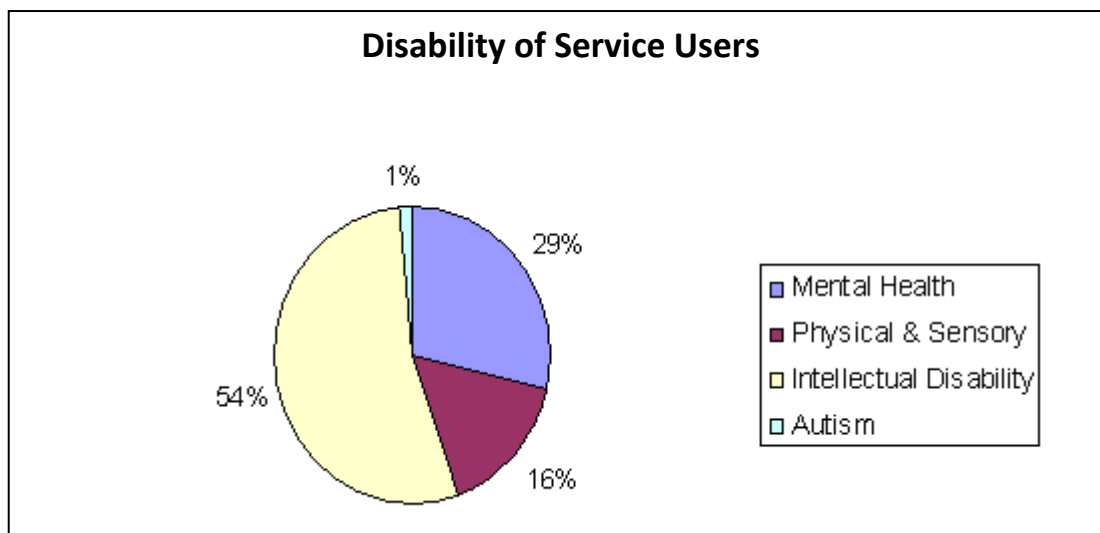


## 5.4 Disabilities and Age Range of Service Participants

People from all disability groupings attend day services although most service users have an intellectual disability. The census data on the primary disability of service users, which used four categories of primary disability (intellectual disability, physical and sensory disability, mental health difficulty and autism), shows that more than half of service users have an intellectual disability.

The size of the population in day services with an intellectual disability in part reflects the long history of voluntary bodies providing services to this group. These voluntary bodies led the way in service provision. On the other hand, the tiny percentage of service users with autism recorded in the census reflects the relative newness of the capacity to diagnose autism as a distinct disability. As a result, adults with autism are included with other disability groups.

The percentage of the overall population of service users recorded in each of the primary disability groups is shown in Figure 5-1. This data indicates the relative size of the population of people within these four disability groups availing of day services. However, it does not capture the extent to which people may have multiple disabilities or their level of disability.



**Figure 5-1 Disability of Service Users**

The census records 13,720 people with an intellectual disability availing of day services. This represents 54% of day service users, the largest group of service users. A total of 7,301 adults (29% of service users) have a mental health difficulty, 3,924 adults (16% of service users) have a physical and sensory disability, and 357 adults (1% of service users) have autism.

Most service users (15,552) fall within the 26-55 age category. Only 139 service users are under 18 years while 2,389 service users are over 65 years of age.

## **5.5 Programmes, Activities and Service Models in which Adults with Disabilities Participate**

Service users participate in a wide range of modules and activities across all the programme types covered by the descriptors used in the census (see Table 5-1). Those who responded to the consultation said they took part in art, music, independent living programmes, community participation, therapeutic work and other forms of work activity.

The demonstration programme that was conducted as part of the review points clearly to the changes that service providers have been introducing into the programmes and services they provide. In the absence of nationally approved standards, the review invited providers to share current practice where this practice showed evidence of change that was moving in the direction of the orientations and themes emerging in the review. These themes were *person-centeredness*, *collaborative working*, *community inclusion* and development of *advocacy*.

Organisations set out how they were working with others to provide a person-centred approach and to develop community inclusion. Structures for collaborative working were informal and depended on local working relationships. There were many references to FÁS and the VEC. Other parties included the Citizens Information Board, the Department of Social Protection, Local Partnership Forums and, at a local level, the Arts Council, the Office of Public Works (OPW), and so on.

Service providers shared the approaches they used to maximise community inclusion for participants. In some cases, there was no actual day service centre and a person's plan was facilitated completely in the community. In other examples, collaborative working helped to deliver part of the service in community locations such as the local VEC or library.

Organisations also shared experiences of innovative practice in the development of advocacy. In some services, participants had ownership of the service. In others, there was a focus on developing the individual through leadership training, to enable them to be active in planning and delivering their own services.

The report on innovative practice which was conducted as part of the census also confirms the extent to which service providers have taken important initiatives to modernise services in line with new thinking about the right of people with disabilities to participate as full citizens in their community and to have choices about how they live their lives.

The most frequently cited innovations were individualised services and, in particular, the development of forms of person-centred planning, community inclusion and innovation in access to social and leisure programmes. Providers cited moves to strengthen partnership with families, to make the times of access to programmes more flexible, to introduce volunteer programmes and to introduce programmes to respond to particular needs such as acquired brain injury. Providers also described how they have introduced new forms of support such as new therapies, a focus on wellness, and individual behaviour plans.

The benefits cited from these innovations included greater empowerment of service users, health and social gain, greater levels of community inclusion and more meaningful social roles for people with disabilities.

These innovations and developments are not universally available to service users. In the absence of national guidance, standards and resources for innovation,

service providers have encountered resource and other attitudinal obstacles in moving their services forward. Nonetheless, there is clear evidence from the census, the consultation and the research that providers, service users and advocacy groups have been making sustained and successful efforts to modernise service provision.

As a result, there is a strong foundation in place for the changes that will be proposed as a result of this review of adult day services.

The research on day services in Ireland points to the extent to which providers have introduced new models of service despite the absence of national guidance or service standards. New models include the 'village model', which spreads a range of services across a number of towns and villages, offering service users options in different locations along with opportunities for community inclusion. The 'recovery model' and 'clubhouse model' offer person-centred services aimed at enabling people with mental health difficulties to take control of the recovery process.

## 5.6 Hours of Attendance

The 25,302 service users attending day services are engaged in a wide range of activities as part of their service. Table 5-3 shows the hours of attendance at each day-service programme. Participants may attend a range of programmes for part of each week.

**Table 5-3 Hours of Attendance at Day Service Programmes**

Type of Programme	Service Users attending programmes of differing duration per week					
	Total Users	6 hrs	12 hrs	18 hrs	24 hrs	>24 hrs
Active Community Participation/ Inclusion	4,607	2,353	1,140	403	224	487
Day Activation/Activity	13,269	3,190	2,788	1,602	1,798	3,891
Day Care Programme	3,618	1,055	812	431	390	930
Education Programme	1,533	1,222	180	33	19	79

External Work 'Like Work' - less than minimum wage	399	231	74	27	32	35
Open Employment (No Supports)	217	37	35	49	36	60
Rehabilitative Training	2,789	110	100	254	418	1,907
Sheltered Work Commercial	2,826	554	437	461	586	788
Sheltered Employment	164	28	36	39	17	44
Sheltered Work Therapeutic	1,749	575	274	175	225	500
Sheltered Work - Like Work	875	211	90	121	158	295
Supported Employment	1,773	621	382	411	242	117
Voluntary Work	246	168	32	17	5	24

The highest number of hours during the week the census was conducted (7<sup>th</sup> – 14<sup>th</sup> January 2008) was registered in the *Day Activation/Activity* programme – a day programme that is essentially a support and therapeutic service designed to meet the needs of people through individual plans.

The second highest level of activity was registered in the *Active Community Participation/Inclusion Programme*, which is a set of programmes and supports targeted at the inclusion and active participation of service users in mainstream community programmes and activities.

## 5.7 Individual Planning

As was noted earlier, individualised planning is being offered across day services in recent years and is one of the main forms of innovation that providers have introduced. Having an individual plan is not universal. Some people with disabilities reported that they have a person-centred plan and a key worker system that works well while others did not. Almost 3,000 participants in day services do not have access to any form of individualised planning process. However, the census shows that most service participants do have access to some form of individualised planning and, in most cases, they have a person-centred plan rather than a nurse-led or clinically-led care plan.

**Table 5-4 Range of Planning Processes in Use**

<b>Plan</b>	<b>Number of service users engaging in this form of planning</b>
Nurse/Clinical-Led Individual Care Plan	8,029
Person-Centred Plan	12,991
Individual Programme/Training Plan	5,746
None of the above	2,990

**5.8 Range and Number of Staff Employed in Day Service Provision**

Of the 5,600 staff engaged in the delivery of day services, most are in care or support roles and in supervisor or instructor roles. A relatively small number (816) are in therapy, clinical or nursing roles.

Staff ratios vary greatly. Just over 13,000 adults (52% of participants) attend programmes where the ratio of front line staff to participants is between 1:4 (one staff member to four service users) and 1:9 (one staff member to nine service users). A further 1,738 service users (7%) have at least 1:1 staff support while 2,109 service users (8%) attend programmes where the ratio of front line staff to participants is as low as 1:15 (one staff member to 15 service users).

**Table 5-5 Staff Groups Involved in Delivery of Day Services**

<b>Staff</b>	<b>Number of HSE Funded WTE (Whole Time Equivalent)</b>
Administration Staff	218.68
Ancillary Support Staff	421.32
Ancillary Therapy Staff	49.08
Care/Support	1650.78
Manager	519.53
Supervisor/Instructor	1930.14
Therapy/Clinical/Nursing	816.81
Total	5606.34

## **5.9 Funding for Day Services**

The overall budget for HSE funded day services in 2007 was €306.7 million. In addition, providers sourced €21.5 million<sup>6</sup> in non-HSE funds to deliver day services in 2007.

In the consultation, service providers raised concerns about many aspects of the funding of services.

Providers were unhappy that funding is based on numbers rather than individual need. They expressed concern about perceived inequity of funding for different disability groups. They also expressed concern about disparity in capitation rates and a lack of transparency in the allocation of funding. The absence of recognition of increased costs of service provision and the enduring problem of core funding deficits were raised.

Service providers have, as has been noted, introduced many innovations into their programmes by using current budgets, fundraising, grant aid or support from community sources<sup>7</sup>. However, providers cited the lack of resources and inflexibility of funding as obstacles blocking innovation; creating barriers to offering staff training and development for new forms of service; responding to increasingly diverse need; and offering resource-intensive individualised programmes.

---

<sup>6</sup> HSE funded day services budget figures are based on planned annual expenditure for day services for the year ended 31 December 2007. Where the budget was not devolved to a unit level, the figures are based on a reasonable approximation of service and/or staffing levels compiled in consultation with finance departments and service managers. Non-HSE funded day services budget amounts represent directly identifiable funding from sources other than the HSE included in the census report returns.

<sup>7</sup> Report on Innovative Practice produced as part of the Census of Day Services 2008

## **6 The Consultation: What We Learned From Service Users, Families and Service Providers**

### **6.1 Messages from the Consultation**

The consultation gave a rich account of the views and experiences of people with disabilities, families, carers and service providers about current day services. They described aspects of the services that are working well, what is not available or not working well, and the kinds of changes and improvements people would like to see in the future.

The main messages from the consultation deal with:

- people's day-to-day experience of services;
- the way in which services are planned, funded and monitored.

### **6.2 People's Day-to-Day Experience of Services**

Service users want a day service where they feel valued and included, one that gives them a structured day, a sense of purpose and a reason to get up every morning. They value the friendships they make, the peer support and the sense of teamwork with staff.

Families and carers value the chance to gain skills, opportunities and a strong sense of self worth:

*'The promotion of self-esteem and self-worth for individuals with disabilities; the consolidation and learning of new skills; the emphasis on social inclusion, advocacy and independence and the development and overall improvement in the quality of life for individuals ... are positive aspects of day services.'*



Many people benefit from their day service, many others find the experience unhelpful and negative. For example, a parent said about their son's day service:

*"My son hates his day service as it is a very depressing place. The building he is in is overcrowded with no windows in the lower part and it is freezing cold. There is no variety in the daily routine. There is not enough staff to support a person-centred plan and the individual needs of service users."*

These striking differences in experience underline the need for reform, for quality assurance systems and for support for providers to help them to achieve common standards.

### **6.2.1 People Want to do Worthwhile Things**

*"I would like to do a FETAC course in self-confidence...We do not have enough stimulation or interesting activities to do every day...The day service that I attend one day a week closes for July and August and that is hard for people who are living alone, isolated and have no access to transport...The atmosphere has become too serious – there is little fun now."*

*"The range of programmes is good and very varied from outdoor pursuits, to fitness, work experience, personal development, literacy and independent living skills."*

These very different comments highlight the mixed experiences of service users in day services. The activities, training and support in day services vary from clearly planned programmes to situations where people spend time with nothing to do or do repetitive activities, which they see as of little use or value.

There are reports of good experiences. Some service users said that they could do activities such as computers, art classes, live music sessions and bingo, and have a visiting dental service and hairdressing service. A number of the older people, in

particular, said that getting a good hot meal at the day centre is important to them as they live alone and cannot cook at home.

Staff and providers described how HSE funded day services provide specialised services while also offering flexibility to respond to the needs of different disability groups with a variety of programme durations, activities and supports.

*"The choices and diversity of activities available to service users through a wide range of programmes is very good. The skills and abilities of service users can be maximised, thereby enhancing their involvement within their own local communities, while also reducing their isolation and difference."*

There was also strong criticism of the lack of choice in activities at many day services. Service users and providers talked about an ethos of care that promotes dependence and an overemphasis on a medical model delivered in a clinical environment. They argued for choice and for programmes and activities that are interesting, meaningful and strengthen capacity for independence.

Staff believe that some clients are 'over-nursed', especially in the learning disability sector, and question the long-term worth of services such as laundry services and hot meals:

*"Many services still do laundry, provide hot meals at lunchtime, and so on. Although we acknowledge the importance and value of providing many of these services, we question the benefits long term for many groups of people... we would prefer to see service users provided with the skills necessary to carry out such activities independently."*

## **6.2.2 Doing Ordinary Things in Ordinary Places**

*"The linkages and strengthening of relationships within the community, for example VEC, FÁS, local area partnerships, clinical teams, and so on has been very worthwhile. There has been positive feedback from service users, their families, clinical teams and the local community."*

People with disabilities and service providers want to use their local services. They want to know local people and do ordinary things in ordinary places. Many make good use of community facilities such as VEC services. Others feel that their service is too centre-based and too cut off from the community. Many staff have had good experiences of working in partnership with local agencies.

The lack of transport is a major barrier to using local services and being part of the community. It forces many day services into a more centre-based service. The cost of transport and the time spent travelling get in the way of using day services, especially in rural areas. The lack of transport affects some people's ability to attend day services on anything more than an occasional basis.

People want smaller centres close to their homes: *"Smaller services allow for more one-to-one work between staff members and the individual accessing the service. By placing the service in the locality where a person lives, they can benefit from the community integration that family and friends can provide. Access to employment is also often easier and more likely where a family connection exists."*

There were very few positive comments about the buildings or locations used for day services.

## **6.2.3 Services that Suit People's Individual Needs**

Many service providers said that people move from children's services into services that provide the same programme year after year without any progression for older people. Day services are trying to provide services for adults from 18 years to 70-

plus in settings that are often quite unsuitable. This situation is made worse by the ever-increasing waiting lists for a place in a day service.

People want services that take account of their particular needs, whether they are school-leavers, young people with mental health problems, people with acquired brain injury (ABI), autism, dual diagnosis, older people or people in residential settings.

#### **6.2.4 Being Healthy and Staying Healthy**

Service users value the support they get from multidisciplinary teams and other supports for their health and wellbeing. Providers of day services to people with mental health difficulties say that multidisciplinary teams offer the best type of support:

*"The mix of disciplines, nurses and instructors working together in the day centre works well. Day centres are places where service users can commence or re-engage in the process of recovery and link into the larger community. The multidisciplinary approach to the care provided in the centres is crucial while the move away from the medical model towards the psychosocial model of rehabilitation is a positive move for the day centres."*

However, there is very uneven access to multidisciplinary teams. People named gaps in the supply of virtually every discipline – psychology, neurology, speech and language therapy, occupational therapy, physiotherapy and social work. People also want other forms of support for their health and wellbeing, such as counselling, alternative therapies and a good diet.

#### **6.2.5 Support for Being Independent**

People felt that a genuinely person-centred service should provide support for a full life in the evenings and weekends, and not only from 9am to 5pm. The lack of links

between day services and residential services is also a barrier to independence and good service provision.

Independence is bound up with money. People felt that training and attendance allowances are too low, especially when the costs of disability and of taking part in day service programmes are taken into account.

People want flexible supports suited to their needs. For example, some need assistive technology, others would benefit from a 24/7 helpline at weekends, staffed by experienced community nurses. Families of service users want to be allowed to play their part in supporting their family member.

### **6.2.6 Being Able to Make Choices and Plans**

Some people with disabilities said they have a person-centred plan and a key worker system that works well; others do not. People were concerned about gaps in advocacy services. They would like to have skilled, independent personal and group advocates. Families want to be part of the team that supports a service user to make life decisions.

### **6.2.7 Training and Work are Very Important**

*"There is no occupational paid activity available in the day centres we attend...some people would like more work within their day service...some of us would like a job but haven't got one...more supported employment/work experience should be available."*

People value access to work and occupation and the chance to earn extra money. Work is what people do and being able to work means being part of the community and mixing with people in ordinary settings. Many people in sheltered work settings said that having a job to go to makes their day worthwhile:

*"The workshop makes me feel good and I also get to learn new skills...  
The work gives me energy and balance... I like working in the nature."*

There is concern among service users and families about the lack of alternatives for service users who were in sheltered work services for many years but whose sheltered workshop closed. Service users felt that they lost their sense of purpose:

*"Service users can no longer avail of a full working week in the workshop due to recent legislation. It is unfair that service users cannot work for the minimum wage in the workshop...It is soul-destroying to go into 'work' and find no work to do but just hang around idly all day."*

Many service users said that they work for part of the week. Very few said they are in paid employment. People would like to have a job but also want to keep the supports in their day service. Some may need a part-time day service. Some who work full time may not need day services, but they and their families may need some link to disability services.

### **6.2.8 Having a 'Say' about Service Policy and Practice**

*"We have an input into our own lives. We like being listened to and being heard through our PCP. We have a representative committee and a good key worker system in the service."*

Some people, like those who made this comment, had good experiences of being involved, consulted and listened to; others did not.

Staff are happy to see moves towards a more person-centred approach where service users make their own choices and decisions. However, many service users said they are often afraid to ask, suggest or complain for fear of 'losing their place' in the service. This can increase dependency rather than independence. Some service users stated that they are not involved in changes and decisions that affect them, for example changes in the centre, recruitment and how funds are spent. One family said they have no way of communicating with their sister's day service:

*"We feel our input and interest is unwelcome. There is no open door where we can meet with staff on a regular basis. We have very close*

*and direct communication with our sister's residential service but this is in direct contrast to our experience with her day service."*

Overall, people felt that there is not enough service user involvement in how services are run. They want access to independent advocacy to help them to engage collectively with service providers and to have a say in policy, planning, service design and issues such as staff recruitment.

### **6.3 How Services are Planned, Funded and Monitored**

#### **6.3.1 Policy into Action**

The shift from a medical model of disability to a social model is very much welcomed. However, people are unhappy about the lack of progress in putting policies and initiatives such as *A Vision for Change* and the *Draft Code of Practice for Sheltered Occupational Services* into practice. Many reviews have been carried out that could make things better in day services, but the view was that few have made an impact on the design and delivery of day services in a meaningful way.

#### **6.3.2 HSE Services and Community Services Working Together**

Services must be joined up to avoid the gaps between day services and the educational, training and employment options that are provided to everyone in the community. Very often, people move from one day service programme to another with no progression or advancement. People get caught in a spiral of using day services when they are truly capable of achieving more. This can lead to institutionalisation and create obstacles to recovery and progression. Furthermore, very few service users are leaving day services and this has a knock-on effect on spaces for other people with disabilities who are waiting for a service.

People want to see stronger formal structures linking the HSE, FÁS and the Department of Education and Skills so that they can have a seamless service. The case was made for a national plan for local engagement that would involve:

- mapping the community and voluntary sector in communities;
- identifying the important local community structures and raising their awareness about adult day services;
- developing pathways for people to access and participate in local structures and services;
- building this plan into the HSE's strategic development plan.

### **6.3.3 Linking Day Services and Employment**

People had particular concerns about the weakness of the links between day services and employment. They see an unacceptable gap between the health and employment services and feel that this gap must be bridged at a local level so that people with disabilities can make real advancement in relation to work and training.

Many providers said that since the division of services between the HSE and the Department of Jobs, Enterprise and Innovation, the purpose of HSE funded adult day services is not clear. Changes to employment law saw many services closing the 'sheltered work' part of their service without a clear vision for what could replace it. Many seem to be struggling to find their 'niche'.

### **6.3.4 The Importance of Planning to Meet Future Needs**

More day services are needed both for those on waiting lists and those who have a very limited service. The range of services must be improved to meet the diversity of need regardless of location, disability or age.

### **6.3.5 Having Clear Pathways to and through Services**

A structure for guidance and referral is essential. People are unclear about how to access services. Self-referral may not be accepted and people may be referred



without knowing what the service is or having a choice about whether to attend or not. In some instances, only a medical referral is accepted by a service provider. These referral processes may not be person-centred and may be based on the referrer's limited knowledge of options and limited awareness of person-centred planning.

If people are to move seamlessly among services as part of a person-centred plan, there must be structured links among providers. This is necessary so that there are no gaps when people leave a service and that people do not stay in a service when they could benefit from more challenging environments and experiences. In many areas, there is no way to help a person move on once they have completed their time in a particular service. One suggestion was to pool resources, information and staff expertise across day services to ease transitions and transfers.

School leavers and adults need comprehensive information about services. The HSE occupational guidance service was seen as an effective source of support and referral. However, there are gaps in this service and because of the focus on rehabilitative training, the approach is not a 'whole person' approach where all options are explored with the individual.

### **6.3.6 Role of HSE Funded Services in Employment and the Future of Sheltered Employment**

It was suggested that the challenges around sheltered employment should be dealt with as part of a coherent set of policies that addresses the connections between social benefits, funding and incentives for service providers in a consistent way. There should be consistency between the Wage Subsidy Scheme policy, the Disability Allowance Disregard and medical card entitlements.

### **6.3.7 Funding and Resourcing**

*"There is a lack of transparency of how funding is allocated to individual service users or trainees. The levels of funding appear to be dependent*

*on what 'funding stream' a day service is funded through, whether it is intellectual disability, physical and sensory disability or mental health services funding."*

Providers expressed concern that funding for day services is based on numbers attending rather than on the needs of individuals. They also felt that there is inequity in the way funding is distributed within the range of day services and among different groups of disabled people.

There is also a disparity in what is paid to agencies to provide services. While the rehabilitative training capitation rate is standard across the country, organisations get different rates of capitation to provide sheltered work services ranging from €5,000 to €10,000 for each place.

Providers were unhappy that funding for day services has been at the same level for a number of years with no increase or recognition of increasing costs. Service providers continue to struggle with core under-funding. They are unable to respond to the increasing demands generated by a shift towards more community-based services and a changing age profile of service users.

Service providers stated that it is essential that the method used to cost and pay for services is based on a person-centred approach. This individualised costing element is necessary to meet the Disability Act 2005, the implementation of the proposed national standards for disability services and the obligations that fall from other legislation and standards.

A number of large service providers in the voluntary sector raised the need to address historical issues related to core funding for day services. Many of these organisations described how they had responded to unmet needs without having the appropriate level of funding provision in place. This resulted in large deficits in the core funding base for the service.

## **Staffing Levels**

*"Because we don't have enough staff, we are not able to go out more...There are not enough personal assistants available...Groups can be too large for us to do what we want as individuals. The staff-client ratio is too low. There should be more staff available for one to one support."*

Day service staffing levels was one of the biggest issues raised in the consultation. Service users said that staff ratios are too low and result in many services users feeling they are 'controlled' rather than facilitated or managed in an empowering way.

Service providers said that the staff to service user ratio is wholly inadequate. In some cases, they see a health and safety risk to both staff and service users due to the staff ratios. They are concerned that they are not able to provide a service that meets individual needs.

Some people with disabilities, such as people with autism, people with acquired brain injuries and people with Asperger's Syndrome can remain isolated and vulnerable because their highly personalised needs require higher ratios of staff and other specialist supports.

*"There is not enough staff in day services, particularly to meet the needs of clients who would very much benefit from community-based supports during the evenings, weekends and over bank holiday periods."*

*"There is an insufficient number of care staff available. Some of the care staff and personal assistants are Community Employment (CE) scheme participants and service users find it difficult when their personal assistants or care staff have to leave their CE place after either one or three years, due to the age criteria for CE participants."*

### **6.3.8 Making Sure People get a Quality Service**

The absence of service standards, external monitoring and evaluation means that programmes can be unplanned and staff-led rather than based on the needs of the service users.

People believe that the HSE has the lead responsibility for such standards and that the standards have to be based on person-centred principles. Work on developing systems for monitoring and supporting quality should be done in partnership with service users and providers. There will also be a need for training to make sure that new approaches are translated into real improvements in front line services.

### **6.3.9 Learning Together to Improve Quality**

There were proposals for staff training and education in line with best practice and with the needs of service users. Increased support and training for staff, through networking days, good practice days and team-building will help to build consistent service in every service. Research will also be needed to make sure that services continue to follow best international practice.

## **6.4 Summary**

The consultation highlighted the striking differences in people's experience of services, underlining the need for:

- quality assurance systems;
- planning to address significant unmet need; and
- support for providers to help them to achieve common high standards.

The strong emphasis was on the need for community inclusion, with less segregation of services, more choice, more worthwhile and meaningful activities, and more flexible, individualised supports that fit with the person's life stage. As people strive for inclusion in the economic and social life of the community, they recognise that they need support to improve the quality of their lives. They want that support to be appropriate to their needs and focused on opportunities to enrich

their personal and social lives and relationships. National policies and guidelines for day services should be based on principles of person-centeredness, quality, equity and responsiveness.

## **7 What We Learned from the International Research**

### **7.1 The Shift in Thinking about Disability**

The earliest disability policies in developed countries focused heavily on a medical model of disability which encouraged segregated services and focused on managing risk and protecting the public.

The de-institutionalisation movement of the 1960s was in response to a recognition that the human rights of people in institutions were being breached and that the way of thinking about disability did not value community participation and citizenship for all. Unfortunately, the movement of people out of large institutions did not lead to productive and meaningful community-based alternatives. The result was a proliferation of smaller but still segregated programmes and services for people with disabilities.

This lack of progression toward full citizenship led to the emergence of a social model of disability, which sees disability as an interaction between a person's health condition and the physical and social environment. When we reduce the barriers to participating in daily living, we see that the disability need not stop a person from participating in the community and in work.

The concept of person-centeredness built on the social model of disability. This concept challenged organisations to move away from segregated service practices that limit people's social roles and citizenship. It placed great emphasis on discovering and building on people's competence and making use of their unique abilities to make a valued contribution in their community. The pairing of the social model with the principles of person-centeredness led to a fundamental shift in thinking about disability and about the appropriate nature of supports for people with disabilities.

## **7.2 Challenges in Moving to a Social Model that Offers Individualised Supports**

The research suggests that systems of service provision are built on five pillars that have remained relatively constant over time. These are culture, policy, infrastructure, payment and quality. The first two pillars – culture and policy – create the conditions under which the other three pillars are defined.

Our disability **culture** has been primarily defined over the past few decades by the struggle to move away from a medical or expert model and to establish the civil rights of people with disabilities. Disability **policy** creates the structures by which our services and supports are designed and implemented. **Infrastructure** is the service delivery system for translating policy into practice and includes the organisations delivering services and those overseeing implementation. **Payment** is the package of incentives provided to put the infrastructure in place. The final pillar, **quality**, has typically been defined by the need to achieve compliance with law and policy.

Over time, there is evidence that service delivery systems have tended to become 'stuck' and have not changed fundamentally to reflect changes in culture and policy, even though there have been many innovations such as supported employment and mainstream education. These developments have tended to be 'added on' and to leave the established systems of service provision, payment and quality largely unchanged. Generally, people with disabilities and their advocates tend to have more influence on policy and culture than on service delivery, payment and quality systems.

The challenge of modernising is often made more difficult by the fact that service providers may have developed successful business models under the existing policy and financing framework and have little incentive to take the risk needed to introduce change. More times than not, a choice is made not to jeopardise 'what is' for 'what could be', resulting in a compromise that minimises the reform and settles for improvements in the existing system.

The research suggests that major change will not miraculously flow from setting out principles and values even though these are necessary. To truly progress toward a person-centred system, it is not enough to give people the opportunity to develop a person-centred plan. People have to be empowered throughout their lives to put that plan into action.

They have to be supported in making choices about the services and support they feel they need to achieve their goals and aspirations. Quality needs to be defined by people's lack of satisfaction with the outcomes they achieve as a result of their efforts.

The research suggests that national policy and strategic priorities appear to be moving well together towards change. However, there is a challenge as to how best to bring about true change in the ways in which people access, benefit from and continue to improve the services and supports they need to experience full community participation and citizenship across all stages of their lives.

The challenge is to move beyond making sure that each individual has the opportunity to engage in the development of their own person-centred plan to making sure that plan is properly implemented.

### **7.3 The Concept of Person-Centeredness**

The research summarises key learning from literature and practice about the concept of person-centeredness and how it works.

Simply thinking that we are being person-centred does not make us person-centred. It is what we actually do in everyday exchanges with people that ultimately reveals our true priorities.

Person-centred planning is an organised way in which one can listen to people and learn about important aspects of their interests and needs. Person-centeredness is about intentionally being with people and may or may not include planning.



Regardless of the method chosen for person-centred planning, there are universal themes within and across all of the planning tools. One such theme is the search for the potential of the person, rather than relating to the person through disability labels. Planners actively look for a person's gifts and talents in the context of community life. The voice of the person and of those who care best about the person becomes the focus of attention and deep listening.

Research evidence has identified benefits from the use of person-centred planning and also barriers to its effective use. These barriers include:

- lack of trained facilitators;
- limited time for conducting planning;
- difficulty in setting up planning sessions with stakeholders;
- limited communication on the part of the focus person;
- opposing views and opinions of supporters and others;
- failure to address ambitious goals;
- goals remaining largely unmet; and
- choices limited to options already available to service users.

These barriers point to systems that have only marginally changed their ways of working, simply adding person-centred planning to their current continuum of services.

Barriers to person-centred service delivery and community participation include:

- attitudes;
- unequal access to employment;
- having to rely on professional help to make important life choices;
- power imbalances; and
- an approach to community inclusion that relies on programmes rather than on helping people to develop rich associations and relationships in communities.

Such limited supports and fragmented services lead to a situation where person-centred planning is simply an extension of existing disabling services.

#### Examples of International Policy Innovations

The international research points to a wide range of new developments in the United States and in Europe. American examples focus mainly on ways in which payment systems have been changed to give the person with a disability control over the way in which resources are used to provide him or her with support, and to move towards a demand-driven model. The concept of the 'money following the person' is at the heart of these initiatives, many of which are supported by legislation, policy and a large support infrastructure.

In the United States, most of these innovations focused on access to work in the community for people with disabilities and reducing the cost of support in segregated settings.

For example, the US *Ticket to Work* legislation and related programmes aimed to remove barriers to work and create a demand-driven, choice-focused voucher programme to support employment. The legislation set up a series of national programmes to support the initiative, consisting of:

- a national system of community benefits practitioners to advise on entitlements,
- a national system for advocacy and protection to help remove legal obstacles to employment; and
- a national corps of work incentive specialists to reform agency culture.

This three-pronged provision allowed people to access information, make informed choices and access advocacy to remove obstacles to work. A total of \$33 million (approximately €22 million) was devoted initially to this infrastructure and over 250,000 people benefited in the first five years of the programme.

With regard to the future development of supports for adults in Ireland, the research points to the benefits of moving from 'fee per item' services to outcomes-based payments for service providers.

However, the research also cautions against a national rollout of such schemes and instead advises small scale pilots to create the right package of incentives for both service users and providers.

The research also describes a range of European initiatives aimed at promoting and supporting models of community inclusion and person-centeredness, Canadian models of individualised funding, Australian models of local area-based co-ordination of community inclusion, and strategies used in the UK and Scotland.

#### **7.4 Moving to a Responsive Person-Centred Approach**

As noted earlier, the international research draws attention to the challenges facing any country that is trying to integrate person-centred planning and person-centeredness into an existing service. It also suggests the following pointers:

- Establish a vision with clear, reasonable time lines.
- Be guided by values and principles.
- Create a strong family support strategy.
- Support workers in adjusting to the change.
- Provide independent facilitators who plan with individuals, families and communities.
- Provide training and support for networking and community-building.
- Create mechanisms for effective resource arrangements.
- Introduce individualised, flexible funding.
- Set up brokerages and negotiation supports.
- Give incentives for service provider innovation.
- Provide opportunities for new, family-governed organisations.
- Create formal and informal safeguards that link quality assurance to individuals, families, services and policy.
- Develop an evaluation process to provide ongoing feedback.

To achieve change, the research suggests that the five 'pillars' – culture, policy, service infrastructure, payment and quality – must change to support community, citizenship and contribution.

**Cultural change** will be fundamental. The research describes the importance of a wide scale cultural change process that taps into the creativity and energy of the people who will be involved in bringing about the change. It stresses repeatedly the importance of a societal vision of individualised service and valued social roles for people with disabilities and suggests that this can be brought about through a national education campaign, with people with disabilities and families championing the message.

The research proposes that **policy development** should be informed by in-depth knowledge about the current experience of people with disabilities, which is gathered regularly. It proposes that a set of national indicators and benchmarks linked to all the important aspects of life such as education, health status, leisure and recreation, relationships and financial status should be used to inform policy and help create a culture that supports change.

The research also underlines the need to strengthen the voice and influence of those who use services.

To change the **service delivery system** or infrastructure, the research suggests that the new vision should be the subject of a 'bold and strong' statement, supported by reward for innovation and for an expanded array of demand-led, individually customised services which give choice and direction to service users. It suggests that a voluntary, demand-led system would give providers time to adjust services in response to changing needs.

The scale of the challenge involved in preparing staff for the new orientation must be grasped, according to the research. Supporting community inclusion, providing individualised supports, being able to recognise the gifts and capacities of individuals and taking risks will involve new skills and ways of working. This shift needs to be supported by peers and management and built into accreditation processes.

The research suggests that reconfiguration will only happen if there are incentives that foster innovation and create a competitive market for adult day services. A voluntary voucher option to be used with approved providers on a pilot basis is described as a way of moving, over time, to a demand-led system.

This pilot would begin only after a thorough analysis of the costs of existing services and supports to ensure cost-neutrality.

The research also deals with ways of measuring success for the purpose of quality assurance. It points to the value of using performance measures that are strongly linked to the desired service outcomes such as person-centred planning, participant access, participant rights and responsibilities, participant outcomes and satisfaction, and system performance.

Finally, the research draws attention to the need for new thinking about the concept of risk in relation to service provision. Traditionally, risk for individuals is assessed by professionals who then take responsibility for decisions. These professionals may prevent the adult with a disability from taking a risk, if there are potential consequences for the organisation. The research argues for a person-centred approach to risk that both enables the person to have control over his or her life and encourages citizenship.

## **8 *New Directions: Personal Support Services for Adults with Disabilities***

### **8.1 *An Overview of New Directions***

Traditionally, day services funded by the health services for adults with disabilities have been specialist services in segregated settings and locations as opposed to mainstream services. In recent years, supported by legislation, the social model of disability and evolving ideas and practices, the main thrust of service provision has been to assist and support adults with disabilities to:

- engage in and be part of their community;
- participate as equal and full citizens in all aspects of social living; and
- make maximum use of mainstream services, in accordance with their wishes, aspirations and needs.

The reconfigured HSE funded service provision for adults with disabilities will involve a radical shift from group programmes provided in mainly segregated settings. In the new approach, each person will be offered a flexible and individualised set of supports so that they can live a life of their choosing in accordance with their own wishes, aspirations and needs.

The core purpose of services will be to enable people to participate as equal citizens in all aspects of social living, to be part of their community and to make use of the services in their community.

The new approach will be called ***New Directions: Personal Support Services for Adults with Disabilities***. ***New Directions*** will be based on the core values of person-centeredness, community inclusion and active citizenship, and high quality service provision.

## **8.2 Core Values of *New Directions***

The approach to the future provision of personal support services for adults with disabilities will be based on the core values of:

- person-centeredness;
- community inclusion and active citizenship; and
- quality.

These values are closely linked. They form the foundation of support for adults with disabilities and should be reflected in governance structures, programmes, policies and relationships.

### **8.2.1 Person-Centeredness**

Person-centeredness is a set of beliefs, attitudes and expectations about the right and capacity of a person with a disability to live their life in accordance with their own wishes, dreams, aspirations, needs and abilities.

A person-centred approach on the part of service providers involves a commitment to facilitating what the person and the person's family believe to be vital quality of life choices. It involves truly listening and respecting the person, and being guided by them. It also involves applying creativity, flexibility and openness to trying what might be possible. A person-centred approach means having high expectations for the individual and helping the individual to manage risk and challenge. It involves facilitating choices that are not limited to the options that can be offered within any one service provider's range of services. Services and supports are tailored on a person-by-person basis, taking account of the diversity of individual need. Person-centeredness must permeate the culture of the service-providing organisation and be reflected in governance, policy, systems and practices.

### **8.2.2 Person-Centred Planning**

One of the key expressions of person-centeredness in service provision is person-centred planning. This is a process designed to help a person to make plans for his

or her future. It is used most often as a life-planning model to enable people with disabilities to improve their independence, quality of life and self-determination. It may be described as a way of discovering how a person wants to live their life and what is needed to make that possible.

Person-centred planning is not needs assessment. It is not individual programme planning although it may operate alongside and include both of these processes at particular times.

No one method or set of tools defines person-centred planning. Core themes in a person-centred planning process include building the capacity and potential of the person, actively searching for skills and talents, and listening deeply to the individual and those closest to him or her.

Person-centred planning has been described as being bound up with the goal of achieving the following five accomplishments:

- Growing in relationships, especially in natural community settings with people who are not paid service providers
- Making meaningful social contributions
- Making informed and real-life defining choices
- Having the experience and dignity of holding valued social roles
- Sharing in the ordinary places of typical associational life.

### **Community Inclusion and Active Citizenship**

Community inclusion and active citizenship is a fundamental right. It is a core value supported by the UN Convention of the Rights of Persons with Disabilities as well as international and national policy and legislation.

It is important to have a clear understanding of what is meant by the term 'being part of one's local community'. This clarity is essential so that in discussion and dialogue about community inclusion and citizenship, everyone has a common, shared understanding of what this involves.



Being part of one's local community means:

- knowing people in the community who are not involved in providing services;
- living and working in ordinary places;
- being able to access publicly-funded community services such as libraries, public offices and adult education programmes;
- using local services and facilities, such as shops, cinemas and pubs;
- being able to contribute to and be part of specialist community associations for people with disabilities;
- being able to contribute to and be part of mainstream community associations such as residents associations, sports clubs and voluntary bodies;
- volunteering; and
- being able to vote and to influence local planning.

The orientation towards community inclusion and active citizenship must be fundamental to a modern, person-centred service. For people with severe and profound disabilities, the scope for community inclusion may be limited but the scope for a meaningful form of inclusion that is respectful of their needs should be part of the person-centred plan.

### **Quality**

The adult with a disability should experience a high-quality service. The commitment to quality should be evident in the way in which the service provider meets service standards and puts in place arrangements for regular monitoring and evaluation of the quality of service.

The commitment to service quality and continuous quality improvement should be reflected in recruitment, induction, staff training, provision for continuing professional development, and in the suite of policies and procedures that govern all aspects of the work of the service.

### **8.3 Introducing the Personal Supports**

Every adult benefits from support in his or her life. People with disabilities need more tailored supports. The purpose of a modern person-centred day service is to offer a flexible and individualised set of supports to enable each adult with a disability to live a life of their choosing in accordance with their own wishes and needs.

The range of supports to which the individual has access should equip him or her to achieve the following outcomes and goals:

- make choices and plans to support personal goals;
- have influence over the decisions that affect his or her life;
- achieve personal goals and aspirations; and
- be an active, independent member of his or her community and society.

The nature of the support will depend on the particular needs and abilities of each individual. It is the responsibility of the service provider to work with each individual to tailor the supports to the individual's needs.

Against the background of a commitment to person-centeredness and community inclusion, the **personal supports** that should in future be available to an adult with disability are:

1. support for making choices and plans;
2. support for making transitions and progression;
3. support for inclusion in one's local community;
4. support for accessing education and formal learning;
5. support for maximising independence;
6. support for personal and social development;
7. support for health and wellbeing;
8. support for accessing bridging programmes to vocational training;
9. support for accessing vocational training and work opportunities;
10. support for personal expression and creativity;

- 11.support for having meaningful social roles; and
- 12.support for influencing service policy and practice.



**Figure 8-1 Personal Supports Services for Adults with Disabilities**



## Support for Making Choices & Plans



### **Outcome**

People will be brought through a process that enables them to make informed choices about what they want to do in the future and the supports they need to achieve their goals.

### **Why this outcome is important and what it means for service delivery**

Many people with disabilities will make their own choices and life plans without assistance. Others may need a range of supports to help them to do this well. Giving people support to take control over their life choices and the plans for how they achieve their goals is fundamental to a person-centred approach.

A key role of the specialist service provider will be assisting the individual with making choices and planning. Every service provider will be required to offer a person-centred planning process to service users.

Person-centred planning means that the service provider must devise an individualised programme of supports with each adult, taking into account their age and life stage and their particular needs, abilities and disability. Where group programmes are on offer, the individual's participation in the group programme should be designed, monitored and evaluated on an individual basis.

To assist choice-making and planning in a person-centred way, service providers will need to:

- provide effective facilitation of a person-centred planning process;
- provide access to information;
- provide access to experiences that will equip individuals to make good choices;
- promote and develop an organisational culture and orientation to person-centeredness;

- put in place staff training in person-centred approaches to choice-making and planning; and
- assist people with disabilities and their families to develop the skills and orientation to person-centred planning for their own lives.

### **Effective facilitation of the person-centred planning process**

The primary role of the plan facilitator is to help the adult with a disability to decide what he or she wants and work out how to attain or achieve this. The facilitator may also help the individual to achieve aspects of the plan, for example by supporting the person to negotiate with service providers or advocating on behalf of the person, if asked.

This facilitation role may be undertaken by a staff member or staff team with special training, by a family member or by an independent advocate. Where a plan is being facilitated within a service, the service provider should put in place ways of making sure that the plan facilitator is autonomous and that the plan stays true to the principle of person-centeredness. This will involve taking account of all the options and possibilities open to the person with a disability, not only those options provided within the particular service.

### **Providing access to information**

People with disabilities need accessible information about options so that they can make well-informed plans and choices. Where people are already attending or receiving a service, the service provider should make sure that information about both specialist and mainstream opportunities are available and accessible.

### **Access to experiences that will equip individuals to make good choices**

People's expectations for their lives can be limited by their experience. Part of the support for person-centred choice-making and planning is to make sure that adults with disabilities are encouraged to try out new situations and experiences and to manage risk-taking.

Opportunities to try out mainstream services, programmes or forms of community engagement will be a core part of person-centred choice-making and planning. The individual is not confined to experiencing only the programmes or opportunities that one service provider can offer or that is available within the specialist services.

### **Organisational culture and leadership for person-centred approach**

One of the main responsibilities of managers of specialist service providers is to create an organisational culture that favours a person-centred approach in the service. Among the strategies for this will be an orientation in person-centeredness for members of boards of directors and senior management, proofing all policies for person-centeredness, and making sure that people with disabilities served by the organisation have structures through which they can contribute to service policy and evaluation. A person-centred approach should be built in to the recruitment processes.

### **Put in place staff training in person-centred approaches to choice-making and planning**

A key element of staff training and development will be familiarisation with the concept of person-centeredness and what it means for day-to-day practice within the service. This should be part of the induction and development of all staff, not only those involved in facilitating person-centred planning.

Management and staff competency frameworks and training should reflect a clear understanding of, and commitment to, the principles and practices of a person-centred approach. The requirements for person-centeredness should be built into recruitment practices.

### **Assist people with disabilities and their families to develop the skills and orientation to person-centred planning for their own lives**

Adults with disabilities may have limited expectations for themselves and may have become accustomed to a culture where professional staff or family members take the lead in the decision-making about the life choices that the adult makes. Service

providers will need to support people with disabilities and their families in a new orientation, where the adult's expectation is that they will take decisions and make choices for themselves, and will be equipped with the skills, information and experience they need to do this well.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this include:</p> <ul style="list-style-type: none"> <li>• information,</li> <li>• communication,</li> <li>• advocacy,</li> <li>• exploring options,</li> <li>• person-centred planning,</li> <li>• decision-making,</li> <li>• experiential events, and</li> <li>• involving families in person-centred planning.</li> </ul>	<ul style="list-style-type: none"> <li>• Each person will begin to build capacity to help them to make choices and plans during their first 12 months in service.</li> <li>• Each person will have completed an individual supports plan and a person-centred plan within a further 12 months.</li> </ul>



## Support for Making Transitions & Progression



### **Outcome**

People experience seamless transition between supports provided by specialist and by mainstream services and will try new experiences on an ongoing basis.

### **Why this outcome is important and what it means for service delivery**

#### **Transitions**

Making transitions is an integral part of the life of every adult. Times of transition can be difficult and some people with a disability will need structured support from family, staff and others to make a successful transition to a new environment. The role of the specialist service provider is to co-ordinate this support.

Formal transition arrangements should be an integral part of any plan for moving to a new programme or activity either inside a particular service or to a community service or other specialist service.

The most challenging transition may be the transition from being in a segregated setting to being part of normal life in the local community, and building relationships in that community. Some transitions, particularly for people with severe and profound disability may be to programmes within a particular service or may involve moving to another service.

The engagement with the individual around a transition should result in a plan that sets out the key issues for the person making the transition. The support for transition should be tailored in the light of those issues and the new relationships that the person will be entering. The transition plan should identify possible barriers or challenges to a successful transition and plan for ways of overcoming those barriers.



The person should be able to try out the new environment and will gain both information and experience in that trial process. They should only be expected to make a final decision and a final transition plan when they have had the opportunity to experience the new environment or situation.

## **Progression**

People with disabilities should be able to make continuous progress towards their goals and towards meeting their aspirations. The reason for a focus on progression is to make sure that people get the support they need to realise their full potential. The service provider will be responsible for helping the person with a disability to plan for a developmental progression in their learning and their life.

Historically, progression tended to be viewed narrowly in terms of 'moving up' or 'moving out', or moving from specialist to mainstream services. It may mean any or all of these, but should not be viewed only in these terms.

For the individual with a disability, progression should mean that people are challenged, encouraged and supported to try new experiences and do new things in their lives on an ongoing basis.

Reviews of individual outcomes should be conducted at regular and appropriate intervals. The review should make sure that each person is being given the opportunity for progression.

## **Accreditation**

In the case of both transitions and progression, achievements should be acknowledged. Any process that people go through successfully should be recognised. This may be by way of formal accreditation or by less formal but structured recognition such as a certificate.

Where possible, mainstream accreditation for learning and achievement should be sought, but other forms of recognition should also be explored.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access to support this include:</p> <ul style="list-style-type: none"> <li>• capacity-building,</li> <li>• positive risk-taking,</li> <li>• information to support community participation,</li> <li>• independent travel training,</li> <li>• social skills development,</li> <li>• confidence-building.</li> </ul>	<ul style="list-style-type: none"> <li>• Transition planning will underpin each individual's support plan.</li> <li>• Progression through support services will be recognised by access to mainstream or specialist accreditation.</li> </ul>



## Support for Inclusion in One's Local Community



### Outcome

People use integrated community services, develop relationships with people who are not involved in specialist service provision and participate in normal, everyday community activities.

### Why this outcome is important and what it means for service delivery

Community inclusion and active citizenship is a basic right enshrined in the UN Convention on the Rights of Persons with Disabilities, and the provision of support for this is a core value in a modern, person-centred service. Being part of one's local community means:

- knowing people in the community who are not involved in the provision of services;
- living and working in ordinary places;
- being able to access publicly funded community services such as libraries, public offices and adult education programmes;
- using local services and facilities, such as shops, cinemas and pubs;
- being able to contribute to and be part of specialist community associations for people with disabilities;
- being able to contribute to and be part of mainstream community associations such as residents associations, sports clubs and voluntary bodies;
- volunteering;
- being able to vote and to influence local planning.

For specialist service providers this means making sure that community inclusion and active citizenship is the primary focus of the work of the service. This focus on community inclusion will have implications for programmes, service locations, staff roles and training, and the skill mix of staff in organisations.

For people with severe and profound disability, the scope for community inclusion may be quite limited and should be guided by their individualised needs and their person-centred plan.

A key task for the specialist service provider will be to work closely with mainstream services, with other specialist agencies and with the wider community to build a joint approach to facilitating community inclusion. Specialist service providers should in the future see the provision of education and advice to community leaders and influencers as an important part of their role.

Service locations should be decided with a view to enabling people with disabilities to be an integral part of their community rather than segregated or removed from the community. As far as possible, buildings where services are provided should be located in integrated settings. Any new physical developments should take the form of a 'hub' from which people with disabilities can be supported to access local services.

Staffing and staff orientation and training should be geared towards making sure that adults with disabilities are supported to be part of their local community. Service providers will need to build expertise in community development approaches and to draw on models of good practice in community inclusion.

Staff roles will focus on equipping people with the skills and capacities for community participation and active citizenship. Service providers should review the skill mix in their service to explore the possibility of re-orientating staff roles towards developing community access and participation. The specialist service provider should support the individual by:

- making available information about community facilities and services;
- offering experiences and familiarisation with aspects of community life;
- finding ways of accommodating the wish to participate;
- supporting the person to get to know the community and local people;

- helping people to build ordinary relationships with people in their community;
- helping people to build or rebuild their confidence to access community services;
- providing people with support to make a contribution to community forums;
- supporting access to community and public services (including physical access);
- providing individualised support structures or modules of preparation;
- providing support to families and siblings that equips families to help the adult with a disability to fulfill family roles, deal with new challenges and experiences, and manage risk-taking.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access to support this include:</p> <ul style="list-style-type: none"> <li>• community information,</li> <li>• independent travel training,</li> <li>• developing relationships,</li> <li>• confidence-building,</li> <li>• advocacy,</li> <li>• social skills,</li> <li>• street-wise positive risk-taking in the community.</li> </ul>	<ul style="list-style-type: none"> <li>• Each specialist service provider should join with mainstream providers and other specialist providers to promote and facilitate community inclusion for all participants.</li> <li>• <input type="checkbox"/> Each specialist service provider should be involved in educating community leaders about disability issues.</li> <li>• <input type="checkbox"/> With the exception of those who need intensive medical and clinical support, <b>New Directions</b> will be delivered in integrated community-based centres which act as a 'hub'.</li> <li>• Service providers should review current staff roles to explore ways of reorienting these roles towards developing community access and participation.</li> <li>• Any staff recruited in connection with the delivery of <b>New Directions</b> should have a community inclusion and participation focus or profile.</li> </ul>



## Support for Accessing Education/Formal Learning



### Outcome

People access formal education programmes in line with their needs and abilities.

### Why this outcome is important and what it means for service delivery

#### Definition of lifelong learning

*'All learning activity undertaken throughout life with the aim of improving knowledge, skills and competencies within a personal, civic, social and/or employment-related perspective' (Report of the Taskforce on Lifelong Learning 2002:6).*

People with disabilities have a right to be able to fulfill their potential for learning and education, and to continue throughout their lives to learn new skills and gain new knowledge, in line with their own wishes, interests and abilities. At different ages and stages of their lives, people will want access to particular learning and knowledge that is appropriate to them at that life stage.

Some adults with disabilities may, for various reasons, have missed out on formal education at primary and post-primary level. Service providers should make sure that adults with disabilities are facilitated and supported to explore options and choices for both formal and informal learning, as part of a person-centred plan.

People with disabilities need to be supported to access mainstream education programmes as a first option. They should be provided with individualised specialist programmes where required. A further role of the specialist service provider is to work with community and mainstream educational providers to widen access for people with disabilities.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<ul style="list-style-type: none"> <li>• In line with the individual's support and person-centred plan, they will need individual support to access mainstream integrated educational programmes from the VEC or mainstream third level institutions.</li> <li>• Where individuals do not have the capacity to take part in integrated, mainstream, education programmes, specialist service providers in conjunction with the Department of Education and Skills will arrange for the continuation or development of tailored, specialist, education programmes to complement the delivery of <b><i>New Directions</i></b>. These programmes will focus on the development of literacy and numeracy skills to support: <ul style="list-style-type: none"> <li>○ independent living,</li> <li>○ community, inclusion and participation,</li> <li>○ making choices and plans.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Service providers should maximise opportunities for participants to access mainstream educational programmes as opposed to developing specialist educational programmes.</li> <li>• For participants who need specialist educational programmes all efforts should be made to provide these in integrated educational settings.</li> </ul>



## **Outcome**

People explore what independence means for them and how they can achieve that independence in line with their capabilities and capacity.

## **Why this outcome is important and what it means for service delivery**

The right to live independently is a basic right (UN Convention on the Rights of Persons with a Disability). Building capacity for independence means equipping people with the skills to manage their own lives and offering opportunities to experience new and challenging situations and to take risks.

The foundation of support for independence is a person-centred planning process that helps the person with a disability to explore the meaning of independence for them and to plan ways of securing that independence. Independence will mean different things to different people, depending on their capacities and circumstances. The person-centred plan should take account of all these factors.

## **Skills Development**

People with disabilities need access to programmes, supports and experiences that will equip them with independent living skills. They need opportunities to test and refine those skills in real-life settings where they can have experiences that build their confidence.

Provision of basic skills development programmes will always be needed. However, the orientation of these programmes needs to be strongly focused on offering supported experiences that will enable people to manage their lives in 'real' situations and in community places, and not only within the specialist setting.



The role of the specialist provider is to offer a range of life skills preparation programmes such as money management, literacy and numeracy development, and maintenance, sexuality and relationships.

Specialist service providers should make sure that there are strong links between home life and other support services to offer the individual a co-ordinated approach to developing their independence.

The range of inputs that the individual may need such as home help, personal assistance and support for community living, should be co-ordinated to form part of an integrated package of supports to meet needs in a person-centred way.

### **Developing Risk-Taking and Mobilising Family Support**

One of the challenging aspects of helping people to maximise their independence is to strengthen their readiness to take risks. Risk assessment processes carried out in partnership with the individual will equip them to manage risk in a positive way.

Families may need assistance and positive support programmes to help them to encourage and enable a family member to take as much responsibility as possible for their lives.

### **Accessing Community Services**

People need to be able to engage with community services that will provide challenge and opportunities for them. Being able to avail of public transport is an essential gateway to independence. For people with physical and sensory disabilities, physical access to community facilities will be especially important.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to support this include:</p> <ul style="list-style-type: none"> <li>• independent living skills,</li> <li>• money management,</li> <li>• sexuality and relationships,</li> <li>• travel training,</li> <li>• social skills,</li> <li>• housekeeping, and</li> <li>• civic awareness.</li> </ul> <p>All of these modules should be delivered with a focus on experiential learning within the community and in people's homes.</p>	<ul style="list-style-type: none"> <li>• Service providers should deliver family support programmes to foster independence for participants.</li> <li>• Risk assessment and positive risk-taking should underpin the delivery of each individual's support and person-centred plan.</li> <li>• Experiential learning to support the development of independence should happen in ordinary and appropriate places, for example the wider community and participants' homes.</li> </ul>



## Support for Personal & Social Development



### Outcome

People's personal and social skills will be developed so that they can realise their person-centred goals and aspirations.

### Why this outcome is important and what it means for service delivery

Personal and social development is the foundation of independence. The individual's personal and social skills – their capacity to engage in relationships with others around them – will shape the extent to which they can benefit from and contribute to all aspects of community living.

Some adults with disabilities may need assistance and support to strengthen both personal development and social and interpersonal skills. These needs should be a key part of a person-centred plan.

Personal and social development programmes should relate to the age and life stage of individuals. For example, in the case of a person preparing for employment, the focus will be on work-related skills and capacities. Programmes should also be differentiated to take account of the particular needs of individuals and their experience. For example, people who have experienced mental health difficulties may need help to rebuild their confidence and re-engage in social activity.

The delivery of individualised personal and social development programmes should be community-focused as far as possible. The specialist service provider should work with local community groups, mainstream service providers and advocacy groups to make sure that adults with disabilities can access opportunities for personal and social development in community settings as far as possible.

## **Adopting a flexible approach in the provision of supports**

People with disabilities need seamless access to support for personal and social development. Support for friendship, social life and community living does not fit neatly within the framework of a nine-to-five day. A person-centred approach will mean that supports are built around the needs of the person and that organisations structure their responses in a flexible way to address person-centred goals that require supports to be offered in the evening and at weekends.

To make sure that person-centred plans are a holistic response to the needs and wishes of adults with disabilities, service providers should examine how day service staff could link with residential, respite and community staff and with parents, carers and families to provide integrated and responsive support.

Service providers should examine how, within the scope of existing resources, supports can be offered outside a nine-to-five service. Recruitment of new staff should include the flexibility to provide support outside of nine-to-five arrangements.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this support include:</p> <ul style="list-style-type: none"> <li>• social skills,</li> <li>• independence skills,</li> <li>• community education, and</li> <li>• work experience.</li> </ul> <p>These modules should be tailored to take account of the particular goals of individuals at different stages, for</p>	<ul style="list-style-type: none"> <li>• Service providers should respond flexibly to personal and social development goals that need to be met outside of normal service delivery hours.</li> <li>• Service providers should work collaboratively with other support services such as residential, respite and community services to maximise the potential to deliver to person-centred social and personal development goals.</li> </ul>

<p>example people transitioning to employment, people recovering from illness, and so on.</p>	
---	--



with their identified needs. Where possible, people are empowered to be responsible for their personal health.

**Why this outcome is important and what it means for service delivery**

People with disabilities need fair and seamless access to health services and to supports for positive health and wellbeing, including health promotion and prevention programmes.

The primary point of contact between a person and the health system at present is the general practitioner. In the longer term, the local primary care team will be a key location for enabling people with disabilities to access a comprehensive healthcare service in the community setting.

The role of the specialist service provider is to make sure that adults with disabilities are empowered with the information, knowledge and skills they need to build relationships with general practitioners, to know about and use local health services, to take responsibility for their health, and to use community facilities such as sports facilities, clubs and gyms. Service providers should support people to keep well, to attend routine appointments and to take personal responsibility for

their health. Programmes and support should take account of changing needs throughout a person's life cycle, as well as any unique needs such as women's health needs, men's health needs, or health needs linked to a particular disability.

The specialist service provider can play an important role in educating and advising community health professions about ways of supporting people with disabilities to make full use of community services through improving access or orienting health promotion programmes to take account of people's needs.

Service providers and service users need a positive and holistic approach to health and wellbeing that values emotional and mental health as well as physical health and wellbeing. Counselling and other emotional health supports may be needed, particularly where a person has acquired a disability.

In addition to accessing community health services, people with disabilities may need specialist multidisciplinary support such as aids, appliances, dental healthcare and specialist technology. There will be an ongoing need to provide for the particular health needs of specific groups such as people with autism, acquired brain injury, neurological conditions, and severe and profound disability. Providers will also need to take account of any emerging research or new developments in managing the health aspects of disability. Health-related supports for these groups may need to be provided in specialist settings over the longer term.

While this support may be one of 12 that most people may avail of, for people with severe and profound disability, it may be the most important support, and there may be limitations on people's capacity to avail of the other supports.

Despite these significant clinical support needs, people with severe and profound disability are entitled to a person-centred planning process and choice, and should have access to community participation to the extent that they can benefit. It is the responsibility of the service provider to translate the values of person-centeredness into suitable services for this group of service users.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual’s participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this support include:</p> <ul style="list-style-type: none"> <li>• personal care,</li> <li>• food choice and health,</li> <li>• healthy living,</li> <li>• exercise,</li> <li>• stress management,</li> <li>• relaxation techniques,</li> <li>• life cycle – health promotion,</li> <li>• art therapy,</li> <li>• music therapy, and</li> <li>• drama therapy.</li> </ul> <p>Therapies will include:</p> <ul style="list-style-type: none"> <li>• physiotherapy,</li> <li>• speech and language therapy,</li> <li>• occupational therapy,</li> <li>• support from a dietician,</li> <li>• psychology,</li> <li>• psychiatry,</li> <li>• behaviour therapy, and</li> <li>• specialist nursing care.</li> </ul> <p>Aids and appliances include special equipment to meet the individual’s identified needs.</p> <p>People with severe and profound disabilities are likely to need more of these programmes and may need a specially-equipped environment.</p>	<ul style="list-style-type: none"> <li>• Service providers should become aware of the primary care structure within their locality so that they can support people to seamlessly access these services.</li> <li>• Multidisciplinary team services should be developed to meet identified need. This development should address the ongoing needs of specific groups such as those with acquired brain injury, brain injury, autistic spectrum disorder, dual diagnosis.</li> <li>• Service providers should form links with community health promotion officers and local agencies involved in health and wellbeing.</li> <li>• Service providers should put in place a truly person-centred assessment for people with severe and profound disability.</li> </ul>



## Support for Accessing Bridging Programmes to Vocational Training



### **Outcome**

People access bridging programmes to vocational training.

### **Why this outcome is important and what it means for service delivery**

Every person with a disability has the right to the best opportunity to participate in the world of work and to earn a wage. Vocational preparation, including work experience, should be part of the range of opportunities available to those who need them. Bridging programmes, organised jointly by the specialist service provider and the mainstream vocational training provider, provide continuity and choice for the individual.

The overall objective of the bridging programme is to help people with disabilities to test, acquire and strengthen their readiness and capacity to move to and benefit from vocational training suited to their needs and wishes.

Although structured and lasting a specific time, the content and duration of a bridging programme will vary to reflect the needs and abilities of different groups of people with disabilities. Programmes should be flexible in duration and content to accommodate these differences.

Bridging programmes should be designed around the capacities of the individual. They should offer access to basic work-related skills such as information technology (IT) skills, which can then be developed in vocational training programmes. Developing capacity for appropriate relationships in the workplace or training setting may be part of an individual's programme in line with their person-centred plan. Programmes should reflect and prepare for the demands of the training setting in a meaningful way.



People with disabilities need access to information about training and work opportunities. They need experiences and opportunities to try things out, so that they can make informed vocational choices in line with their capacities, abilities and interests.

As part of planning and arranging for access to training, the individual with a disability should identify the range of support services they need so that they can make the most of their training opportunity. The role of the specialist service provider is to make sure that these supports are put in place.

A bridging programme may be part of a wider life skills development programme where, as part of a person-centred plan, the orientation or pace is adjusted to emphasise skills that would be needed to enter vocational training. Bridging programmes may be provided as a distinct programme.

### **Work Experience**

Work experience may be part of a bridging programme. The purpose of work experience may change at different stages of a person's vocational development. As part of a bridging programme, work experience may include:

- providing an individual with a 'taster' of different kinds of work to help them explore their abilities and interests and get information and insight to make an informed choice of training;
- learning about work opportunities within one's community;
- developing skills for life and independence.

Work experience that forms part of a bridging programme offers the person a chance to familiarise themselves with the demands and content of a particular job or jobs and helps them to make decisions about future areas of training and employment.

Work experience must be clearly differentiated from employment.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this support include:</p> <ul style="list-style-type: none"> <li>• capacity-building,</li> <li>• relationships in the workplace,</li> <li>• work-related IT skills,</li> <li>• personal and social skills,</li> <li>• travel awareness,</li> <li>• money independence,</li> <li>• therapeutic work,</li> <li>• work experience.</li> </ul>	<ul style="list-style-type: none"> <li>• There should be agreement about a workable model of bridging between the HSE and vocational training providers.</li> <li>• The agreed bridging model should be piloted in selected agencies.</li> </ul>



## Support for Accessing Vocational Training & Work Opportunities



### **Outcome**

People are supported to move from personal support services to vocational training and employment.

### **Why this outcome is important and what it means for service delivery**

Each person with a disability should have the specific support they need to participate in and benefit from vocational training and to maximise their chances of working in the open labour market.

### **Vocational Guidance**

Each person with a disability needs access to vocational information and vocational guidance to help them to explore their readiness for vocational training or employment and to select the kind of training most suited to their needs, abilities, and wishes. They should be able to move smoothly from HSE funded personal support services to vocational training or employment, with minimum barriers.

### **Support for Accessing Employment Opportunities**

Each person with a disability who aspires to being employed will need access to a continuum of work opportunities that may include open employment, supported employment and sheltered employment. Each individual will draw on those opportunities in line with their person-centred plan. By providing a range of supports, including support for independence, personal development and transitions, the specialist service provider will play an important part in equipping the adult with a disability to access employment opportunities in their community, or to access supported or sheltered employment programmes.

Some people with disabilities may be unable to benefit from open or sheltered employment. They may need a specialised response in relation to work or

occupation. They may benefit from access to therapeutic occupational activities on a regular basis as part of their HSE funded support service (see also the section on *Support for Having Meaningful Social Roles*).

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this support include:</p> <ul style="list-style-type: none"> <li>• social skills,</li> <li>• independent living,</li> <li>• work experience,</li> <li>• work-related social skills,</li> <li>• work-related money management,</li> <li>• work-related IT skills,</li> <li>• community information – travel,</li> <li>• time management.</li> </ul>	<ul style="list-style-type: none"> <li>• HSE funded service providers should no longer provide sheltered employment or supported employment.</li> <li>• The status of people currently involved in sheltered work or 'like work' should be examined in a person-centred way with each individual.</li> <li>• The HSE should examine how agencies are funded to make sure that funding is only provided to those agencies for health and personal social service supports.</li> </ul>



## Support for Personal Expression & Creativity



### **Outcome**

People will have explored their own creativity and found their own means of self-expression.

### **Why this outcome is important and what it means for service delivery**

The need for self-expression and creativity is an important dimension of a rich experience as a person. People with disabilities should be offered the opportunity to explore and discover their own creativity and find their preferred means of self-expression. This may involve challenging established ideas about disability and any narrow, care-focused view of 'needs'.

Self-expression and creativity will mean different things to different people. Some will want to engage in artistic projects, dance, sport, music or drama. Others will find expression in making or growing things. Support programmes need to be flexible to facilitate these unique personal preferences. Staff may need to be encouraged to acknowledge and recognise the value of creative expression as a core part of support programmes. The therapeutic value of creative self-expression needs to be facilitated and supported, ideally within the community.

The role of the specialist service provider is to help people with disabilities to come to an understanding of their own creativity and what it could mean in their lives. They may need opportunities to explore their talents and abilities and to find the best ways for them of expressing those talents.

Many local authorities are heavily involved in supporting art and artistic programmes and make grant aid available to promote this area. Many community groups involved in creative projects actively encourage people with disabilities to take part. The specialist service provider should help the adult with a disability to tap into and participate in community opportunities for creativity.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen.</p> <p>The programmes and modules that people may need to access for this support include:</p> <ul style="list-style-type: none"> <li>• art,</li> <li>• drama,</li> <li>• pottery,</li> <li>• weaving,</li> <li>• dance,</li> <li>• writing, and</li> <li>• therapeutic work.</li> </ul>	<p>There will be a need for flexibility to deliver support as many activities may be outside normal 9-5 hours.</p>



## Support for Having Meaningful Social Roles



### **Outcome**

People explore, identify and take up what they choose as valued social roles.

### **Why this outcome is important and what it means for service delivery**

People have a strong need for a sense of purpose, for a sense of their own dignity and personal worth. This is a deeply felt human need. People with disabilities have the right and the need to take their place in society, and to benefit from and contribute to that society as active citizens. They should be encouraged and facilitated to explore, identify and take up what they choose as valued social roles.

Potential social roles to be explored could include roles as volunteer, family member, advocate, peer, friend, learner, parent, member of a parish, or member of a local group or committee. Some will find their valued social role through therapeutic work that may be provided in their community or by specialist providers.

The movement towards greater community inclusion and active citizenship for people with disabilities will be a key part of the process of making sure that people with disabilities can hold valued social roles. People with disabilities will find opportunities for taking up valued social roles in the everyday exchanges of living in a community, a neighbourhood, a family, or engaging with peers in the ordinary activities of living .

The specialist service provider should make sure that people with disabilities can explore what, for them, would represent valued social roles in their community. Some may need information and familiarisation with the concept of holding valued social roles, particularly where their life experience has been one of seeing themselves as recipients or beneficiaries of others' social roles, rather than as

contributors. Some may need support to recognise and value what they can bring to their community and family.

The exploration of family roles may be sensitive, involving helping people to understand and even challenge their current status in the family. Historically, families of people with disabilities may have followed well-established patterns in respect of the role played by them and by their family member with a disability. However, those roles are changing rapidly as family relationships and responsibilities change. Family members may also need support to review and evaluate how they can enable their family member to take up a valued role in the family.

Any social role requires knowledge and especially experiences that give insight and understanding as to what the role means and involves. Each individual will need a process and a plan for achieving, managing and enjoying the roles they choose. They will also need to be equipped with the skills and experiences they need to fulfil this role well. The names of the roles given by service providers to people with disabilities who use specialist services deserves serious consideration and dialogue within services as well as nationally.

The term 'service user', though accurate and useful, does not communicate a valued role, nor does it convey the changing relationship between the person with a disability and the service provider to one of partnership and shared responsibility for service outcomes.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>In line with the principles of person-centred planning, the individual's participation in any programme or module should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. The programmes and modules that people may need to access for this support include:</p>	<ul style="list-style-type: none"> <li>• The concept of people with disabilities holding meaningful social roles should be developed through training for providers and staff.</li> <li>• Communities should be supported to embrace the notion of people with disabilities holding meaningful social roles.</li> </ul>



<ul style="list-style-type: none"><li>• active citizenship,</li><li>• community,</li><li>• families and relationships,</li><li>• independent travel,</li><li>• personal social skills,</li><li>• capacity-building,</li><li>• experiential learning, and</li><li>• support to maintain the social role.</li></ul>	
---	--



## Support for Influencing Service Policy & Practice



### **Outcome**

People have opportunities to be involved in all service planning, development, monitoring and evaluating, including staff recruitment.

### **Why this outcome is important and what it means for service delivery**

Any service must be built around the needs, rights and dignity of the individual it serves. This commitment to the centrality of the individual in the planning and delivery of services is at the heart of a person-centred approach. It must be translated into practical mechanisms so that people with disabilities, individually and collectively, can bring their influence to bear on service delivery on an ongoing basis.

People with disabilities can contribute to policy development, exploration and review of best practice in service practice, monitoring and evaluation of services, preparation and review of service plans, selection of service locations, recruitment, staff training and development, peer training and development.

People with disabilities need both structures and supports to be able to contribute their views on issues of service policy and practice and the design of their own service.

Those structures need to be set up at every level in the service-providing organisation, and consideration given to ways of building these structures into processes such as service planning and recruitment. This is a challenging project, involving new roles for staff and service users. It will involve a major cultural shift in organisations and a shift in beliefs and values.

Service users will need information about the organisation, and they need to be equipped with the skills to negotiate around their needs and expectations. Staff will

need training so that they can hear and respond to service users. This requires an investment of time and resources.

In the development of these structures and practices, there is a need for a balanced focus on equipping staff and families as well as service users for the task of working together and having dialogue about policy and practice.

<b>Programmes and Services to Deliver this Support</b>	<b>Key Modernisation and Reconfiguration Issues to Deliver this Support</b>
<p>Both service users and provider organisations need programmes and services to enable people to influence their own service and the policies, plans and practices in the service they attend.</p> <p>Service users</p> <ul style="list-style-type: none"> <li>• Advocacy</li> <li>• Leadership</li> <li>• Communication</li> <li>• Confidence-building</li> <li>• Self-esteem</li> <li>• Interviewing skills</li> <li>• Capacity-building</li> </ul> <p>Provider organisations</p> <ul style="list-style-type: none"> <li>• Staff training in policy and planning together</li> <li>• <input type="checkbox"/> Self-assessment questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Service providers should put formal structures in place so that service users are represented and included in the process of service planning, delivery, monitoring, evaluation and staff recruitment .</li> <li>• Staff will work in new environments where the user is a partner in service rather than a recipient.</li> </ul>

## **9 Making it Happen: the Changes Needed to Implement *New Directions***

***New Directions*** will mean that adults with a disability are offered a flexible and individualised set of supports to enable them to live a life of their choosing in line with their wishes and needs. A core objective will be to enable adults with disabilities to live normal lives as part of their local community.

Achieving this objective will require change through all levels of HSE funded service provision and in wider public services. Opportunities for community living and integrated services must be created that will break down barriers and change attitudes and perceptions while meeting needs.

To deliver ***New Directions***, specialist service providers and mainstream providers must work together to offer a seamless set of support services. The new approach means enabling people to move freely among services, with a minimum of barriers. For this to happen, government departments, the HSE and providers must manage their respective policies, budgets, programme requirements and administrative systems in joined-up ways.

The new approach will have implications for service provider culture, work practices, programme content, staff roles and service user roles. The extent of the change required in any service will depend on the gap between current systems and practices, and what is needed to deliver a modern, person-centred service. It will depend on the capacity of specialist providers to offer flexible, needs-led, individualised supports based on person-centred policies, philosophy, culture and practice.

As part of the move to ***New Directions***, the HSE must clarify its role in the provision of supports for employment, training and work opportunities. That role

must fit within the HSE's remit for delivering health and personal social services and must reflect the role that has been assigned to other government departments and agencies as part of the National Disability Strategy.

The HSE must also develop strategies to help providers deliver person-centred services and must put in place a strong infrastructure to support service quality, monitoring and evaluation of services, long-term planning, and funding systems that meet the vision and principles of ***New Directions***.

A significant level of change can be achieved using resources currently available for adult day services. However, a national change management process led by the HSE will be essential to mobilise the capacity within the system and make sure it is fully oriented towards implementing ***New Directions***.

In summary, the initiatives needed to make ***New Directions*** happen involve:

- supporting the change management process (9.1);
- using the potential of the National Disability Strategy to deliver ***New Directions*** (9.2);
- strengthening capacity for person-centeredness (9.3);
- clarifying the future HSE role in relation to employment, training and work opportunities (9.4);
- making sure that HSE systems for planning, monitoring, supporting and quality assuring service provision are aligned with ***New Directions*** and well placed to support its implementation (9.5); and
- aligning funding systems with ***New Directions*** (9.6).

## **9.1 Supporting the Change Management Process**

***New Directions*** will represent a significant change of approach for many service providers as well as for service participants and families. It will call for changes in organisational culture, in programmes and practices, and in the way staff expertise is deployed. For some organisations, the change will be significant. For others which

have been introducing innovations in areas such as person-centred planning and community inclusion, the change may be less radical. The approach to implementation will be a partnership approach, by means of which the HSE must take account of the differing capacities of providers.

The key change needed in organisations will be cultural change. There have been significant shifts in the cultural norms that shape service delivery both internationally and in Ireland.

The most significant change has been the move from a medical model to a social model of provision, and the recognition of the right of people with disabilities to community inclusion and active citizenship. However, although there is evidence of innovation and good practice, progress has been uneven across disability groups and agencies.

***New Directions*** will require a culture of person-centeredness within the HSE and within HSE funded service providers. Such cultural change is challenging. Its importance can be overlooked and investment in it given a low priority despite its significance for achieving change.

The work of the review has followed well-established change management principles by creating a shared vision for change, engaging key stakeholders and adopting a comprehensive communications strategy. The implementation process should continue to be guided by these principles by:

- making sure that the needs of service users are at the core of the change process;
- building a whole-system approach, focusing on the connections, relationships and dependencies among different parts of the system;
- encouraging collaboration among agencies, local communities, services and teams and among national, area and local levels;
- promoting active engagement and participation of services users and staff;
- placing a particular emphasis on partnership and team-working;

- prioritising long-term sustainable change and improved organisational effectiveness;
- providing for the transfer of knowledge and skills so that the system equips itself to manage change;
- promoting organisational learning through regular feedback, measurement and evaluation at all stages of the change journey;
- locating the responsibility to manage change at all levels of the system – individual, group and organisational and at local, area and national levels.

The process of implementing ***New Directions*** will require:

- a national change management plan; and
- an implementation plan within each service provider organisation.

The proposed Quality Assurance System with associated Guidelines (see 9.5.2) will be the essential foundation for national and organisational change planning. This Quality Assurance System will be developed in consultation with key stakeholders. It will translate the principles of ***New Directions*** into a detailed set of programme indicators. The guidelines will assist providers in making the change to the new approach. The Quality Assurance System will also support the process of planning and commissioning services at local level.

### **9.1.1 A National Change Management Plan**

The success of ***New Directions*** depends on the emergence of a new culture of person-centeredness among service providers.

The new approach is framed in the context of 12 service supports. These 12 supports replace all existing descriptions and definitions that have operated within the day service sector.

***New Directions*** will require policy makers, providers, funders and service users to use a new language and terminology to understand and describe the service being provided. A communications strategy will be needed to disseminate the key

messages and concepts underpinning the review recommendations to all stakeholder groups.

The change process can be progressed with the help of people at all levels of the service delivery system who have key skills, positive attitudes to risk-taking and who can be champions for change. Identifying and enabling these people and equipping them through management development programmes should be part of the implementation plan.

There is a significant body of good practice in the development and delivery of person-centred services and services with a strong orientation to community inclusion. The changeover to ***New Directions*** should be supported through demonstration projects that extend the positive work begun on sharing organisational learning during the course of this review. Formal mechanisms will also be needed at national level to promote innovation.

A plan for building in reflective practice and feedback mechanisms at all stages of the change process is essential to make sure that the change effort is regularly reviewed, refined and, if necessary, refocused.

An evaluation should be put in place at the start of implementation, using an appropriate evaluation research methodology. A protected line of investment, even if modest, will be needed to enable innovation to grow and take root in the system.

### **Recommendation 1**

**The HSE, in collaboration with the Office for Disability and Mental Health and key stakeholders, should develop a national change management plan for *New Directions*, with an assigned budget.**

**The plan should be based on collaboration with service participants, service providers, government departments, local authorities and key mainstream agencies. The National Change Management Plan should**



**include:**

- **a communications and promotional strategy for *New Directions*;**
- **a national demonstration programme to test and promote innovation;**
- **dissemination of the Quality Assurance System and associated guidelines;**
- **a workforce skills audit to identify champions for change;**
- **management development programmes;**
- **a centre for innovation and change to support shared learning and dissemination of good practice; and**
- **a strategy for evaluating progress in implementing *New Directions*.**

### **9.1.2 A Reconfiguration Plan within each Service Provider contracted by HSE**

A Quality Assurance System with associated Guidelines will set out the criteria that service providers must follow to deliver the 12 individual supports and will provide a self-assessment tool to help providers assess and plan for the change needed in their particular case.

The census data highlights the diversity of current day service provision. Services are provided by 81 statutory and non-statutory organisations, ranging from organisations meeting the needs of 20 people to those providing services to over 1,000 people. For reasons such as length of time in operation and access to resources, some of these providers are better placed to bring about the change needed to deliver ***New Directions***.

The HSE should work in partnership with individual service providers to support a planned change process that takes account of this diversity.

### **Recommendation 2**

**With the help of the initiatives in the national change management plan, service providers will be supported to carry out a self-assessment process to benchmark their existing service against each of the 12 supports.**

**Following the self-assessment process, each service provider should propose a reconfiguration plan for delivering *New Directions*, within existing resources. The plan for bringing about sustainable change should be the subject of dialogue with the HSE with a view to delivering it in an agreed and manageable time frame and as part of the service arrangement process.**

## **9.2 Policy into Action – Using the National Disability Strategy to support the delivery of *New Directions***

### **9.2.1 Strengthening Collaborative Working at National and Local Level**

In the course of the work of this review, it became evident that mainstream services are critical to enabling those currently using adult day services to participate fully as citizens and members of the community. For example, without affordable, accessible transport, people cannot readily be part of their local community. Income support arrangements and housing provision affect the extent to which people can aspire to independence. Access to further education is central to making sure that people can advance their learning throughout their lives. Vocational training and employment opportunities are a key element of the spectrum of opportunities for adults with disabilities.

The success of *New Directions* depends in a fundamental way on national and local co-ordination of the delivery of specialist and mainstream services to adults with disabilities. The HSE funded support services and the mainstream services must join together to form a seamless continuum of support. Effective structures to enable people to make smooth transitions across this continuum of support are essential.

The sectoral plans and associated arrangements for cross-departmental linkages are the key policy instruments for strengthening mainstreaming and social inclusion for people with disabilities, and for linking mainstream and specialist services.

### **9.2.2 National Co-ordination**

At national level, the Office of the Minister for Disability and Mental Health, established in January 2008, has a specific role in improving co-ordination and communication across a number of government departments (Department of Health, Department of Jobs, Enterprise and Innovation, Department of Education and Skills, Department of Justice and Equality) and state agencies in their delivery of services for people with disabilities and mental health issues.

A high-level group of senior officials reporting directly to a Cabinet sub-committee chaired by the Taoiseach is responsible for monitoring and reviewing the sectoral plans.

These national co-ordinating processes are a clear recognition of the need for all government departments to come together to enable people with disabilities to navigate across the range of public services. Without such robust and visible structures, seamless access to services will not be a reality.

#### **Management Structures to Support National Co-ordination**

There must be clarity about where the lead role lies, in terms of management and operational responsibilities, for making sure that mainstream services and the specialist HSE funded support services work closely together. Clarity about funding responsibilities for the various services needed by people with disabilities is also essential.

#### **Recommendation 3**

**To facilitate the delivery of a seamless service to people with disabilities at local level, the Office for Disability and Mental Health should agree the need for a lead function to manage the co-ordination of delivery and**

**funding of support provision for people with disabilities in the context of sectoral plans and the EPSEN Act. A decision should be made as to where this function should rest.**

**Recommendation 4**

**The HSE should ask the Office for Disability and Mental Health to use the national collaborative structures provided for under the National Disability Strategy to bring the change agenda for *New Directions* to the attention of key government departments so that ways of implementing *New Directions* can form part of future sectoral plans and related action plans.**

**9.2.3 Local Co-ordination**

In the future, the primary focus of the specialist service provider will be on supporting each individual to participate in the community as an active citizen.

The orientation of support provision will be towards enabling people to be part of their own community and to do ordinary things in ordinary places. At the heart of a person-centred service delivery system will be the scope for each individual to move seamlessly across specialist services and between specialist services and mainstream services.

A key task for the service provider will be to work closely with mainstream services, with other specialist providers and with the wider community to build a joint approach to community inclusion. In the future, specialist service providers should see the provision of education and advice to community leaders and influencers as an important part of their role.

To facilitate these vibrant linkages, local structures for co-ordination and collaboration will be needed. Such structures will in part facilitate joint service planning at local level. These local structures should also be used to determine how best to use the overall resource allocated to meeting the needs of people with disabilities.

The outcomes of local planning could play an important role in feeding in to the scheduled national reviews of the sectoral plans of each department and to national monitoring and evaluation of the plans.

At present, co-ordinating structures for bringing together the health services and the other public services which people with disabilities need are emerging at local level. The HSE needs to examine these emerging structures to see how it can support ***New Directions*** and agree with local parties to the sectoral plans how best to develop local co-ordinating structures.

Each specialist service provider will be expected to participate in, contribute to and facilitate any formal collaborative structures that are set up in their area.

#### **Recommendation 5**

**The HSE should seek support from the Office for Disability and Mental Health for the setting up in each county of a local structure for collaborative working to support *New Directions*. Such a structure should facilitate appropriate and easy access to the new supports approach regardless of county or service provider boundaries.**

### **9.3 Strengthening Capacity for Person-Centeredness**

#### **9.3.1 Supporting Person-Centred Planning**

One of the key expressions of person-centeredness in service provision is person-centred planning, a process designed to help a person to make plans for his or her future. Inconsistency in the provision of support for choice-making and planning was described in the consultation process. From the census of day services, it appears that over 25% of existing service users do not have a person-centred plan or an individual programme plan.

Person-centred planning means that the individual has access to the widest possible range of opportunities, not only those on offer by a particular service provider. This in turn means that staff working with the individual need knowledge of and familiarity with opportunities outside their service. They must also be ready to help the person to transition out of the service if that is what they need and want.

The basic principle of person-centeredness and person-centred planning is the focus on the individual and their life plan, as distinct from a focus on the service. The service must be responsive to individual need and individual aspirations.

A key challenge for service providers will be to bring about a change in culture and orientation so that the work of the service at every level, reflects this person-centred culture and approach. It should be evident at governance level and at senior management level as well as underpinning all work practices.

All service providers will be required to offer a person-centred planning process to service users. Staff, service participants, families and providers will need support and orientation to enable them to use this form of planning.

### **Recommendation 6**

**The HSE, together with relevant specialist and mainstream support service providers, should drive the implementation of a standardised approach to person-centred planning and support this through awareness and training programmes targeted at front line staff, adults with disabilities, families and all other stakeholders.**

### **9.3.2 Facilitating Access to Advocacy Services**

People with disabilities will need access to various forms of advocacy, including access to independent advocacy so that they can contribute to service design, planning and monitoring, engage in person-centred planning, and negotiate inclusion in the community.

Every specialist service provider will be required to put in place systems so that service users and families have a say in service policy, governance, planning and evaluation.

Under the provisions of the National Disability Strategy and the Citizens Information Act 2007, responsibility for the development and delivery of advocacy services rests with the Citizens Information Board, which currently operates a programme of pilot advocacy approaches. While these pilot projects have worked well for those users who have access to the service, there are many people with disabilities who do not have the opportunity of accessing these services. The development of the Personal Advocacy Service (PAS) provided for in the National Disability Strategy under the auspices of the Citizens Information Board will play a key role in facilitating ***New Directions***. A pause in the roll out of this service is currently in place, however.

Advocacy groups and specialist service providers continue to promote, develop and deliver a range of advocacy supports to people with disabilities. However, this provision is not uniformly available.

#### **Recommendation 7**

**The HSE and national advocacy organisations should actively promote a range of advocacy models.**

**The HSE, together with the Office for Disability and Mental Health, should engage with the Department of Social Protection to highlight the importance of advocacy services and to explore possibilities for speeding up the provision by the Citizens Information Board of the Personal Advocacy Service.**

### **9.3.3 Providing a Guidance Structure**

People with disabilities need access to a structured, independent guidance service to support them in making life choices. This guidance service should offer information and advice about mainstream and community-based options as well as

helping people to make decisions involving health and personal social services and supports.

The guidance service should be independent of service providers. It should be available nationally to people with physical and sensory disabilities, intellectual disabilities and mental health difficulties and be provided in a nationally standardised way. At local level, the guidance service should offer a single point of contact where people with disabilities and families can access service information and individual guidance.

The 10 rehabilitative training guidance units set up by the Department of Health following the dissolution of the National Rehabilitation Board in 2000 provide an independent, person-centred advisory service to those availing of rehabilitative training. Essential skill sets in the provision of information and guidance have been developed within these guidance units, embedded in an independent structure and process. However, this is limited to those accessing rehabilitative training.

This service is a diminishing resource due to the recent reduction of the service, mostly due to guidance officers being successful in their application for assessment officer posts under the provisions of the Disability Act 2005. Not filling vacant posts has also had an impact on the availability of the service.

The challenge now is to mobilise the existing rehabilitative training guidance resource and to reframe it within a new overarching, independent, nationally available structure. The new structure should link to mainstream guidance roles. For example, the guidance structure would have links with FÁS occupational guidance services and with the special needs organisers in the National Council for Special Education.

### **Recommendation 8**

**An independent, national guidance service for adults with disabilities should be developed by the HSE, building on the existing skill base, processes and**



**resources within the HSE's rehabilitative training guidance service and linked to relevant mainstream guidance services. This structure should be agreed within the framework of the National Disability Strategy.**

#### **9.3.4 Facilitating Continuity of Support throughout a Person's Lifecycle**

The support services that adults with disabilities need will vary at different points in their lives. The need for age-appropriate supports gives rise to several challenges for service providers. The first challenge is to make sure that support programmes do not try to cater for an unreasonably wide age span within one programme and in one location.

A further challenge is to meet the needs of those adults with disabilities who are over 65 years of age. At present, almost 2,400 adults in day services are over the age of 65 and this figure could increase. While service providers can and do tailor supports to meet emerging needs on an individual basis, it is evident that the provision for those over 65 years needs to be supported by a national strategy.

In the census of day services conducted during January 2007, there were 139 children under 18 years attending adult day services. Existing adult services are unlikely to be suited to the needs and aspirations of these children. While the time lapse since the census was conducted may have led to a significant reduction in this number, an appropriate service must be set up for those children with disabilities who remain in current adult day services and also for those aged 16-18 who may need day services in the future.

Providing services that meet the particular needs of these two groups represents a major service gap that needs to be prioritised.

### **Recommendation 9**

**The HSE should engage with all providers of services to adults over the age of 65 (both HSE and non-statutory providers) to make sure that older people in current day services have access to a continuum of support that respects their rights, dignity and choice and is provided within the relevant older person's policy and legislation.**

**The HSE, together with the Office for Disability and Mental Health, should also engage with all providers of day services to children under the age of 18 (both HSE and non-statutory providers) and with the Department of Education and Skills to make sure that those children can access suitable support services, and that any support service offered complies with approved child care guidelines and legislation.**

**Note: Work was initiated in relation to these recommendations as part of the Priority Issues of Concern Project (see Chapter 10).**

### **9.3.5 Ensuring Access to Primary Care Services and Multidisciplinary Team Specialist Services**

Currently, people availing of HSE funded adult day services can access generic community health care services in their local community. Multidisciplinary specialist team services are also available in some areas. These specialist services are provided by both the HSE and the non-statutory sector and have resulted in the building up of significant clinical expertise in all disability areas. Providers and people with disabilities express concern about a shortage of multidisciplinary teams. They point to the need to develop these specialist services further and to address fair access for those requiring them.

Under the HSE Transformation Programme, primary care teams and managed care networks will provide for most of the health needs of the population they serve, including people with disabilities. Primary care teams will have access to a range of

specialist services in each network, including specialist multidisciplinary teams for people with disabilities. Protocols will outline the respective roles and responsibilities of primary care teams and specialist multidisciplinary teams. This integrated approach to meeting the health needs of people with disabilities is designed to make sure that generic health needs, which can be met at primary care level, are addressed by primary care teams and that only needs where specialist knowledge, skill or expertise is required are referred to specialist services.

### **Recommendation 10**

**People with disabilities need equitable and seamless access to health services and to supports for positive health and wellbeing, including health promotion and prevention programmes. Within the framework of the HSE Transformation Programme and the development and implementation of primary care teams, the HSE should speed up the development of protocols to enable people with disabilities to access primary care and specialist multidisciplinary services.**

## **9.4 Clarifying the Future Role of the HSE in Employment, Training and Work Opportunities**

### **9.4.1 Overview**

Access to employment is an important route to independence and community inclusion for people with disabilities. Historically, the provision of employment supports for people with disabilities rested with the Department of Health. HSE funded employment and training provision developed over time as a response to need, policy and development opportunities offered by European Social Funding (ESF).

Following from the Report of the Commission on the Status of People with Disabilities (1996), a government decision was made to mainstream provision of public services to people with disabilities. As the mainstream agency for providing labour market services, FÁS undertook this additional responsibility following the dissolution of the National Rehabilitation Board (NRB) in June 2000.

The sectoral plan of the Department of Health (2006) envisaged a phased transfer of funding and responsibility for sheltered and supported employment to the Department of Jobs, Enterprise and Innovation by 2010, in line with the government decision (1998) that this transfer of responsibility should take place. The sectoral plan sets out its intention that an action plan for this transfer will form part of an agreed protocol with the Department of Jobs, Enterprise and Innovation.

A further factor that must be taken into account in planning for the future role of the HSE in employment and work is the substantial body of equality and employment law enacted over the past 10 years. The Employment Equality Acts 1998 and 2004 prohibit discrimination on nine grounds including disability, and provide for equal pay for like work. Any legal issues arising from this legislation should be addressed in an open and transparent way. This will involve setting out a suitable course of action to address any legal difficulties in a way that keeps the wellbeing of the individual with disabilities at its centre while making sure that the HSE and providers are not exposed to avoidable legal risk.

#### **9.4.2 Future role of the HSE in relation to Employment, Training and Work Opportunities**

Clarity is essential about the future role of the HSE in the areas of employment, training and work opportunities for people with disabilities, and how this role intersects with the roles of the Department of Jobs, Enterprise and Innovation and FÁS.

The 'drivers' for the future role of the HSE in relation to employment, training and work opportunities are:

- the need for HSE funded services to fit within the HSE’s remit for provision of health and personal social services;
- the need to conform to government policy on the transfer of responsibility for employment programmes and supports to the Department of Jobs, Enterprise and Innovation and FÁS;
- the need to make sure there is legal clarity about the employment status of people currently in HSE supports or programmes and to minimise any legal risk for the HSE or providers while making person-centred provision for participants; and
- the need to make sure that, in the future, there are seamless links between HSE funded supports and mainstream employment supports provided by government departments and agencies.

### **Sheltered Employment**

In the census carried on as part of this review, sheltered employment is described as ‘employment in an enterprise established specifically for the employment of people with disabilities and which is in receipt of designated funding from the HSE. It refers to employment under sheltered conditions where workers have a contract of employment and are in receipt of the minimum wage’.

Government policy recognises that responsibility for the provision of sheltered employment rests with the Department of Jobs, Enterprise and Innovation (DJEI). During census week, 164 adults were involved in employment activities that met the criteria for the sheltered employment descriptor. There is now a need to identify the individuals, locations and employment activities associated with these 164 adults. Once this exercise is complete, discussions should be held with the Department of Jobs, Enterprise and Innovation to agree those services that can be transferred to DJEI.

### **Recommendation 11**

**The HSE should begin an exercise to identify the work activities engaged in by the 164 people in sheltered employment. Following this exercise, discussions should be held with DJEI to arrange for the transfer of those services that meet the criteria for sheltered employment.**

### **Sheltered Work**

The HSE funds the following sheltered work programmes for people with disabilities:

#### ***Sheltered Work Commercial***

This is described in the census as 'a day programme, which comprises work activity. In these situations, the public has access to the product or service, and contract work is carried out for a third party. Money is exchanged for goods or services. Service users may or may not receive allowances or discretionary top-up payments'.

#### ***Sheltered Work – 'Like Work'***

This is described in the census as 'a day programme which involves service users working within HSE or service provider organisations in what could be described as 'like work' situations. This includes service users working in kitchens, maintenance work, landscaping, office, administration, post room, catering, hospital shops, canteens, and so on.

Service users in this category receive a discretionary top-up payment for activities they undertake.

The purpose of the discretionary payment is to give the service user a sense of worth and reward and an inducement to continue with the activity. This payment could be argued to be an important part of the therapeutic aspect of the work done.'

### ***External Work – ‘Like Work’ – less than minimum wage***

This is described in the census as ‘a day programme which involves service users working in external ‘like work’ situations. In most cases, the service provider sources the placement in an open employment setting as part of the individual’s day programme.

Minimum wage or Disability Allowance plus rules do not apply but the employer normally makes a discretionary top-up payment, either directly to the individual or to the service provider to allocate at its discretion. Examples of this are service users working in supermarkets, fast food chains, and so on. Short-term work placements that are part of a recognised training programme are not included.’

The number of service users involved in these programmes during census week was recorded with reference to the number of hours they worked that week. Those service users may have accessed two or more of the work categories during census week and many will also have been involved in other programme activities.

Although the census was not planned or delivered to capture individual service user census information, it is clear that the number of adults involved in these three work areas during census week does not exceed 4,200.

Clarity is now needed as to the employment status of the groups concerned. The HSE cannot allow the situation to continue where there is ambiguity for the group concerned about their employment and entitlements, and potential risk for service providers regarding financial obligations.

Legal advice commissioned to clarify the employment status of these service users underlines the complexity of this question. The relationship depends on a number of factors:

- the core purpose of the service;
- the particular conditions that affect each individual case and whether the conditions are such as to constitute an employer/employee relationship; and

- the circumstances that relate to the particular service provider.

The circumstances of each individual and their service should now be reviewed. This group of adults may have been in sheltered programmes for many years. Some may have had limited opportunity to explore other options or to have access to any form of person-centred planning. These people should be offered a person-centred planning process where they can explore their options and be offered programmes that are within the scope of the HSE's remit for health and personal social services.

Should the outcome of this process point to the need for a form of sheltered work, the HSE should be proactive in bringing this to the notice of policy makers.

### **Recommendation 12**

**The HSE, in consultation with the Office for Disability and Mental Health, should begin a national exercise to review the status and circumstances of those people identified through the census who currently participate in sheltered work or 'like work' programmes. This exercise should involve a person-centred process of exploration with participants to find out their wishes about alternative service provision and to make sure that their service falls within the HSE's remit to provide for the health and personal social service needs of individuals.**

### **Recommendation 13**

**If this person-centred process of exploration points to the need for a developed form of sheltered work or 'like work' in Ireland, the development of such models should be examined within the framework of the National Disability Strategy, informed by international best practice in the provision of models of sheltered work provision for people with disabilities.**

***Note: Work was initiated in relation to these recommendations as part of the Priority Issues of Concern Project (see Chapter 10).***



## **Therapeutic Work**

Therapeutic work is described in the census as 'a centre-based programme designed to provide constructive occupation for an individual or group where work activity is a key element of the programme. The work is carried out in a centre or location designed for that purpose but there is no third-party involvement, that is, no contract work and not open to the public. Examples of this could be a day service that focuses on cooking and baking or arts and crafts. The product is consumed within the service. They may also hold coffee mornings to showcase their work and sell some of their products at nominal cost to encourage service users and prevent a build up of stock. Service users may or may not receive allowances or discretionary top-up payments'.

Therapeutic work should continue to be available as part of ***New Directions***. It can offer support for independence, personal development and an outlet for personal creativity. Work has an important therapeutic value for individuals. The recovery model in mental health emphasises the importance of work in the recovery process.

The Quality Assurance System and associated Guidelines will provide clear direction to service providers about good practice in providing therapeutic work so that there is no risk of exploitation of service users and providers can be sure that they are not creating a contractual employment relationship with a service user involved in therapeutic work.

## **Supported Employment**

Specialist providers deliver supported employment programmes through which people access paid employment in the open labour market with ongoing supports. The minimum wage and full employee status applies. Most participants need ongoing support to stay in the employment setting. A total of 1,773 service users in HSE funded day services participate in supported employment. Of these, 1,414 (79%) spend less than 18 hours in supported employment.

In line with government policy, the HSE should no longer fund supported employment programmes as part of ***New Directions***. A plan should be developed in collaboration with FÁS for the supported employment currently funded by the HSE to be transferred to the Department of Jobs, Enterprise and Innovation.

Supported employment programmes funded through the HSE adopt broader criteria and provide access to a more sustained period of support than the FÁS model. The transition plan should make sure that this greater level of support is available within the FÁS supported employment scheme on an ongoing basis.

The resources that are currently invested by the HSE in funding supported employment programmes are an integral part of the current day service funding for health and personal social services. For example, the transport availed of by supported employment participants is not ring-fenced for this purpose but is part of the wider day services transport provision.

#### **Recommendation 14**

**The Office of the Minister for Disability and Mental Health should progress a plan for the transfer of supported employment programmes funded by the HSE to the Department of Jobs, Enterprise and Innovation (DJEI).**

**As part of the planning process, the Office of the Minister for Disability and Mental Health should address with DJEI the need to develop the current FÁS supported employment programme to accommodate the greater needs of people with disabilities.**

#### **Work Experience**

While precise figures are not available on the numbers of people in HSE funded day service programmes who do time-limited work experience with employers, this is

an established element of rehabilitative training programmes and forms part of other day service programmes.

Work experience should form part of ***New Directions***. The HSE's Quality Assurance Framework and associated Guidelines will guide service providers as to the appropriate use of work experience as part of an individual's support programme.

## **Training**

The present rehabilitative training programme came into being following the transfer of responsibility for vocational training to FÁS in 2000. The HSE currently funds rehabilitative training for 2,798 people. The strengths of the rehabilitative training programme have been identified in the course of this review. These include clear programme content, defined structure and funding, a national guidance structure as part of the service, and a national quality standard governing the programme. The learning from the operation of rehabilitative training has informed the thinking of the National Working Group (NWG) about the future shape of support services for adults with disabilities.

There is a strong overlap between the supports envisaged as part of the new approach and the programmes being offered by rehabilitative training. The current rehabilitative training programme will fit well as an integral part of ***New Directions***. The strategic consequence is that when the new approach is fully implemented there may not be a need for the rehabilitative training programme to remain as a separate, structured programme within the supports menu. In making the transition to ***New Directions***, the good practices and expertise embedded in the delivery of rehabilitative training, in the settings where they are in place, represent a valuable resource to support the transition to the new approach. There is also excellent scope for current providers of rehabilitative training to make the transition to become providers of ***New Directions***.

In addition to the formal training provided in the rehabilitative training programme, HSE funded day service programmes offer a wide range of skill development programmes and modules that equip people to maximise their independence, offer personal and social development opportunities and increase people's readiness to

go on to rehabilitative training or the formal vocational training programmes provided by FÁS and other vocational training providers. Bridging programmes to enable people to transfer from ***New Directions*** to FÁS vocational training are essential to deliver a person-centred plan for many service users. Work is under way to agree a national framework for bridging programmes.

FÁS provides vocational training for people with disabilities. While ***New Directions*** will not provide vocational training, it will offer skill development modules, where appropriate, as part of individualised supports. These modules should have suitable accreditation.

### **Recommendation 15**

**The potential of the existing rehabilitative training programmes to support the transition to *New Directions* should be used and their scope to provide additional service capacity should be examined.**

#### **9.4.3 Seamless Access between *New Directions* and Mainstream Training and Employment Programmes: Pathways for Transition**

Participants in ***New Directions*** must be able to move in a seamless way between ***New Directions*** and mainstream training and employment programmes, as part of their person-centred plan.

People who need to opt out of FÁS vocational training or employment options should be able to return to ***New Directions*** with a minimum of delay and access mainstream services again as their needs change. This is especially important for people with mental health difficulties. The various providers should agree protocols to facilitate seamless transitioning.

## **9.5 Strengthening HSE Systems for Planning, Monitoring and Quality-Assuring Service Provision**

### **9.5.1 Development of Integrated Information on Disability**

The review highlighted that information on adults with disabilities is not detailed enough to allow for monitoring of the range of day service options available to people. The census developed a set of service descriptors that allowed the National Working Group to examine these options and get more information on the circumstances of those in a range of programmes and settings.

At present, there are a number of separate information systems for disability and mental health, each with a different approach to data gathering and management, and each recording data for different purposes.

- The National Intellectual Disability Database and the National Physical and Sensory Disability Database are service planning tools of the Department of Health which record the service usage and service needs of people with disability.
- The Occupational Guidance Service Database tracks those who are registered with the occupational guidance service within the HSE.
- A National Psychiatric Inpatient Reporting System (NPIRS) captures activity in in-patient adult and child centres in the mental health area. A new WISDOM system, which is currently being piloted by the Health Research Board and the HSE, collects a wide range of patient information (such as activity, diagnosis, clinical interventions, and so on). These mental health systems will provide essential information for policy, planning and management of services.
- Information for reporting on needs assessments under the Disability Act, 2005 has been collected since June 2007 for children up to the age of 5. It is intended that this will be extended to older children and adults in the future.

There is a clear need for a more integrated solution to the information needs of the HSE in relation to services provided, the locations where the support is provided, the agencies providing support, activities, programmes and staffing, and service outcomes. To allow for monitoring, there should be an interface between the financial and fiscal packages used by the HSE and the information on services and supports provided. The impending roll-out of service arrangements to all providers provides an opportunity to link reporting on services, tracking of progress and funding received.

#### **Recommendation 16**

**The HSE should develop an integrated solution to its information needs in the disability area. Any solution should incorporate an individual tracking system that will deliver clear and current data about all aspects of service delivery to adults with disabilities, and have links to financial systems. It should also provide a basis for effective monitoring, support the identification of unmet need and be capable of reporting key performance information.**

### **9.5.2 Ensuring Quality in HSE Funded Adult Day Services**

The census and the consultation process highlighted the need for a consistent approach by service providers to the delivery of high-quality services to people with disabilities. According to census data, 61% of organisations use a range of quality systems and have been accredited or are in the process of achieving accreditation from awarding bodies such as the European Foundation for Quality Management (EFQM), the European Quality in Rehabilitation Mark (EQRM), the National Accreditation Committee, the International Organisation for Standardisation (ISO), Council for Quality and Leadership (Personal Outcome Measures) and Excellence Through People.

This work represents a significant resource within the sector dedicated to achieving consistent quality in disability services. However, many providers have no quality systems. There have been several initiatives over the past 15 years to develop quality systems for disability services. These include a **draft Code of Practice for Sheltered Occupational Services 2002** and **draft National Standards for Disability Services (NSDS) 2004**, prepared by the National Disability Authority. These focused on rehabilitative training and sheltered occupational services as well as residential services for people with disability. However, neither of these draft standards became policy.

More recently, the Health Information and Quality Authority (HIQA) has produced draft standards for residential services in the disability sector. The production of standards in disability day services is included in HIQA's future plans. The Mental Health Commission is charged with the establishment and maintenance of standards in mental health services. It carries out annual inspections of mental health services, including day services and day hospitals, and produces reports which recommend actions.

The National Accreditation Committee (NAC) has acted since 1996 as an independent accrediting body for specialist vocational training. This committee was set up as an independent accrediting body made up of representatives from across the sector. It has a separate funding secretariat and was originally governed by the National Rehabilitation Board which had responsibility for vocational training for people with disabilities. Since 2000, its role has also been to quality-assure rehabilitative training and rehabilitative training providers.

The secretariat of the National Accreditation Committee (NAC) was provided by FÁS until 2005 when it transferred to the Department of Health. The NAC continued to provide accreditation for rehabilitative training until December 2006. In February 2007, the HSE agreed to the transfer of responsibility and associated financial allocation for the NAC secretariat from the Department of Health to the HSE. An options appraisal was carried out to determine the most appropriate future role and focus of the NAC.

Taking account of the underpinning principle of mainstreaming contained in the National Disability Strategy, the outcome of the options appraisal pointed to the need for the development of a quality assurance system for all HSE funded adult day services which would:

- draw on good practice to date;
- complement existing systems such as FETAC; and
- focus on the requirements of a modern health and social care service.

A decision to disband the NAC was taken by the National Disability Steering Group, which, in its capacity as the governance group for the National Review of HSE Funded Adult Day Services, requested the National Working Group for the review to progress the development of this quality assurance system.

The quality assurance system will serve as the basis and foundation of the change process within service providers for the implementation of ***New Directions***. It will both drive and support change in the delivery of HSE funded supports. It will translate the key principles underpinning ***New Directions*** into a comprehensive set of indicators covering each of the supports. It will incorporate guidelines for service providers in respect of ***New Directions***.

The guidelines will include an audit tool to assist with self-evaluation, internal monitoring and continuous quality improvement. This system will form the basis of a quality framework, which will be used to:

- approve service providers;
- enter into service arrangements; and
- monitor service delivery by HSE funded services on an ongoing basis.

Following development and dissemination of the quality assurance system, providers will be expected to build the guidelines into their internal quality assurance, quality control and accreditation systems, and to comply with them on an ongoing basis.



### **Recommendation 17**

**The work to progress the development of a quality assurance system to underpin the delivery of *New Directions*, which began during the review, should be completed. This process should include consultation with the relevant stakeholders. An audit tool to help with self-evaluation, internal monitoring and continuous quality improvement should also be devised. The quality assurance system will apply to all providers in all disability sectors.**

**Following development of the quality assurance system and guidelines, a process should be put in place to:**

- **introduce the system to service providers;**
- **outline how they should incorporate the guidelines into their internal quality assurance, quality control and accreditation systems; and**
- **set out how the framework links with the responsibility of other bodies with responsibilities in relation to quality standards (HIQA, the Mental Health Commission and the National Qualifications Authority of Ireland).**

**Note: Work was initiated in relation to this recommendation as part of the Priority Issues of Concern Project (see Chapter 10).**

## **9.6 Aligning Funding Systems with the New Service Approach**

The census report completed in connection with the work of the review was the first comprehensive national initiative to capture the total resources linked to the delivery of HSE funded adult day services. It indicated that the HSE budget for adult day services in 2008 was €307.2 million. In addition, a further €21.5 million of non-HSE funding was sourced to provide day services. The Department of Health (DOH) Value for Money (VFM) and Policy Review will provide a further level of analysis of the costs associated with day services (this information will enhance the data in the report to support implementation of the report recommendations).

The funding method for adult day services comprises a mixture of historical budgets, capitation payments and multi-annual development monies. These three funding streams have generated a significant funding base for day services for adults with disabilities. However, the mechanisms for allocating monies have in some instances created inequities in funding that can result in unequal service quality. It has also resulted in a lack of clarity about what costs are met.

In progressing ***New Directions***, there is a real opportunity to address issues of quality and fairness alongside a reconfiguration of the service to enable people to have maximum access to choice, independence and community inclusion.

To deliver a modern, person-centred service, a radical reappraisal of resource use will be needed at service provider level. As part of their planning for reconfiguring their service, service providers will need to examine how resources can be redirected to provide the new supports. For example, the requirement for person-centred planning and community inclusion will mean that service providers should shift resources from internal programme delivery to developing opportunities for community inclusion.

The new service arrangement being developed to govern the contractual relationship between service providers (including the HSE as a service provider) and the HSE as funder of services will underpin the delivery of ***New Directions***. The quality assurance system with associated guidelines, together with the service arrangements, will help service providers to decide how best to restructure resource use and management in support of ***New Directions***.

Considerable resources are invested at present in a range of support services and functions that support the delivery of front line services in HSE funded services. These include staff training and development, human resource management, finance and quality systems.

In the interests of optimising the use of these resources across the sector, effective and efficient ways of sharing these services is being examined. As part of the move to ***New Directions***, service providers will be asked to engage in an exploration of ways to advance this process.

A recurring theme in both the census report and in research papers was how the health system could support individuals in having greater control over how 'their' budget is spent. Although some funding is based on a fixed or capitation rate for each person, the connection to service users stops there, as typically these rates are the starting point in negotiations between the commissioner (usually the HSE) and the provider. They are not available to the service user to make choices about his or her service. In models of funding in other countries, the service user has greater control over and more choice as to how that budget is spent. There is scope for testing such a model in the Irish context.

The process of compiling the census report revealed variations in the levels at which day service financial information is held by the HSE and service providers. In many cases, the funding is aggregated with other elements of service such as residential and respite services. The challenge is to isolate as far as possible the day service element. To achieve this, it is necessary to have both the financial systems and the data standards that will allow for measurement and comparison. This benefits the national monitoring process and also facilitates local managers in making sure that financial control exists.

The census shows the current arrangements regarding payment of allowances to participants of adult day services. Top-up payments and attendance allowances are paid not only to participants involved in sheltered and 'like work' activities but also to participants of other day services currently provided. Top-up payments and attendance allowances will not be paid to new entrants to ***New Directions***.

**Recommendation 18**

**Within the framework of the new service arrangements being implemented**

**with all non-statutory service providers, the HSE should develop a process that will provide detailed financial and human resource information about all of the cost elements associated with day services nationally. This process should apply to day services provided directly by the HSE.**

**Using the data from this process, the HSE should agree a national funding framework to support the delivery of *New Directions*. This framework should be designed to make sure that resources are allocated fairly on the basis of population and identified need. A plan to address resource equity issues in services should be developed.**

#### **Recommendation 19**

**The HSE should identify the resources associated with the payment of top-up and attendance allowances to participants involved in the areas of sheltered work and 'like work'.**

#### **Recommendation 20**

**The HSE should not fund attendance or top-up allowances for new entrants to *New Directions*.**

#### **Recommendation 21**

**The HSE should agree a system for piloting ways to give service users greater control over how their service's budget is used to achieve their chosen goals. This system should be tested in situations where individuals, support networks or organisations are managing the budget.**

## **10 Addressing the Priority Issues**

### **10.1 Overview**

During the initial consideration of *New Directions* by HSE and the Department of Health, a number of priority issues, linked to recommendations in *New Directions*, were identified as requiring immediate action. The areas that were deemed a priority for immediate attention were:

- Clarifying the future role of HSE in employment, training and work opportunities (10.3)
- Strengthening the HSE Systems for planning, monitoring and quality assuring service provision (10.4)
- Strengthening capacity for person-centredness (10.5).

An additional issue that was identified in the course of the work of *New Directions*, but which fell outside its remit was the instances of funding of day services through residential funding streams in a small number of service settings. This issue was also considered a priority for immediate action and is dealt with in 10.6 below.

### **10.2 The Approach to Addressing the Priority Issues**

The Priority Issues of Concern Project (PIOC) was established in August 2009, and a Project Team appointed.<sup>8</sup> The work was concluded in December 2010. The work of the Project Team was guided by and followed the key principles of best practice on which the work of *New Directions* is grounded:

- Communication
- Partnership

---

<sup>8</sup> Membership of the Project Team and Project Sub Group is set out in Appendix 7.

- Person-centredness
- Consultation

The methodology and work plan for the project reflected these principles through involvement of key stakeholders in the work, consultation with stakeholders, and a person-centred approach to the engagement with service users with whom the project team worked<sup>9</sup>.

### **10.3 Clarifying the future role of the HSE in Employment, Training and Work Opportunities**

#### **10.3.1 Rationale**

*New Directions* emphasises the need for clarity about the future role of the HSE in the areas of employment, training and work opportunities for people with disabilities, and how the role intersects with the roles of government departments and agencies charged with mainstream responsibility for employment and training (see *New Directions* 9.4.2). Among the main 'drivers' for the future HSE role in this area, *New Directions* lists:

- the need for HSE funded services to fit within the HSE's remit for provision of health and personal social services;
- the need to conform to government policy on the transfer of responsibility for employment programmes and supports to relevant government departments/agencies
- the need to make sure there is legal clarity about the employment status of people currently in HSE programmes and to minimise any legal risk for HSE or providers while making person-centred provision for participants.

---

<sup>9</sup> The terms of reference, governance structure and overall methodology used by the Project Team is described in Appendix 8.

It was the view of the HSE in discussion with DOH that immediate action was needed in respect of this work. The recommendations in *New Directions* that were the focus of the Project were:

***New Directions Recommendation 11***

*The HSE should begin an exercise to identify the work activities engaged in by the 164 people in sheltered employment. Following from this exercise, discussions should be held with DJEI to arrange for the transfer of those services that meet the criteria for sheltered employment.*

***New Directions Recommendation 12***

*The HSE in consultation with the Office for Disability and Mental Health, should initiate a national exercise to review the status and circumstances of those individuals identified through the Census who currently participate in sheltered work/like work programmes. This exercise should involve a person-centred process of exploration with participants to find out their wishes about alternative service provision and to make sure their service falls within the HSE's remit to provide for the health and personal social service needs of individuals.*

***New Directions Recommendation 13***

*If this person-centred process of exploration points to the need for a developed form of sheltered work or 'like work' in Ireland, the development of such models should be examined within the framework of the National Disability Strategy, informed by international best practice in the provision of models of sheltered provision for people with disabilities.*

**The key tasks undertaken in relation to these *New Directions* recommendations were<sup>10</sup>:**

- A comprehensive case management data collection project identifying all individuals engaged in work and employment activities as of February 2010.
- A person-centred exploration process with all those engaged in sheltered work activities.
- Qualitative research with service providers about models of work/employment for people with disabilities.

### **10.3.2 PIOC Processes and Outcomes**

#### ***The Case Management Data Collection Process***

The purpose of the case management data collection project was to identify and collate details on all individuals currently engaged in work/employment activities as described in the Census conducted as part of the work of *New Directions*. That Census used seven categories of work and employment activities, with a descriptor for each category<sup>11</sup>: Although for the purpose of its proposals on priority issues, the focus of the project team was on service users in the categories of sheltered work/commercial, sheltered work/like work, external work/like work and sheltered employment, the case management data collection project gathered information on the status and circumstances of service users in each of the seven census categories. This additional data will be highly relevant for the implementation of the various recommendations in *New Directions* relating to cross sectoral work on employment and training strategies for people with disabilities. In particular, details are now available about service users engaged in Supported Employment funded by HSE, and in relation to numbers in Sheltered Employment. This data will facilitate FAS in speedy implementation of policy in respect of Supported Employment and

---

<sup>10</sup> Details of the methodology used is contained in Appendix 9.

<sup>11</sup> For descriptors of these terms, see *New Directions*, Table 5-1 Programme Descriptors.



will inform work on Sheltered Employment within the Cross Sectoral Group on the Employment of People with Disabilities.

The key information gathered through the case management data collection includes:

- Numbers and locations of service users engaged in work and employment activities and the provider organisations
- Their disability, gender and age profile
- Hours per week spent in employment and work activities
- Weekly attendance allowances and discretionary top up payments

According to the data collected, the numbers involved in the categories of work/employment that were the focus of the project are as follows:

**Table 10-1 Number of Service Users engaged in Sheltered Work Activities in 2010**

<b>Work/Employment Category</b>	<b>PIOC 2010</b>	<b>Census 2008</b>
Sheltered Work/Like Work	696	875
External Work/Like Work	301	399
Sheltered Work Commercial	1,521	2,826

*It is important to note that Service Users may attend more than one of the above categories as part of their weekly programme therefore, double counting of individuals is included in the above table.*

The data indicated that 2,367 service users are engaged for some part of their week in Sheltered Work/Like Work, External Work/Like work and Sheltered Work Commercial programmes, provided by 57 organisations in 209 locations.

Of the total number of service users in Sheltered Work/Like Work and External Work/Like Work (997), 243 Service users spend all of their weekly hours in these programmes.

The majority of those involved in External Work/Like Work (301) attended for up to 6 hours per week, indicating that they participate in a range of other day service programmes.

Of the 1,521 service users engaged in Sheltered Work Commercial, 475 people are engaged for up to 6 hours, 275 people for between 18 and 24 hours. 321 people engage in Sheltered Work Commercial for over 24 hours and of these, 158 indicated that they do not engage in any other day service.

There was a significant decrease in the numbers engaged in Sheltered Work Commercial from Census 2008 to PIOC 2010. This would indicate that service providers are actively moving away from this type of activity.

### ***The Person-Centred Exploration Process***

When the case management data collection project was completed, a person-centred exploration process was undertaken with the 2367 service users involved in Sheltered Work/Like Work, External Work/Like Work and Sheltered Work Commercial <sup>12</sup>.

The person-centred exploration was undertaken in cooperation with service providers and local advocacy structures. The views of service users were sought about what work means to the individual and what supports they would like to have in the future. The outcome of this process pointed to the very strong value that service users place on the work they are engaged in.

---

<sup>12</sup> Details of the methodology used are contained in Appendix 10.

### ***Qualitative research with service providers about models of work/employment for people with disabilities<sup>13</sup>***

The primary focus of the qualitative research with service providers was on the role of the HSE in relation to employment, training and work opportunities, in the context of HSE remit for health and personal social services, government policy on mainstreaming, and the need for a strategy to ensure seamless links between HSE and mainstream departments and agencies within the framework of the National Disability Strategy<sup>14</sup>.

The approach used involved a focus group methodology, augmented by a questionnaire that included both qualitative and quantitative questions on key issues. Service provider views of day service provision in the areas of employment training and work opportunities were gathered. The main areas of enquiry included an examination of the 'drivers' behind current provision, success factors that will support implementation of *New Directions*, challenges and opportunities in the shift to mainstream and inclusive provision, and the critical issues that must be addressed as part of a roadmap for mainstreaming in the context of the National Disability Strategy.

The report from the Qualitative research project sets out a supportive policy framework for mainstreaming in the areas of employment, training and work opportunities for people with disabilities. The framework is aligned to the National Disability Strategy, and takes account of the relevant legislation, cross sectoral roles in relation to assessment and planning, the role of medical assessment for eligibility for benefits by the Department of Social Protection, the role of Citizens

---

<sup>13</sup> For details on the methodology used, see Appendix 11.

<sup>14</sup> There has been significant restructuring in the titles, and remits of key departments and agencies whose work is relevant to the implementation of *New Directions* recommendations in relation to employment, training and work opportunities for people with disabilities.

Information Board, in provision of information and advocacy, and the role of the Department of Education and Skills in the area of life long learning.

### **10.3.3 PIOC Recommendations**

The work undertaken by the PIOC Project Team generated a series of recommendations in relation to:

- Sheltered Work/Like Work and External Work/Like Work
- Sheltered Work Commercial
- Sheltered Employment
- Implementation of the policy framework for mainstreaming employment, training and work opportunities for people with disabilities

In probing solutions, the Project Team considered the type of sheltered work engaged in by service users, and the hours per week spent in sheltered work, and the length of time each service user has been involved in this form of sheltered work. The Team also considered the outcome of the person centred exploration carried out with each service user, and the findings from the qualitative research project.

#### ***Sheltered Work/Like Work and External Work/Like Work Recommendations***

- For the 243 service users who spend all their weekly hours in Sheltered Work/Like Work, or External Work/Like Work, either internal or external to their service provider, this activity needs to be regularised. An examination of the circumstances and nature of each person's current activity and its duration should be conducted. Depending on the outcome, Sheltered Work/Like Work should be revised into one of the following typologies:
  - Supported employment
  - Voluntary work in the community
  - Work experience

Work experience should be defined by the following criteria:

- Time limited
  - Properly defined and monitored
  - Regularly evaluated
  - Considered not as an end in itself, but as part of a progression
  - An intrinsic part of mainstream intermediate labour market or activation measures
- For service users who spend part of their week in Sheltered Work/Like Work or External Work/Like Work, these activities need to be transitioned into work experience placements or community employment positions.
  - Work experience should be managed by the Department of Social Protection and transition arrangements developed through the Cross Sectoral Group on Employment for People with Disabilities.
  - There should be no expansion of existing Like Work activities, and a planned phase out of existing allowances implemented accordingly.
  - For a person who choose to work for no remuneration for types of activity that are deemed to contribute to the community, a formal Volunteer Agreement should be formulated that deals with the legal and insurance status of the person.

### ***Sheltered Work Commercial Recommendations***

1,521 service users engaged in Sheltered Work Commercial, 475 people are engaged for up to 6 hours, 275 people for between 18 and 24 hours. 321 people engage in Sheltered Work Commercial for over 24 hours and of these, 158 indicated that they do not engage in any other day service.

Traditional centre based work activities are generally regarded as unacceptable and are being phased out. However, there is a view that social economy and commercial work activities can play a useful role in vocational rehabilitation and in the pathways approach to labour market inclusion, not only for people with disabilities, but for all those at a distance from the labour market.

- Through the Cross Sectoral Group on Employment for People with Disabilities the potential of existing sheltered work commercial arrangements to transition to mainstream social enterprise/economy initiatives should be examined immediately.
- The appropriateness of the existing mainstream social enterprise/social economy framework should be examined and the need to develop the framework to regulate existing sheltered work commercial arrangements explored.
- In line with the disability strategy, social enterprises should be managed by the government department and agency with responsibility for active inclusion and employment.
- Sheltered Work Commercial arrangements that do not have the potential for inclusion in the mainstream social enterprise/economy framework require to be reevaluated in the context of the HSE's remit in providing Health and Personal Social Services and the opportunities provided within the sectoral plans. It should be acknowledged that the existing sheltered work commercial arrangements grew and were built on the expertise, experience and resources in service provider organisations, very often supported by the local business community. This expertise and local support has strong potential to be harnessed in transitioning to social enterprises and should lead to sustainable job creation for all in the local community.
- There should be no expansion of existing sheltered work commercial arrangements or services pending implementation of the recommendations set out above. A planned phase out of existing allowances should be implemented. In this regard, consideration should also be given to services that depend on income from commercial activities to ensure transitional arrangements are put in place to support their reconfiguration where appropriate.

## ***Recommendations regarding a Policy Framework for mainstreaming work and employment services for people with disabilities***

The HSE and the Office for Disability and Mental Health, through their membership of the Cross Sectoral Group responsible for developing a comprehensive employment strategy for people with disabilities should take the following actions:

- Share the contents of the report on 'Qualitative research with service providers about models of work/employment provision for people with disabilities' completed by the Work Research Centre with the members of the Cross Sectoral Group on the Employment of People with Disabilities
- Arrange for the Cross Sectoral Group on Employment of People with Disabilities to engage in a facilitated forum to consider the proposed Framework and agree a plan to advance the integrated approach to meeting the needs of people with disabilities in line with the principles of the National Disability Strategy
- Contribute to the development of an Implementation Plan to progress the reconfiguration of service in line with the agreed approach.

### **10.4 Strengthening the HSE Systems for Planning, Monitoring & Quality-Assuring Service Provision**

#### **10.4.1 Rationale**

The census and the consultation process carried out as part of the work of *New Directions* highlighted the need for a consistent approach by service providers to the delivery of high-quality services to people with disabilities. The report provides an overview of the various initiatives undertaken over the years to develop quality systems for disability services are described (9.5.2). In particular, the work of the National Accreditation Committee (NAC) since between 1996 and 2007 as an independent accrediting body for specialist vocational training is described.

In 2008 the HSE reviewed the National Accreditation Committee (NAC) process and structure. The review identified the need to develop a quality assurance system for all HSE funded adult day services, which would:

- draw on good practice to date;
- complement existing systems such as FETAC; and
- focus on the requirements of a modern health and social care service.

In view of the HSE's decision to develop a Quality Assurance System for all HSE Funded Adult Day Services, the National Working Group for the Review of Day Services was requested to extend its remit to undertake research and consultation in regard to current national and international Quality Assurance Systems underpinning disability day service delivery.

It was recommend that a dedicated resource be assigned to this task and that implementation would run parallel to or as part of the National Review of HSE Funded Adult Day Services. The outcome from this work resulted in the following recommendation contained in *New Directions*:

**New Directions Recommendation 17**

*The work to progress the development of a quality assurance system to underpin the delivery of New Directions, which began during the review, should be completed. This process should include consultation with the relevant stakeholders. An audit tool to help with self-evaluation, internal monitoring and continuous quality improvement should also be devised. The quality assurance system will apply to all providers in all disability sectors.*

Following development of the quality assurance system and guidelines, a process should be put in place to:

- introduce the system to service providers
- outline how they should incorporate the guidelines into their internal quality assurance, quality control and accreditation systems and



- set out how the framework links with the responsibility of other bodies with responsibilities in relation to quality standards (HIQA, the Mental Health Commission and the National Qualifications Authority of Ireland).

The PIOC undertook to progress the work on a Quality Assurance System begun during the National Review of HSE Funded Adult Day Services in order to ensure good governance and accountability for delivery of quality day services.

#### **10.4.2 PIOC Processes and Outcomes<sup>15</sup>**

The HSE's Integrated Framework for Quality Safety and Risk Management is currently used in all areas of service delivery in the HSE. Its use has provided services with a clear and consistent Framework, supported by a Self Assessment Tool and Guidance Document, from which gaps in quality can be identified and in turn leading to the development of improvement plans.

Through the PIOC, a proposal has been developed for the tailoring of the Integrated Framework for Quality Safety and Risk Management to provide quality assurance and continuous quality improvement in the delivery of day services within *New Directions*. The proposal includes a recommended approach to the completion of this work.

#### **10.4.3 PIOC Recommendation**

The HSE's Integrated Framework for Quality Safety and Risk Management and associated Self-Assessment Tool and Guidance Document should be tailored for Disability Services as a whole so that it can be applied within all Disability settings.

Specific self-assessment questions should be developed in relation to distinct aspects of the service, such as Day Services. This development process should be

---

<sup>15</sup> For further details on this task, see Appendix 11.

done in conjunction with nominees of the National Care Group Lead, Disability Services, HSE's Quality and Clinical Care Directorate and the non-statutory provider sector.

## **10.5 Strengthening Capacity for Person-Centeredness**

### **10.5.1 Rationale**

One of the basic principles of person centeredness is the focus on the individual and their life plan as distinct from a focus on the service. The service must be responsive to individual needs and individual aspirations throughout the different stages of the life cycle. Arising from the Census of Day Services completed as part of the National Review, it was reported that there were 139 children placed in adult day services and 2,389 adults over the age of 65 years located in day services where the majority of service users were in the age range of 25 to 55 years. Both of these situations require to be resolved as a matter of urgency in the context of the vulnerability of the service users involved.

*New Directions* made the following recommendation in connection with the appropriate placement of children and older people:

#### *New Directions* Recommendation 9

- *The HSE should engage with all providers of services to adults over the age of 65 years (both HSE and Non Statutory Providers) to make sure that the older people in current day services have access to a continuum of support that respects their rights, dignity and choice and are provided within the relevant older person's policy and legislation.*
- *The HSE together with the Office for Disability and Mental Health should also engage with all providers of day services to children under the age of 18 years (both HSE and non-statutory providers) and with the Department of Education and Skills to make sure that those children can access suitable support services, and that any support service offered complies with approved child care guidelines and legislation.*

During the work of the PIOC on the two groups whose needs were the subject of *New Directions* Recommendation 9, a further potential risk to vulnerable adults and children with disabilities was identified when it emerged that in some situations children with disabilities on reaching adulthood were retained in children's day services. The remit of the project team was extended to establish the extent of this.

### **10.5.2 PIOC Processes and Outcomes**

Children under 18 years in adult day services

1. All children (under 18 years) currently attending adult day services were identified and their placements were reviewed
2. A risk assessment of all placements was carried out arising from the review
3. Reports were sent to all Regional Directors of Operations (RDOs) arising from the risk assessment process pointing to specific organisational provider issues requiring immediate attention to ensure safe care. These reports also advise regarding the need to identify and review any additional placements that may have occurred since the identification process was completed in April 2010.

The completion of this exercise indicated that at the time of data collections there were 50 children placed in adult services. Some children were due to reach adulthood before the end of 2010 but it is important to put on record that the process completed refers only to children placed in adult services during the first quarter of 2010. Until a national policy is agreed and implemented in regard to the future placement of children in adult services there is need for an interim National Protocol to address safe care arrangements in respect of children placed in adult services.

#### **Adults with Disabilities in Children's Services**

A scoping exercise was carried out in respect of service users who were appropriately placed in a children's day service during childhood years but who

have remained in the children's service on reaching adulthood. The report on the scoping exercise provides the following information:

- The numbers and locations of service users with disabilities who on reaching adulthood have remained in a children's day service
- The organisations that provide these inappropriate placements
- Recommendations as to how this area of inappropriate placements should be managed in order to address the identified risk

The scoping exercise indicates that 26 adults with disabilities have remained in children's services at three service locations throughout the country. Service Management at a further four locations reported that they previously had adults who continued in a children's service on reaching adulthood but did not have any such placements at the time of the data collection exercise.

In reviewing the individual client information gathered as part of the scoping exercise it is a concern that some adults have been retained in children's services for in excess of ten years. While the information gathered as part of this scoping exercise related only to the provision of day services, there may also be issues relating to appropriate residential accommodation for some of the service users identified.

### **Adults over 65 years in Day Services**

Adults over the age of 65 years currently involved in day services were identified and their circumstances reviewed. A report has been prepared giving details of:

- The disability day service locations where adults over the age of 65 are placed.
- The staff in day service locations that provide services to those over the age of 65 years.

Because the majority of the 2,389 adults over the age of 65 years receive their day service in general adult day service locations, there are considerable staff numbers that require training and awareness in the HSE Policy on Elder Abuse. With the growing number of adults reaching the age of 65 years and bearing in mind that

the onset of characteristics associated with the vulnerability of older people can occur in the intellectually disabled population at an earlier age, there is an urgent need to develop age appropriate services for this group of adults.

Services for Older People have agreed to include the identified staff in their schedule of Information and Training Session regarding the HSE Policy on Elder Abuse.

### **10.5.3 PIOC Recommendations**

#### ***Children under 18 years in adult day services***

- The National Director, Children and Family Services, should arrange for the production of a national policy in regard to the placement of children in adult services (the formulation of this national policy has commenced in 2011 between the National Children and Family Services and National Disability Services).
- An Implementation Plan should be agreed to ensure that this national policy is implemented throughout the country
- Until a national policy is implemented, the Regional Directors of Operations should request the immediate development and implementation of an interim national protocol and working arrangements between Disability Services and Children & Family Services to monitor the placement of any child in the region in an adult service on an ongoing basis. Immediate attention should focus on any children placed since data was gathered in 2010 and also on the organisational issues that require attention which were notified to the Regional Directors of Operations on 8<sup>th</sup> December 2010.

## **Adults with Disabilities in Children's Services**

- There is an urgent need at service operational level to review the care plans in respect of the 26 adults currently placed in Children's Disability Day Services. This review should focus on the following:
  - A risk assessment with interim control measures, which should be implemented to ensure safe care for these individuals while they are awaiting relocation to an appropriate day service
  - The appropriateness of residential services provided (if relevant)
  - Planning to relocate these individuals to an appropriate adult day service
  - Planning to relocate any service users in inappropriate residential placements
  
- The National Director for Children & Family Services should arrange for the development of a clear policy position in regard to the placement of adults in children's day services.
  
- The Assistant National Director for Disability Services should prioritise any allocation for additional day service funding to provide appropriate day services to the 26 adults involved in day services. If inappropriate residential placements are being provided to any of these service users, the allocation of residential services funding should be prioritised to provide an appropriate residential service to the individuals at issue.

## **Adults Over 65 Years in Day Services**

The HSE's Assistant National Director for Services to Older People and the Assistant National Director for Disability Services together with the Regional Directors of Operations, should ensure that all staff providing for the needs of people over the age of 65 years currently in adult day services should complete the Training & Awareness Sessions provided by the Older Person's Elder Abuse Case Managers.

The HSE's Assistant National Director, Disability Services together with the Regional Directors of Operations should ensure that the National and Regional Implementation Plans for *New Directions* should focus on the development of more age appropriate services for people over the age of 65 years.

## **10.6 Day Services provided through a Residential Funding Stream**

### **10.6.1 PIOC Rationale**

The National Review of HSE Funded Adult Day Services focused only on day services provided through a day service-funding stream. During the course of the Review it became apparent that some residential service providers were providing structured day services through their residential funding. This situation needed to be addressed for the following reasons:

- The status of these services is unclear in the context of their need to embrace and implement *New Directions* - the future vision for HSE Funded Adult Day services
- There was concern that part of the day service activities offered by these service providers included some sheltered work activities. The need to identify the individuals involved in Sheltered Work is one of the main objectives of the PIOC.

### **10.6.2 PIOC Processes and Outcomes**

Adults who are in residential placements and receive a structured day service as part of that residential placement were identified. A report was prepared giving the following details about individuals whose day service is funded through a residential funding stream:

- The number of service users engaged in work and employment activities
- The organisations involved in providing **Department of Communications, Energy and Natural Resources** work and employment activities

- Recommendations as to the changes needed in the provision of sheltered work to address the HSE's requirement to comply with Employment & Equality Legislation
- Recommendations as to the future status of these organisations in the context of New Directions.

The report shows that three national agencies were identified in this exercise that have a total of **225** service users receiving day services. **44** of these service users are engaged in Sheltered Work Commercial, Sheltered Work/Like Work and External Work/Like Work. What is significant in respect of the total numbers engaged in work and employment activities is that **200** service users are involved in Sheltered Work Therapeutic. The large number of service users engaged in Sheltered Work Therapeutic strongly reflects the ethos of the provider agencies, where the focus is on living as part of a community and being as self sufficient as possible.

The challenges for these agencies is that while the form of Therapeutic Work they offer will meet some of the characteristics of the recommended new categorisation of Therapeutic Occupational Activity, elements of the new approach such as offering service choice and the development and monitoring of therapeutic goals may be contrary to the ethos of these agencies.

### **10.6.3 PIOC Recommendations**

- The status of the agencies as recognised day service providers funded by the HSE and subject to implementing New Directions as the future day service vision, needs to be confirmed both to the agencies and to the wider HSE system.
- There is a need to determine the various funding streams being provided to these agencies. It appears that one agency has some separate day service



funding for some clients while the remainder receive their service through a residential funding allocation.

- Recommendations relating to the areas of Sheltered Work outlined earlier in this report must be embraced by these agencies.
- As a significant number of service users are engaged in the area of Sheltered Work Therapeutic, the criteria relating to this service should be reviewed to ensure that service providers are providing this activity within criteria that does not compromise their compliance with employment legislation.

## 11 Implementation Plan

### Critical Issues

The implementation plan timeframe is planned on the presumption that **New Directions** will have the approval of the HSE and the other stakeholders whose co-operation will be needed to embrace this new service vision.

The majority of actions needed to support the implementation of **New Directions** can be progressed within existing HSE resources. However, a number of critical actions are needed to underpin the complete implementation plan and to address the risk issues in respect of employment legislation. It will not be possible to advance this new vision for service delivery or attend to the issues relating to sheltered work, 'like work', or commercial work unless there is a strong commitment to progressing these underpinning actions.

These issues are highlighted in grey in the implementation plan.

The Implementation Plan has been updated to reflect actions completed as part of the Priority Issues of Concern Project 2009 / 2010.

## Implementation Plan

### Change Management

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>A national change management plan to support the change management process</b></p>	<p>The HSE and the Office for Disability and Mental Health (ODMH) to convene forum of all stakeholders to approve change management plan for <b><i>New Directions</i></b> and to prioritise the budget requirements in respect of this plan. This forum should address the development of strategies as outlined in the recommendation.</p>	<p>Resource availability.</p>	<p>Immediate implementation following report approval.</p> <p>Change management plan to be completed in 2012.</p> <p>Stakeholder forum to be commissioned in 2012.</p> <p>Plan to be reviewed at the end of 2012 and annually after that.</p>
<p><b>A reconfiguration plan within each organisation contracted by the HSE</b></p>	<p>The HSE to provide guidance to specialist providers to assist in the completion of the self-assessment process.</p> <p>The HSE to approve each individual reconfiguration plan and the timeframe for delivery.</p>	<p>Capacity of guidance structure to support this process.</p> <p>Co-operation of providers to complete this process.</p>	<p>Immediate implementation following report approval and the publication of the Guidance/Quality Assurance System.</p> <p>To be completed by mid-2013.</p> <p>A three-year plan to be completed for each organisation with annual targets.</p> <p>Review end of , 2012 and 2013.</p>

### Policy into Action

Recommendation	Actions	Dependency	Timeframe for Implementation
<b>National lead function to manage the co-ordination of supports delivery within the context of the sectoral plans</b>	ODMH to initiate discussions with all parties to the sectoral plans and the Department of Education and Skills to agree a structure for the integrated delivery of <b>New Directions</b> and appoint a lead function.	Willingness of all parties to the sectoral plans to engage in this process.	Immediate commencement following report approval. 2012.
<b>New Directions --- Inclusion of change agenda as part of each sectoral plan</b>	ODMH to arrange for inclusion of <b>New Directions'</b> recommendations in all cross sectoral implementation plans.	Willingness of all parties to sectoral plans to agree this approach.	Immediate commencement following report approval. 2012.
<b>Local collaborative working structure</b>	<p>The HSE to examine existing, collaborative working, local structures to determine suitability to progress <b>New Directions</b> recommendations.</p> <p>The HSE to agree and commission or revise the structure for local collaborative working.</p>	Willingness of all stakeholders to participate in this structure.	<p>Immediate establishment following report approval. 2012.</p> <p>Implementation in 2012/13.</p>

## Implementing *New Directions*

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Development and implementation of person-centred planning</b></p>	<p>Implement an agreed approach to person-centred planning at Service Area Level, informed by the work of the National Disability Authority (NDA).</p>	<p>Completion of quality system to guide standardised approach to person-centred planning.</p>	<p>Commence capacity building within services during the 1/2year of implementation 2012/13</p>
	<p>Identify existing good practice and expertise in person-centred planning at local levels.</p>	<p>Development of local collaborative structure to facilitate this development.</p>	<p>Each person to have completed person-centred planning before end of second year of implementation. 2013</p>
	<p>Set up local person-centred planning networks and use existing expertise to devise and deliver awareness and training on new guidelines to all stakeholders.</p>	<p>Development of local collaborative structure.</p>	<p>Immediate objective for local collaborative structure on formation. 2012/13</p>
	<p>Use census data to identify the service locations where service users are not involved in any form of person-centred planning. Start an awareness and training package with that group as a priority.</p>	<p>Capacity of guidance structure to facilitate this development.</p> <p>Development of local collaborative structure and willingness of parties to that structure to target some of the existing allocated resource to address this priority group of participants.</p>	<p>Immediate objective for local collaborative structure. 2012/13</p> <p>Priority. For immediate commencement following report approval. 2012.</p> <p>To be completed by end of 2013.</p>

## Advocacy Services

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Access to advocacy services</b></p>	<p>The national disability advocacy organisations should work with specialist and mainstream service providers to make sure that self-advocacy skills training is available to all participants in a HSE funded service.</p>	<p>Co-operation of advocacy organisations to facilitate this development.</p>	<p>For immediate implementation following report approval.2012.</p>
	<p>A philosophy of active involvement in decision-making should be promoted in each service.</p>	<p>Development and completion of quality system to guide this development.</p>	<p>For immediate implementation following report approval 2012.</p>
	<p>Service providers should actively encourage access to independent advocacy services.</p>		<p>For immediate implementation following report approval. 2012.</p>
	<p>Training in advocacy should be provided to people with disabilities, management and staff.</p>	<p>Development of local collaborative structures and willingness of parties to those structures to target some of the existing allocated resource to complete the required training.</p>	<p>For immediate implementation following report approval. 2012.</p>

## Guidance Structure

Recommendation	Actions	Dependency	Timeframe for Implementation
<b>Providing a guidance structure</b>	On behalf of the HSE, the Office for Disability and Mental Health should initiate discussions with the relevant government departments to agree how the linkages with mainstream guidance structures will be developed.	Willingness of other parties to sectoral plans to agree structure.	Priority. For immediate implementation following report approval. 2012.
	The HSE to devise and agree a plan to reconfigure the existing guidance resource to support the development of a National Guidance Service.	Resourcing of National Guidance Service.  Agreement by existing staff involved.	Priority. For immediate implementation following report approval.2012.

## Continuity of Services throughout the Lifecycle

Recommendation	Actions	Dependency	Timeframe for Implementation
<b>Facilitating continuity of support throughout a person's lifecycle</b>	The HSE should communicate with all providers of day services to adults with disabilities over the age of 65 to confirm their requirement to provide age-appropriate supports to all such adults, underpinned by current best practice, national standards and older person's policies and legislation.		Partially completed as part of the PIOC Project in 2009/2010. Remaining actions to be implemented in 2012/13
	The process of person-centred planning should be started within each service to establish the appropriateness of supports for each of the 2,400 current service users who fall within this category.	Reconfiguration plans to include provision for age-appropriate responses.	To be addressed in the context of implementation of person-centred planning. To be completed by late 2012.

	<p>Consistent with the commitment to provide an appropriate continuum of care for all adults with disability, the HSE should examine the resource and operational issues needed to provide appropriate supports for older people in line with their changing needs, and plan for the implementation of these supports.</p> <p>The HSE should take immediate steps to confirm and validate that the services being provided to those under the age of 18 are being provided in line with child care guidelines and legislation. This process should be completed by child care, disability and occupational guidance services in each local health office area. A report addressing the individual circumstances of each child should be produced and where the outcome points to the need for a more appropriate service response, this service development should be prioritised.</p> <p>The Office for Disability and Mental Health together with the HSE should initiate discussions with the Department of Education and Skills about the development of an appropriate service for children with disability between the ages of 16-18 years. Until an appropriate service response has been developed and provided for children aged 16-18, the HSE should instruct all day service providers that the future placement of children aged 16-18 in HSE funded adult day services will only be permitted in exceptional circumstances where a comprehensive evaluation of all service options points to the child's needs best being met within the adult service. Where these exceptions arise, it will be necessary for the service provider to show compliance with child care guidelines and legislation. Child care services should be involved in monitoring these individual plans.</p>	<p>Policy response to address this issue.</p>	<p>Planning to be addressed during 2012. Targets reviewed in 2013.</p> <p>Completed as part of PIOC Project in 2010.</p> <p>New children's service to be developed for implementation in 2013.</p> <p>Priority. For immediate implementation in 2012.</p>
--	---	---	---



### Primary Care and Multidisciplinary Team Specialist Services

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Ensuring access to primary care and multidisciplinary team specialist services</b></p>	<p>Within the process already underway to develop the primary care team and network structure the HSE should identify a Service Area where this development is at an advanced stage. A process should be set up in that area to map access routes for people with disabilities to both primary care and specialist services.</p> <p>The analysis of this mapping exercise should inform the completion of protocols to ensure seamless access to appropriate services for adults with disabilities.</p> <p>Within the framework of the service arrangements, the composition and location of all specialist multidisciplinary teams should be identified. The purpose of the exercise is to examine Value for Money (VFM) in the context of the existing resource linked to multidisciplinary teams and to deal with future service needs within an integrated shared service response.</p>	<p>Development of local collaborative structure to address issues of access and equity.</p>	<p>For immediate implementation in 2011/2012.</p> <p>Protocols to be completed 2012. Protocols to be implemented in 2013.</p> <p>Mapping exercise to be completed in 2013. Reconfiguration plans to be completed and implemented in 2013/14.</p>

## Sheltered Work, Sheltered Employment and Supported Employment

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Transition of sheltered employment to Department of Social Protection (DSP)</b></p>	<p>A detailed report on the individuals, locations and employment arrangements in place for those in sheltered employment should be provided to the DSP.</p> <p>The HSE should engage with the providers and individuals concerned and communicate with them about any discussions and any implications for them arising from these discussions.</p>	<p>Willingness of DSP to progress transfer.</p>	<p>Information to be provided in 2013.</p> <p>Transfer plan to be agreed in 2012.</p> <p>Transfer to start in 2013/14.</p> <p>To be arranged after initial discussions with DSP 2012.</p>
<p><b>Attending to the issues of sheltered work, 'like work' and commercial work</b></p>	<p>The Office for Disability and Mental Health should direct that there should be no development or further extension to current forms of sheltered work, 'like work' and commercial work. In future funding allocations, no further funding will be allocated for these activities.</p> <p>In agreement with the Office for Disability and Mental Health, the HSE should plan and put in place a process for enabling adults engaged in sheltered work and 'like work' programmes to participate in a person-centred planning process to enable them to review their options and possibilities.</p> <p>This process should take account of the circumstances of the adults involved, their</p>	<p>Resource needed to enable training in person-centred planning process for staff, participants and families.</p> <p>Depending on outcome of person-centred</p>	<p>For immediate implementation in 2012.</p> <p>Completed as part of PIOC Project 2010.</p> <p>Person Centred Exploration Process facilitated by Service</p>

	<p>capacity for engaging in decision-making, and their need and their family's need for support in any transition to a new programme or setting.</p> <p>National advocacy organisations to support the completion of this process.</p>	<p>planning process, resource requirement to transition participants to supports service.</p> <p>Willingness of national advocacy organisations to support this process.</p>	<p>User Advocacy structure Seasamh - as part of PIOC Project 2010.</p> <p>Completed as part of PIOC Project 2010.</p>
<p><b>Replacement for or regulation of sheltered work, 'like work' and commercial work</b></p>	<p>The HSE to provide a detailed report to the Office for Disability and Mental Health about the outcome of the person-centred planning process for participants involved in sheltered work, 'like work' areas, with recommendations as to how the outcomes from this process be progressed.</p>	<p>Resource requirement arising from outcomes of person-centred planning process.</p> <p>Potential need for policy and legislative regulation depending on outcome of this process.</p>	<p>Completed as part of PIOC Project March 2011.</p>
<p><b>Transition of Supported Employment to the Department of Social Protection</b></p>	<p>The Office of Disability and Mental Health should give Department of Social Protection detailed information from the census about those people currently in HSE funded supported employment, to inform the planning for transferring responsibility for this programme to Department of Social Protection in collaboration with FÁS.</p>	<p>Willingness of Department of Social Protection to progress transfer of service.</p>	<p>For immediate implementation in 2012.</p>

## Rehabilitative Training

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Integrating rehabilitative training into <i>New Directions</i></b></p>	<p>The HSE should select a number of rehabilitative training programmes where the process of integrating rehabilitative training into <b><i>New Directions</i></b> can be demonstrated over a two-year period. The learning from these demonstration pilots should be used to inform the re-branding and restructuring of the rehabilitative training system as part of the new approach to day service provision.</p> <p>To facilitate the restructuring process, vacant places in rehabilitative training programmes in the demonstration sites from September 2011 should be offered to adults as part of a person-centred planning process leading to a broadly-based support plan, rather than as part of an individual training plan with a narrower vocational focus.</p> <p>An evaluation of the impact of the implementation of <b><i>New Directions</i></b> for the rehabilitative training service should be completed to determine the future delivery of the rehabilitative training programme.</p>	<p>Capacity of guidance structure to progress this process.</p> <p>Co-operation of rehabilitative training service providers.</p>	<p>For immediate implementation in 2012.</p> <p>Demonstration projects to be evaluated in 2012/13.</p> <p>For immediate implementation in 2012/13.</p> <p>Evaluation to be completed in 2014.</p>

### Planning, Monitoring and Quality Assurance

Recommendation	Actions	Dependency	Timeframe for Implementation
<b>Strengthening the system for planning, monitoring and quality assurance</b>	The Department of Health with the HSE should set up a project group and identify their information needs with regard to service planning, monitoring of provision in line with new service arrangements, case-management and tracking trends over time, and to design an integrated process which should also be capable of linking with financial systems.	Resource required to support development of dataset.  Willingness of all relevant parties to engage in development.	Implementation to commence in 2012 and system to be developed in 2013.

### Quality

Recommendation	Actions	Dependency	Timeframe for Implementation
<b>Ensuring quality in HSE funded adult day services</b>	A detailed plan should be put in place for the completion of the quality system and its introduction into the HSE funded service delivery system.  On completion of this quality system, a training and communication plan to be completed to guide and support service providers with implementation and compliance to this system.	Assignment of personnel with expertise in the area of quality, standards and disability to bring this task to fruition.  Availability of occupational guidance personnel to provide specialist expertise in monitoring and evaluation functions of the quality system.  Current moratorium on recruitment in the public service.	Commenced as part of PIOC Project 2009/2010. Remaining actions to be completed in 2012/13.

### Funding of *New Directions*

Recommendation	Actions	Dependency	Timeframe for Implementation
<p><b>Aligning funding with the new service approach</b></p>	<p>A financial template, building on the baseline financial and human resource details contained in the service arrangement, should be devised to capture detail in respect of all the cost elements in day services.</p> <p>This template needs to capture detailed information in a manner and under headings that will facilitate the HSE to have dialogue with service providers about ways of implementing the new support arrangements.</p> <p>The template should also gather data on aspects of funding where comparisons among the funding provided to organisations is essential to plan for equitable distribution of budgetary resources (that is, dependency levels of participants, funding of increments, pensions, training and development staff posts, quality officer posts).</p> <p>This revised financial template should be used for all providers of HSE funded adult day services including those services directly provided by the HSE.</p> <p>A timeframe for the completion of this detailed analysis should be agreed.</p> <p>The HSE should review the detailed information arising from this process to advise about the development of a national funding framework to address the new approach to the delivery of day services.</p>	<p>Assignment of national finance lead function to manage and co-ordinate the work required.</p> <p>Identification of local finance and disability personnel to progress this work.</p> <p>Setting up of local collaborative working structure to facilitate communication of this process.</p>	<p>The DOH Value for Money and Policy Review which is due to report in 2012, will provide much analysis of the costs associated with funded adult day services. These planned actions will need to be reviewed following the publication of the Value for Money and Policy Review.</p>

	<p>This framework should address how the overall dedicated day service resource can be used to best effect and should address issues relating to the potential for shared services among providers. The issue of what cost elements are the responsibility of the HSE should be clarified following this analysis.</p> <p>The development of the national funding framework should be linked to the work of the quality assurance system so that a set of performance indicators can be agreed to assist in the future allocation of resources.</p> <p>Arising from the analysis of the detailed information gathered as part of this in-depth process, the HSE should agree a system for the governance of the day service resource and this should include clear budget accountability at local level by named post-holders.</p> <p>The national funding framework should be linked to the development of person-centred planning so that arrangements are agreed as to how to reconfigure existing resources to meet individual person-centred identified needs.</p>		
--	---	--	--

<b>Recommendation</b>	<b>Actions</b>	<b>Dependency</b>	<b>Timeframe for Implementation</b>
<b>Attending to the issue of top-up and attendance allowances in</b>	A template needs to be devised and completed to capture the number of participants who receive top-up allowances in sheltered and 'like work' areas and the amount of resource involved.	Capacity of guidance structure to facilitate this work.	Completed as part of PIOC Project. 2009/2010.

<p><b>sheltered work, 'like work' and commercial work</b></p>	<p>Once the person-centred planning process has been completed with participants involved in these service areas, the HSE needs to consider how this resource should be used to develop a reconfigured service for these participants.</p>	<p>Redeployment of national lead finance function to support and manage this work.</p> <p>Establishment of local collaborative structure to agree development and reconfiguration plans.</p>	<p>Remaining actions to be completed in 2012/13.</p>
<p><b>Attending to the issue of top-up and attendance allowances for new entrants to <i>New Directions</i>.</b></p>	<p>The HSE should inform the sector that new entrants to <b><i>New Directions</i></b> should not receive any form of top-up or attendance allowance.</p> <p>The HSE should identify the current resource associated with top-up and attendance allowances to participants in all day services except the areas of sheltered and 'like work'.</p>	<p>Capacity of guidance structure to facilitate this process.</p>	<p>For immediate implementation in 2012.</p>
<p><b>Facilitating person-centred budget control</b></p>	<p>The HSE should convene a forum of stakeholders to discuss and agree ways of giving service users greater control over how the budget for their service is used to achieve their chosen goals.</p> <p>Arrange for piloting of selected systems to promote person-centred budgetary control.</p> <p>Arrange for monitoring and evaluation of pilot projects.</p>	<p>Establishment of local collaborative working structure to facilitate this development.</p> <p>Identification of funding stream to support this development.</p>	<p>For immediate implementation in 2012/13.</p> <p>Pilots to start in 2012/13.</p> <p>Evaluation of pilots to be completed in 2013.</p>



## **Acknowledgements**

The HSE would like to acknowledge the support and cooperation provided by the following national organisations in nominating representatives to participate in the National Working Group and for the active role they played in promoting and communicating the work of the review to their wider membership:

- Department of Health
- National Federation of Voluntary Bodies
- Health Research Board
- National Disability Authority
- People with Disabilities Ireland
- Disability Federation of Ireland
- Not for Profit Business Association
- Inclusion Ireland
- Irish Advocacy Network

The Chair and members of the National Working Group for the Review of HSE Funded Adult Day Services wish to extend sincere thanks to all of those involved in preparing this review report. Special thanks to service users and their families for attending consultation meetings and for the written submissions received. Thanks also to all service providers for their cooperation and commitment in supporting all of the strands of work connected with the review including the Census of Services, the Consultation Process and the Demonstration Seminar.

The National Working Group wishes to acknowledge the professionalism and expertise of the following independent consultants who facilitated the consultation process, completed the required research and prepared and edited the final report:

- Anne Colgan, Consultant, Colgan & Associates.
- Nuala Crowe Taft, Consultant, Development Options.
- Winifred Jeffers, Consultant, Development Options.
- Jacqui Browne, Disability Equality Consultant.

- Thomas P. Golden, Associate Director, Employment and Disability Institute, Cornell University.
- Carol Blessing, Project Director for the New York State Office of Mental Health Career Development Initiative, Employment and Disability Institute, Cornell University.
- Dr. Susanne Bruyère, Director, Employment and Disability Institute, Cornell University.
- Dr. Pauline Conroy, Consultant, Ralaheen Ltd.
- Michael O'Connor, Mental Health Consultant.
- Clodagh McCarthy, Plain English and Internal Support Co-ordinator, National Adult Literacy Agency.

Particular thanks to Martina Lanigan, National Federation of Voluntary Bodies for providing the administrative support to the National Working Group and the Project Management.

## **12 Appendices**

### **12.1 *New Directions* Appendices**

#### **Appendix 1 – Terms of Reference for the Review**

##### **Context**

Early in 2005, the Department of Health asked service providers for information on the funding of sheltered work services. This information was given to the HSE which moved quickly to address the issues that the information raised.

In October 2005, the HSE as part of its obligations under equality legislation and the Disability Act began conducting a National Review of Sheltered Services. The purpose of the review was to obtain information on all aspects of the services including establishing a listing of sheltered services by location, capacity and occupational activities. The level of HSE funding and method of payment for each sheltered service was also to be identified.

The National Review of Sheltered Services examined data relating to adults in various types of sheltered services, day services and employment-related programmes, drawing on the national disability databases and other sources. This desktop review identified risk areas where adults with disabilities were participating in various forms of sheltered provision, and where their employment status was unclear.

The National Review of Sheltered Services concluded that a complete examination of adult day services was needed together with a comprehensive census which would provide complete and accurate data about key aspects of day service

provision. It then generated the terms of reference for the wider review of all day services.

### **Aim of the National Review of HSE Funded Adult Day Services**

The aim was to complete a strategic review of HSE funded adult day services in order to reconfigure adult day provisions to comply with the Disability Act 2005 and equality legislation. The National Working Group (NWG) was charged with completing the review by the end of August 2008.

### **Objectives for the Review**

The objectives set for the review were:

1. *To advise on the reconfiguration and modernisation of existing HSE funded adult day services to reflect an approach to service delivery and development that is in line with the principles enshrined in the health strategy (access, quality, accountability and person-centeredness) and that incorporates the following approach:*

- *best practice,*
- *good value for money,*
- *better outcomes for service users, and*
- *compliance with relevant legislation and national standards.*

*This process will result in a clear outline of a recommended service model(s) that is reflective of the above principles and will culminate in the implementation of this model(s) in a number of selected services during 2008. An implementation plan to support all current services to reconfigure and modernise existing services will be completed and activated pending the experience and outcome of the new model from the services selected for piloting.*

2. *To validate findings of the scoping exercise already completed (National Review of Sheltered Services).*

3. (i) To oversee the completion of a national census of current service provision, identifying the characteristics of all HSE funded adult day services in terms of:

- number of service users,
- disability,
- locations,
- service costs,
- staffing arrangements,
- operating standards,
- agency status, and
- approaches/models of service.

(ii) To devise and implement a process to validate and sign off on the accuracy and completeness of the data gathered during the national census process.

4. To arrange for the completion of a census of those service users engaged in activities undertaken within HSE funded adult day services which may be described as 'like work' including those where top-up allowances or other bonus arrangements are in place, giving the following data:

- number of service users,
- disability,
- locations,
- description of activities,
- service costs,
- staffing arrangements, and
- operating standards.

### **Desired Outcomes for the Review**

The outcomes expected from the review were:

- a report detailing an accurate and complete census of HSE funded adult day services;
- recommendations for the reconfiguration and modernisation of HSE funded adult day services;

- a clear description of a recommended model(s) of day service delivery that is embedded in best practice, complies with all relevant legislation and reflects a robust consultative process with all relevant stakeholders and, in particular, service users;
- an implementation plan to progress the introduction of the new recommended service model within a number of selected services during 2008;
- a process to review the experience and outcome of the new service model in the selected pilot sites;
- an action plan and recommended timeframe for the reconfiguration and modernisation of all services.

### **Scope of the Review**

It was decided that the review would focus on all of the following HSE funded services for adults with intellectual disability, physical and sensory disability, and mental health difficulties:

- sheltered enterprises,
- sheltered work services,
- activation services,
- supported employment programmes,
- open employment programmes,
- day service programmes,
- rehabilitative training programmes,
- resource centres, and
- ☐therapeutic services and communities.

### **Deviations from the Terms of Reference**

In the course of the review, a number of deviations from the terms of reference were agreed. The terms of reference that were adjusted were:

- the proposed development of a 'recommended service model';

- the requirement to implement the recommended model in a number of pilot sites, and to develop an implementation plan based on the experience of the pilot sites; and
- timelines for completion of the review.

### **Proposed Development of a 'Recommended Service Model'**

In the course of the work of the review, it became clear that the concept of a single model of service could not generate a person-centred response to the diversity of support needs of adults with disabilities, who cross the spectrum of intellectual disability, mental health difficulties, physical and sensory disability, as well as a range of ages, interests and geographic locations.

The findings emerging from the various strands of the work of the review – the consultations, research and census – led the National Working Group to the view that its proposals should aim to deliver radical system change. It was felt that such a shift in practice would best be set out in terms of a broad new approach to building and delivering services that would be capable of responding to the diversity of the needs of adults with disabilities, rather than in a single model.

### **Requirement to Implement the Recommended Model in a Number of Pilot Sites**

The decision to move away from the concept of proposing a single model of service led logically to the decision not to set up a series of pilot programmes to test the service model, and to move from the plan to frame an implementation plan based on the evaluation of the pilot projects.

It was decided that the purposes of the review and the advancement of the proposed changes in service delivery systems would be better served by focusing on how systemic change could be introduced to adult day services.

A key outcome of this decision was a productive partnership engagement with service providers where they showcased examples of how changes are already being introduced that reflect the key themes that were already emerging clearly

from the review process – the themes of person-centeredness, community inclusion, collaborative working and advocacy.

### **Deviation from Timelines**

The National Working Group (NWG) was charged with completing the review by the end of August 2008. A three-month extension was sought on account of the challenges posed by the census validation process and some drift in the research reports. This extension was granted. Towards the end of November 2008, concerns within the NWG about the need to give appropriate time for discussion and involve all members in reaching conclusions, led it to ask for a further extension, which was agreed.



## Appendix 2

### Membership of the National Working Group and National Disability Steering Group

<b>Membership of the National Working Group</b>	
Mr Leo Kinsella	Lead LHM Dublin North East and Chair of the NWG
Ms Anne Melly	HSE Dublin North East
Ms Ann Roche	HSE Dublin Mid Leinster
Ms Anne Marie Ward	HSE West
Mr Joe Sweeney	HSE National Disability Services
<i>replaced by:</i>	
Ms Rosaline Keenan	HSE Dublin North East
Ms Marie Kelly	Not for Profit Business Association
Mr Gerry Raleigh	HSE Dublin Mid Leinster
Mr Pat Reen	National Federation of Voluntary Bodies
Ms Clíona Ní Chualáin	Inclusion Ireland
<i>replaced by:</i>	
Mr Mick Corrigan	Inclusion Ireland
<i>replaced by:</i>	
Mr Jim Winters	Inclusion Ireland
Mr Donal Cooper	People with Disabilities Ireland
Ms Mary Meaney	National Disability Authority
<i>replaced by:</i>	
Ms Frances Hannon	National Disability Authority
<i>replaced by:</i>	
Ms Marion Wilkinson	National Disability Authority
Ms Arlette Howell	HSE Dublin North East
Mr Jim Sheehy	HSE South
Ms Margaret McDonnell	Department of Health
Ms Breda Lawless	HSE Mental Health National Services
Mr Brian Miller	HSE Dublin Mid Leinster

Ms Sarah Craig	Health Research Board
Ms Mary Smyth	Disability Federation of Ireland
Ms Angela Moran	HSE National Disability Database Services
Ms Colette Nolan	Irish Advocacy Network
Mr John Scannell	Department of Health
Ms Mary Smyth	People with Disabilities Ireland
Mr Paraic Casey	HSE West

<b>Membership of National Disability Steering Group</b>	
Mr Seamus McNulty	Assistant National Director, PCCC West
Ms Catherine Cunningham	General Manager, AND Office, PCCC West
Ms Deirdre Scully	Lead LHM, HSE South
Mr Ger Reaney	Lead Disability Implementation Act
Mr Leo Kinsella	Lead LHM Dublin North East and Chair of the National
Mr Pat Dolan	Working Group
Ms Marion Meany	Lead LHM, HSE West
Ms Liz Doherty	Lead LHM, Dublin Mid-Leinster
Mr Jim Sheehy	Disability Specialist, HSE West
Ms Violet Harford	Disability Specialist, HSE South
	Disability Specialist, HSE Dublin North East

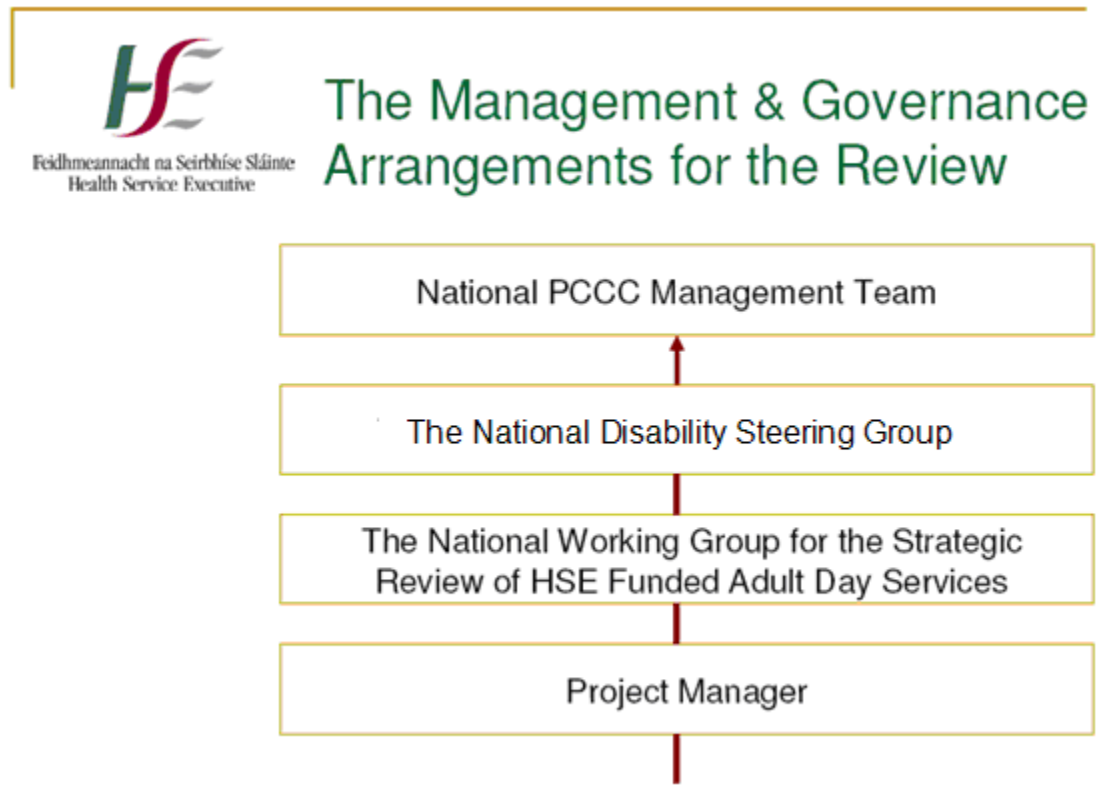
## Appendix 3

### Review Methodology

#### Structures for the Review

The structures supporting the review process were:

- the management and governance arrangements; and
- the National Working Group for the Strategic Review of HSE Funded Adult Day Services.



**Figure 12-1 Management and Governance Arrangements: Project Organisation Structure**

The Review of HSE Funded Adult Day Services was commissioned by the National Disability Steering Group<sup>16</sup>, which had oversight of the work of the review. Monthly reports on the work of the review were submitted to the governance group.

### **The National Working Group for the National Review of HSE Funded Adult Day Services**

The National Working Group (NWG) was commissioned at the planning stage of the review. Its membership was broadly representative of advocacy groups, service providers, policy makers and the research community. The NWG membership reflected the three strands of disability – intellectual disability, mental health, and physical and sensory disability.

The main tasks of the NWG were to:

- advise on the planning of each element of the work of the review;
- participate in the strands of the work;
- examine the themes and findings emerging from the work of the review; and
- develop proposals about the future shape of a modern, person-centred service for adults with disabilities.

Once the direction of the future service delivery system emerged, the NWG examined its implications in terms of service delivery, policy, funding and quality systems, and in terms of the change process that would be needed to implement the new service approach.

The NWG held 21 meetings during the lifetime of the review, including two workshops held over a two-day period to undertake detailed work on analysing findings and identifying future directions for provision of services.

---

<sup>16</sup> Membership of the National Disability Steering Group is given in Appendix 2.

## **Overview of the Review Methodology**

The methodology used to undertake the review and prepare the report on its findings and recommendations was multifaceted. The review was undertaken using the Prince 2 project management system which involves four stages with associated timeframes. The stages of the work were planned to deliver on each of the terms of reference of the review.

The key stages were:

- the planning stage;
- data collection and validation, and researching the new service delivery system;
- validation of data collection and research findings;
- analysis of data and completion of report.

A demonstration phase was also incorporated into the project plan and a communications plan paralleled the work of the review body at each stage. The key tasks undertaken at each stage and the structures supporting the work are described below.

### **Planning Stage**

The key tasks at the planning stage of the review were as follows:

- commissioning the National Working Group;
- inviting written submissions from organisations represented on the NWG which set out their vision for the future of adult day services;
- identifying resources needed for the successful implementation and completion of the project including specialist supports to facilitate key elements of the review (financial legal, research, information technology, data gathering and analysis, risk assessment, report writing).

## **Data Collection and Validation Stage**

During this stage, the key elements of the work of the review were commissioned. These strands of the work were overseen and managed by three sub groups of the NWG. The strands were:

- the programme of research (Objective 1 of the terms of reference);
- the consultation process (Objective 1 of the terms of reference);
- validation of the findings of the initial scoping exercise on sheltered services (Objective 2 of the terms of reference);
- the census (Objectives 3 and 4 of the terms of reference).

## **Research Programme**

The research sub group of the NWG scoped the terms of reference for the independent research programme to inform the future development of adult day services for people with disabilities. The Health Research Board (HRB) commissioned the research on behalf of the NWG.

It was not possible to commission the research on Irish and international dimensions of the research from a single researcher. As a result, the terms of reference were revised and two research projects were commissioned – one dealing with matters to do with Ireland and one dealing with an international perspective.

## **Terms of Reference of Research Project 1 (Ireland)**

The aim of the research was to compile a comprehensive overview of policy and practice in relation to current adult day service provision for people with disabilities which would feed into the deliberations of the NWG and to assist with the development of recommendations on reconfiguration and modernisation of services.

The scope of the research should be broad enough to encompass the totality of adult day services for people with intellectual, physical and sensory disabilities, and mental health difficulties.

The research should explain how and why services have developed over time. The research had three key objectives.

1. Identify the factors that have helped shape and are shaping day service provision for adults with disability in the Irish context.
2. Construct a framework of provision that would assist the NWG with its deliberations about the piloting of new ways of working in future day service provision. This framework should include critical evaluation of existing day service provision and practice and should identify elements of good practice that could be drawn upon for the future.
3. Bring together the work on the above two objectives with the work to be completed as part of the research on international good practice.

### **Terms of Reference of Research Project 2 (International)**

As with the Irish research project, the aim of this research was to compile a comprehensive overview of policy and practice in relation to current adult day service provision for people with disability, to feed into the deliberations of the NWG and to assist with the development of recommendations on reconfiguration and modernisation of services.

The scope of the research should be broad enough to encompass the totality of adult day services that are provided to people with intellectual, physical and sensory disabilities, and mental health difficulties. The research should provide some understanding in relation to how and why services have developed over time.

The research had the following objectives.

1. Complete and synthesise an international literature search to identify international trends and developments in day service provision for adults with disabilities.
2. Identify best practice approaches in day service provision for adults with disabilities.

### **Consultation Programme**

The aim of the consultation was to capture the views of all stakeholders on how best to progress a modern person-centred service. To make sure that the views of

all stakeholders with an interest in adult day services for people with disabilities were captured, an independent and extensive consultation was undertaken on behalf of the consultation sub-committee of the NWG.

The consultation comprised three core elements. Firstly, service users, service providers and other interested parties were invited to make a formal submission to the review group. Secondly, people in need of a day service, service users, their families and carers were invited to participate in focus group meetings. Finally, four open public consultation meetings were held around the country.

To standardise the approach to the gathering of views, a set of questions was devised which formed the basis of all strands of the consultation process. These questions were:

- What is working well in HSE funded adult day services?
- What is not working or not available in HSE funded adult day services?
- What are your suggestions for change in HSE funded adult day services?
- Have you an ideal model or an example of good practice that you would like to see developed in HSE funded adult day services?

National advocacy groups facilitated the focus group meetings. A structured briefing programme was provided to the facilitators to make sure that comparable information was gathered from each group.

The response was as follows:

- 180 people and groups made written submissions;
- 193 people attended 14 focus group meetings;
- 642 people attended four public meetings.

A detailed account of the consultation process is provided in Appendix 4.



## **Validation of the Findings of the Initial Scoping Exercise on Sheltered Services**

One of the terms of reference for the review was to validate the findings of the scoping exercise already completed. The Health Research Board co-ordinated the work in relation to this task. Following initial consultation, a template was compiled identifying key statistical information set out in the scoping document. The template was sent to the Department of Health and key informants in the HSE for completion. Most of the data were validated from the information sources that had been initially used and referenced. Some information that had been estimated, particularly that relating to the number of people with mental health difficulties who were receiving top-up payments, proved difficult to validate. This information was based on personal knowledge of the mental health services and did not have any other attributable information source.

The validation confirmed the need for a full census of adult day services to capture accurate information about the area of sheltered work.

## **Census**

The aim of the census was to agree a process for the collection, analysis and validation of information about current services which would provide clear information about all aspects of existing services.

The work involved:

- agreeing the contents of the census questionnaire to capture all relevant information relating to service provision;
- arranging a system of data collection and analysis;
- identifying from the data analysis key issues to be addressed in recommendations for a reconfigured, modernised service.

A national list of HSE funded adult day services was compiled from national databases and from information submitted by disability and mental health service managers and local health offices. This exercise identified 81 organisations

providing HSE funded adult day services at 817 locations nationally. All 817 locations completed the census.

A census data validation process was agreed. The aim of this process was to conduct a data integrity check to verify the data provided by service providers. The process made every effort to make sure that data used in the production of the final analysis report was as complete and accurate as possible.

Assistant national directors of Primary, Community and Continuing Care, asked local health office managers to commission validation teams in their respective areas. Validation team members comprised service managers and staff with responsibility for day services across intellectual, mental health, and physical and sensory disability services, and finance officers.

Rehabilitative training co-ordinators briefed validation team members on the process and verification criteria checklist and worked closely with them during this phase. The complexity of the day service structure and system resulted in varying local approaches to completing the validation process. Bearing in mind that this was not an audit and considering the range of issues which exist within the system, the validation teams are satisfied that the data gives the most accurate picture of HSE funded day services available to date.

A more detailed account of the census methodology is given in Appendix 5.

### **Validation of Data Collection and Research Findings**

This stage of the project plan involved the continuation of the research and consultation work programmes and the validation of the census data. It was not possible to complete a more in-depth validation of selected locations as originally intended due to the scale of work involved in validating the complete census data.

## **Analysis of Data and Completion of Report**

Following completion of the data gathering and validation processes, the National Working Group (NWG) engaged in a process of analysing the findings from the various strands of the work.

For the purpose of this work, the NWG was restructured into four sub groups, each working on one of the high-level thematic areas emerging from the work (policy, culture, funding and quality). In addition to working on these dimensions of future provision, all members worked on the development of the core proposals about the future shape of support services for adults with disabilities.

Much of this work was done in workshops and was supported by the project specialist engaged to assist the NWG in extracting the key components of the new approach to services from the work strands.

As the work approached its final phase, an editorial advisory group was formed through which members of the NWG assisted the project manager and the project specialist to complete the report of the work of the review.

## **Demonstration Phase**

The demonstration phase of the review process where innovative practice was demonstrated was organised in partnership with Inclusion Ireland, People with Disabilities Ireland, the Disability Federation of Ireland, the Not For Profit Business Association, the Department of Health, the National Disability Authority, the Health Research Board, the Federation of Voluntary Bodies and the Irish Advocacy Network. A sub group of the NWG oversaw the planning of this phase and all NWG members participated in the seminar.

Provider organisations were invited, through their representative body, to identify and share recent innovations in the provision of day services to people with disabilities that reflected the key themes which had emerged from the work of the review. These were:

- person-centeredness;

- collaborative working;
- development of advocacy services; and
- community integration.

Briefings were provided for the organisations nominated by the representative bodies and the work of 15 organisations was presented at a seminar titled 'Demonstrating Change in the Provision of Day Services to People with Disabilities', held in November 2008.

The seminar showed the sector's ability to implement the changes that will be needed to activate the recommendations in the review. A total of 260 people from 57 organisations attended the seminar.

### **Communications Plan**

The communications plan for the review was supported by HSE Communications and managed by the project manager for the review. The main elements of the communications plan were:

- a review website, where information on key aspects of the work programme of the review was updated continuously;
- a review newsletter which was published on the website in accessible formats three times during the lifetime of the review;
- a dedicated email address;
- briefings for the Department of Health;
- sector briefings.

## **Appendix 4**

### **Public Consultation**

#### **Introducing the Consultation**

To ensure the inclusion of everyone possible, the consultation process comprised three core elements. Firstly, service users, service providers and other interested parties were invited to make a formal submission to the review group. Secondly, people in need of a day service, service users, their families and carers were invited to participate in focus group meetings. Finally, four open public consultation meetings were held around the country during the last week in April and the first week in May 2008.

The questions used throughout the consultation process were as follows:

1. What is working well in HSE funded adult day services?
2. What is not working well or not available in HSE funded adult day services?
3. What are your suggestions for changes in HSE funded adult day services?
4. Have you an ideal model or an example of good practice that you would like to see developed in HSE funded adult day services?

A report of the formal submissions was prepared by Ms Jacqui Browne, independent consultant. Focus groups with service users were carried out by Inclusion Ireland, People with Disabilities Ireland (PWDI) and the Irish Mental Health Coalition. In addition, four public consultation meetings were held around the country to inform further the consultation process. These public consultation meetings were managed by Development Options on behalf of the consultation sub-committee of the National Working Group. National review staff from the HSE managed each of the four events and Development Options managed the process.

Ms Browne also prepared a composite report of the entire consultation process, comprising:

- a detailed report of the 180 formal submissions (comprising the views of more than 670 people);
- the report of the four open public consultation meetings (comprising 642 people), and
- the outcomes of the 14 focus group meetings (comprising a total of 193 people).
- The following section details the times, dates, and so on of the entire consultation process.

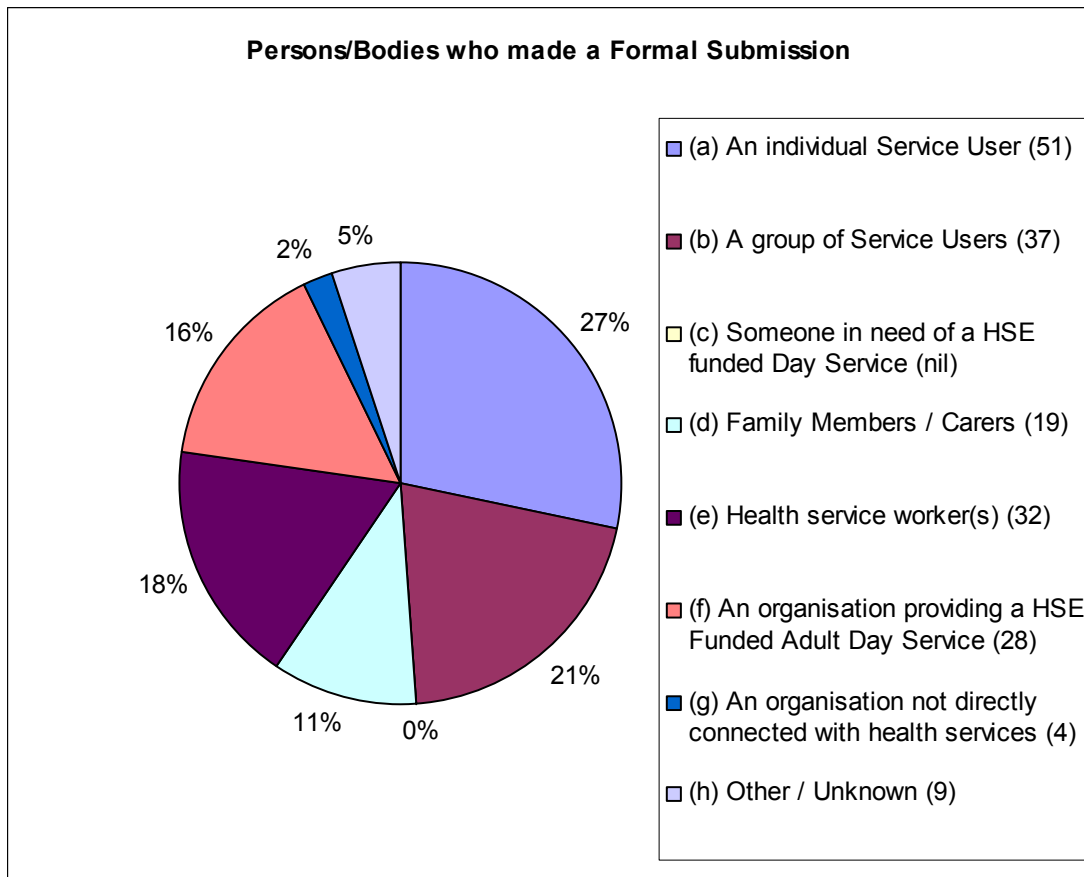
**1. Formal Submissions:** The call for formal submissions initially went up on the HSE day services review website in the 1st week of January 2008. Submissions were also invited in the first and second editions of the HSE day service review newsletter which was circulated widely throughout the sector, including to the members of the National Working Group, People with Disabilities Ireland (PwDI), the National Council for the Blind of Ireland (NCBI) and Inclusion Ireland. Copies of the newsletter were provided in braille, audio, large print and standard formats. An invitation to make a formal submission was also advertised in three national newspapers.

**Table 12-1 People and Organisations who Made a Formal Submission**

<b>Persons / Organisations who made a Formal Submission</b>	
An individual Service User	<b>51</b>
A group of Service Users	<b>37</b>
Family Members / Carers	<b>19</b>
Health service worker(s)	<b>32</b>
An organisation providing a HSE Funded Adult Day Service	<b>28</b>
An organisation not directly connected with health services	<b>4</b>
Other / Unknown	<b>9</b>
<b>Total number of Formal Submissions</b>	<b>180</b>

A total of 180 formal submissions were received. The pie chart shows the percentages received from various demographic categories .

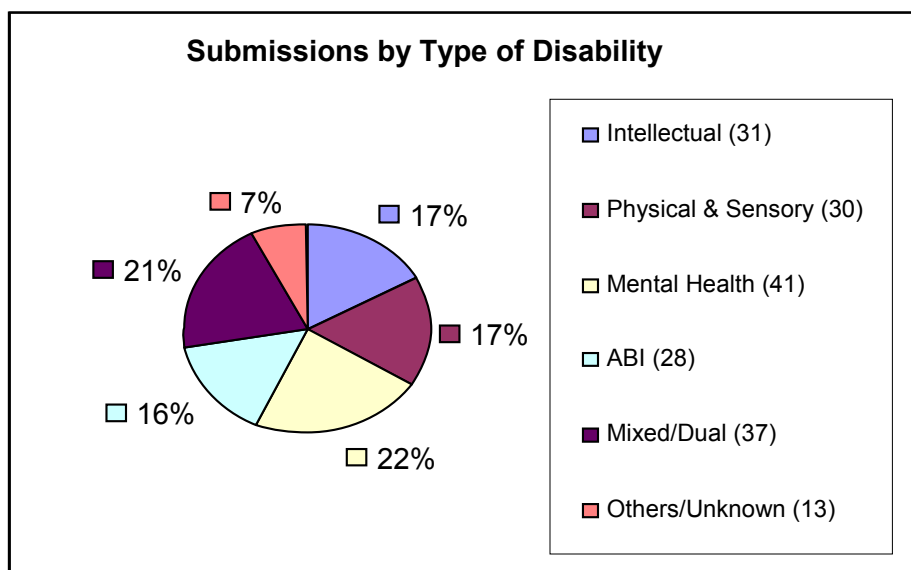
The number of submissions received under the demographic category 'Someone in need of a HSE funded day service' was nil. However, 16 people also identified themselves as 'in need of a HSE funded day service'. Typically, these were older people attending a day activity centre one day each week. It appears that what they really were saying was that they needed access to a day service on a more frequent basis.



**Figure 12-2 People and Organisations who made a Formal Submission**

It is interesting to note that 48% of the formal submissions came from service users, while service users and family members and carers together comprised nearly 60% of the submissions. Health service workers and service providers comprised 34% of the submissions.

The ratio of submissions from females to males was nearly 2:1. Most submissions were from people between the ages of 26 and 65.



**Figure 12-3 Submissions by Type of Disability**

It was evident in the early stages of receiving the submissions that most were from people with disabilities and that a significant number of those who identified themselves as having a disability were speaking from their personal experience of living with a mental health difficulty.

Overall, there appears to be a balance in percentage terms in the submissions received from people with different types of disabilities. It should be noted that the figure of 21% for 'mixed/dual' includes a significant number of people with



intellectual or learning disabilities, as many service providers have mixed populations of service users with dual or different types of disability.

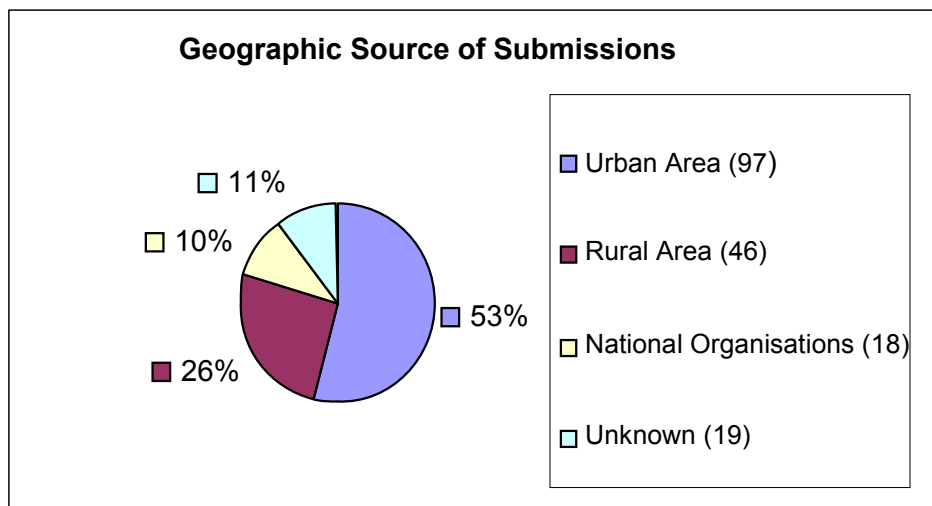


Figure 12-4 Geographic Source of Submissions

Formal submissions were received from 21 out of the 26 counties. No formal submissions were received from counties Kerry, Laois, Longford, Westmeath or Wexford. However, 18 of the 180 formal submissions were from national organisations. A nationwide spread of participants was also represented through the 14 focus group meetings and the four open public consultation meetings.

**2. Open Public Consultation Meetings:** These were advertised through the HSE day services review website, in the widely circulated second edition of the HSE day service review newsletter and in three national newspapers (the Irish Independent, The Irish Times and the Irish Examiner on Saturday, 12 April 2008).

To ensure a mix of people who use services, provide services, or live or work with people who access services, places for each group were restricted. The attendance at the open public consultation meetings (including the support staff and facilitators) was as follows:

**Table 12-2 Attendance at Public Consultation Meetings**

Venue	Kildare	Meath	Galway	Cork	All meetings
Totals	171	151	152	168	642

The four public consultation meetings took place on the following dates and in the following locations:

- Tuesday, 29 April, 2008, Keadeen Hotel, Newbridge, Co. Kildare;
- Thursday, 1 May, 2008, City North Hotel, Gormanston, Co. Meath;
- Tuesday, 6 May, 2008, Carlton Shearwater Hotel, Ballinasloe, Co. Galway;
- Thursday, 8 May, 2008, Sheraton Fota Island Hotel, Fota Island, Co. Cork.

At each location, Development Options delivered a training session before the public meeting for the volunteer facilitators and note-takers who then worked with groups of attendees during the public consultation.

The training focused on the facilitation process and the programme plan. Following each public consultation meeting, the facilitators and note-takers collated their notes and returned them to Development Options which then compiled an overall report of the outcomes from the four public meetings. This report was then forwarded to Jacqui Browne, independent consultant, for inclusion in the overall report of the consultation process.

### **Structure and Process**

Each of the public consultation days followed the same timing and format. Tea and coffee were available between 1:30 and 2:00pm during registration, and the formal meeting commenced at 2pm. Each meeting began with opening remarks by Nuala Crowe Taft of Development Options, followed by a presentation on the overall review process by Anne Melly of the HSE and project manager of the review group. Participants then broke into smaller groups to discuss the four questions: what is working well in HSE funded adult day services, what is not working well, what changes would people like to see brought about, and what examples of models or good practice would they like to share.

Nine to eleven groups were facilitated at each meeting, with each group consisting of 8-25 participants. To maximise the opportunity for participants to contribute, groups were made up of stakeholders with similar interests, for example service users, service providers, family members and carers, and a general interest group. Every effort was made to limit the service user and family/carer groups to 12 participants. There were an average of 20 participants in the service provider groups.

All groups were invited to discuss the four questions that were used in each strand of the consultation process. A volunteer facilitator and note-taker worked with each discussion group. Volunteers were recruited from the HSE and voluntary service providers that had registered to attend the public consultation meetings.

Groups had about one hour to discuss the four questions then, following a comfort break, all groups convened in one room for feedback. The facilitators from each group reported a summary of the findings from their group to the full assembly. The public consultation meetings closed at 5pm.

### **Evaluation**

Attendees were invited to evaluate and comment on the process of the open public consultation meetings through a variety of channels such as completing an evaluation form, or emailing or phoning the review team or the independent consultants from Development Options. In general, participants reported that they found the process very comfortable and felt that they had an opportunity to share their views. In some venues, a number of participants reported difficulty in hearing other participants due to other groups working in the same room. Problems such as these were addressed at subsequent meetings by increasing the number of breakout rooms. Overall, the feedback from participants was very positive.

**3. Focus Group Meetings:** To ensure the full inclusion of people with learning disabilities, mental health difficulties, and physical or sensory impairments, the

consultation sub group of the National Working Group asked three bodies – Inclusion Ireland, the Irish Mental Health Coalition (IMHC) and People with Disabilities Ireland (PwDI) – to facilitate focus group meetings with groups of members, service users and individuals who need or want to access day services.

<b>Attendance at Focus Group Meetings</b>	
Inclusion Ireland	42
Irish Mental Health Coalition	91
People with Disabilities Ireland	60
Total	193

Altogether, 14 focus group meetings were held. Four each were facilitated by Inclusion Ireland and PwDI, while the Irish Mental Health Coalition facilitated six focus group meetings.

Development Options was engaged to advise and support the three organisations in carrying out their focus group sessions. Facilitation guidelines were given to the three organisations by Development Options, with the understanding that the facilitators of the focus groups could also draw on their own skills to explore in depth the four consultation questions with participants.

It was agreed that each organisation would compile one report of its focus group meetings which would reflect the answers to the questions asked in the consultation template. Development Options was available to support the three organisations by phone throughout the process.

The reports from the three organisations were forwarded to Jacqui Browne, independent consultant, for inclusion in the overall report of the consultation process.

## **Appendix 5**

### **Census Methodology**

The sub group of the National Working Group (NWG), which was assigned responsibility for undertaking the census, developed the census methodology.

A comprehensive list of all HSE funded adult day services was collated. A census questionnaire with guidelines was developed, piloted and agreed by the NWG. The HSE Occupational Guidance Service managers and guidance teams were engaged to support and facilitate the completion of the census form by all service providers.

A number of briefing sessions were held in each Occupational Guidance Service manager's area with HSE Mental Health Service personnel, HSE Disability Service managers and all service providers to introduce the census form, clarify the questions and arrange for the completion of the form during a designated census week. Occupational Guidance Service teams facilitated a support system during census week (7-14 January 2008).

A census data validation process was agreed. The aim of this process was to conduct a data integrity check to verify the data given by service providers. This process made every effort to ensure that data used in the production of the final analysis report was as complete and accurate as possible.

Assistant National Directors of Primary, Community and Continuing Care (PCCC) asked all local health office managers to commission validation teams in their respective areas. Validation team members consisted of service managers and personnel with responsibility for day services across intellectual, mental health, physical and sensory disability services, and finance officers.

Rehabilitative training co-ordinators briefed validation team members on the process and verification criteria checklist and worked closely with them during this

phase. The complexity of the day service structure and system resulted in varying local approaches to completing the validation process.

Bearing in mind that this was not an audit and considering the range of issues which exist within the system, the validation teams are satisfied that the data provides the most accurate picture of HSE funded day services available to date.

The census form was set up on the national occupational guidance database to facilitate the analysis of all data. Guidance service staff at local level entered the validated forms on the national database. The national database manager ran a complete series of data verification checks in consultation with the Occupational Guidance Service managers before running final data analysis reports.

### **Organisations**

A national list of HSE funded adult day services was compiled from existing national databases and from information submitted from disability and mental health service managers and local health offices. This exercise identified 81 organisations providing HSE funded adult day services nationally.

### **Service Users**

The census returns showed that there are 25,302 service users accessing adult day services nationally. It is important to note that a very small number of individuals may be dual service users, that is, attending two day services and therefore picked up twice in service user numbers. Every effort has been made to minimise this but as the census was a location-based census and not an individual service user census, this could not be totally prevented.

## **Appendix 6**

### **A Summary of Departmental Sectoral Plans**

#### **Department of Health**

The Department's sectoral plan provides for an assessment of need process to be extended to adults as soon as possible but no later than the end of 2011. The plan provides for a phased transfer of funding and responsibility for appropriate employment services including sheltered and supported employment from the health sector to the Department of Jobs, Enterprise and Innovation and FÁS.

The plan provides for protocols to be agreed between the HSE and housing authorities to govern liaison concerning the housing needs of people with a disability.

A protocol has been agreed with the Department of Social Protection to make sure that income supports and associated benefits do not create financial barriers to people with disabilities taking up employment. Protocols will also be developed to provide a strategic framework for inter-departmental and inter-agency co-operation between the Department of Health, the Department of Jobs, Enterprise and Innovation, the HSE and FÁS.

#### **Department of Environment, Community and Local Government**

This Department's sectoral plan is aimed at improving the accessibility of the built environment. The plan provides for development of a new housing strategy for people with disabilities. Local authorities will improve accessibility to the streetscapes, services, information, public buildings, facilities and amenities under their control.

#### **Department of Social Protection**

Key policy issues to be addressed in this Department's plan include the commitment to developing services that give people with disabilities financial

security and encourage and support their maximum participation in society so that the contributions and talents of no individuals are overlooked. Over the period of the plan, the Department will seek to deliver support to people with disabilities to reduce their risk of dependence.

The plan also provides for the development of advocacy services under the auspices of the Citizens Information Board.

### **Department of Jobs, Enterprise and Innovation**

This plan contains a number of key initiatives to promote equal opportunities for people with disabilities in the open labour market, further develop the 'mainstreaming' agenda within the Department and its agencies, help people with disabilities to increase their economic and social independence, promote greater social inclusion, and develop a comprehensive employment strategy for people with disabilities.

### **Department of Communications, Energy and Natural Resources**

The sectoral plan of the Minister for Communications, Energy and Natural Resources focuses on the broadcasting and energy supply sectors. In relation to broadcasting, the plan deals with the role of the Broadcasting Commission of Ireland and its responsibilities for regulating the sector, including RTE, as well as the Commission for Communications Regulation (Comreg) and its roles in respect of Eircom and An Post. In the energy field, the plan covers services provided by energy suppliers in the context of the role of the Commission for Energy Regulation.

### **Department of Transport, Tourism and Sport**

This sectoral plan sets out a series of policy objectives and targets for accessible transport across all modes of transport, including measures to make trains, buses, taxi and hackney services, as well as air and marine transport accessible to people with mobility, sensory and cognitive impairments. The plan promotes the principle of mainstreaming by requiring accessibility to be an integral element of the public transport system.



## 12.2 Priority Issues of Concern Appendices

### Appendix 7

#### Membership of the Priority Issues of Concern Project

Membership of Priority Issues of Concern Project	
Mr Leo Kinsella	Lead LHM Dublin North East and Chair of the
Ms Anne Melly	NWG
Ms Ann Roche	HSE Dublin North East
Ms Anne Marie Ward	HSE Dublin Mid Leinster
Ms Arlette Howell	HSE West
Mr Brian Miller	HSE Dublin North East
Ms Sarah Craig	HSE Dublin Mid Leinster
Ms Angela Moran	Health Research Board
Mr Paraic Casey	HSE National Disability Database Services
Ms Cornelia Stuart	HSE West
Mr Jim McDonnell	HSE Dublin North East Quality & Risk Manager
Ms Bried Kelly	HSE South
Mr Se O'Connor	HSE Dublin North East
Ms Fiona McManus	HSE Assistant National Director Human
<i>replaced by:</i>	Resources
Mr Ray Parkinson	HSE West
	HSE Dublin North East

**Membership of Case Management Data Collection Subgroup**

Ms Anne Marie Ward	HSE West
Mr Brian Miller	HSE Dublin Mid Leinster
Ms Angela Moran	HSE National Disability Database Services
Ms Sarah Craig	Health Research Board
Mr Paraic Casey	HSE West
Mr Pat Reen	CEO Prosper Fingal (member of National Federation of Voluntary Bodies)
Mr Trevor Jacob	CEO CWCW Enniscorthy (member of National Federation of Voluntary Bodies)
Mr Kevin Hoey	Sunbeam House Services (member of National Federation of Voluntary Bodies)

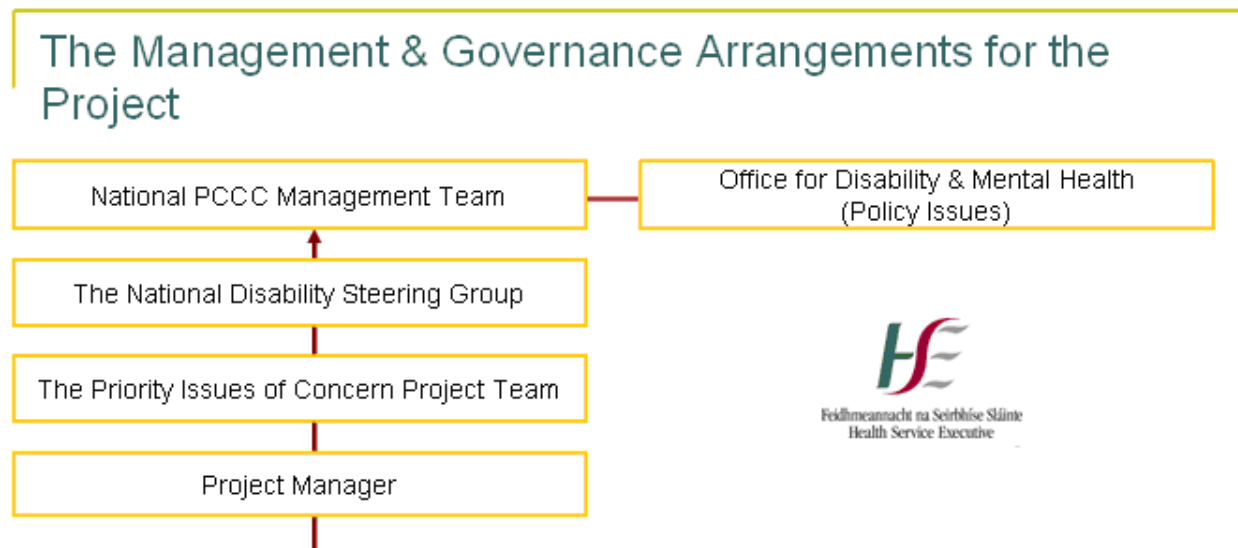
*Seasamh Model of Advocacy* prepared the DVD for the Person Centred Exploration Process

## Appendix 8 - Overview of PIOC Project Methodology

### Project Structure

The structures supporting the project were:

- the management and governance arrangements; and
- the Project Team



**Figure 12-5 Management and Governance Arrangements: Project Organisation Structure**

The Project was commissioned by the National Director PCCC and the project plan was approved by the National Disability Steering Group who were provided with regular updates regarding the status of the project work. At the commissioning stage, it was agreed that ODMH would co-govern the aspects of the project dealing with Disability Policy issues. In this context the work undertaken to clarify the HSE's role in work and employment issues was jointly governed by the HSE and Office for Disability and Mental Health.

## **The Project Team**

The Project team was commissioned at the planning stage and membership reflected the fact that the major work of the project would be on implementing some aspects of the recommendations contained in *New Directions*. In this regard, the membership largely comprised HSE operational personnel with knowledge of *New Directions*. A representative from the HRB also participated in the team to provide process and research advice. It was agreed at an early stage that the wider Disability Stakeholder group would be involved at subgroup level in specific project work modules.

The main tasks of the Project team were to:

- Plan each element of the work of the project
- Participate/Lead in the project work modules
- Deliver outcomes and recommendations relevant to the work modules
- Agree the overall project outcomes and recommendations.

The Project team met during the period of the project and members facilitated a series of briefing sessions with the sector regarding the outcomes from *New Directions* and the project work agreed to address the priority issues arising from the report. Team members were also actively involved in facilitating the process of person centred exploration that was planned and conducted in all HSE regions with service users engaged in Sheltered Work as part of their day service.

## **Overview of the Project Methodology**

The project was undertaken using the Prince 2 project management system, which involves two stages with associated timeframes. The stages of the work were planned to deliver on each of the terms of reference of the project.

The key stages were:

- Planning and commencement of Case Management & Quality Assurance process to address all priority issues.
- Person Centred Exploration process, report writing and consultation.

## **Module Work Structure**

Arising from the planning completed during stage one, the work of the project was divided into six modules with different members of the Project team assigned as Module Leaders. The six modules were as follows: -

- Module 1            Case Management and Quality Assurance of Data relating to service users engaged in work and employment activities.
- Module 2            Qualitative Information on work and employment activities.
- Module 3            Quality Assurance System.
- Module 4            Children in Adult Services.
- Module 5            Older People's Services.
- Module 6            Identification of Day Services provided via residential funding.

## **Appendix 9**

### **Case Management Data, Work and Employment Activities – Methodology**

A sub group of the Priority Issues of Concern Project Team (PIOC), which was assigned responsibility for undertaking this element of work, developed the methodology. The sub group was representative of stakeholders including service providers and members of the Project Team.

A list of agencies and locations engaged in work/employment activity descriptors, as per the 2008 Census was compiled and a template for final report content was agreed by the HSE and Department of Health.

An Individual Client Data Form and Location Summary Sheet was designed to collate information on each individual engaged in work/employment activity. The forms were piloted, amended and agreed by the Project Team. The Occupational Guidance IT system was modified to include descriptors and facilitate data collection and reporting.

Rehabilitative Training (RT) Co-ordinators and Guidance Officers co-ordinated the process at local level, other relevant HSE personnel were also engaged and briefed to support the process at a local level. Briefing sessions were then held for all relevant service providers to explain the data collection process and what they were required to do.

98% of Service Locations approached completed and returned forms, within the project timelines, at local level. Data was then input, analysed and reported on. Data gathered was also used to identify locations and individuals involved in the three work descriptors and utilised to complete the Person Centred Exploration Process.

The Priority Issues of Concern Project Team also agreed that a quality assurance process be built into the data collection process. The aim of the QA exercise was a) to check quality of the data returned b) validate information received with regard to the descriptors and to ensure that there was clarity and consistency in relation to the descriptors chosen and applied to service delivery c) sites visits ensured that the process wasn't simply a paper exercise but that there was real engagement with services on the current models of provision.

### **Organisations**

A list of agencies and locations engaged in work and employment activity was compiled from the Census 2008 Report. This exercise identified 60 organisations delivering work and employment activity in 344 locations.

### **Service Users**

The data returned identified 5,192 service users engaged in work and employment activity for part or all of their weekly person centred programme.

## **Appendix 10**

### **Person Centred Exploration Process - Methodology**

The sub group of the Priority Issues of Concern Project Team (POIC), which was assigned responsibility for collecting the Case Management Data, also undertook this element of work and developed the methodology. The sub group was representative of stakeholders including service providers and members of the Project Team.

The Person Centred Exploration was carried out in cooperation with the Service Providers and local advocacy structures. An initial questionnaire was sent out to service providers asking them to indicate if they had an advocacy structure and the extent to which it operated. Discussions commenced with a good practice advocacy structure who presented at the demonstration event held as part of the initial Review of HSE Funded Adult Day Services. This resulted in the advocacy group undertaking design of a user-friendly package to facilitate service users with an intellectual disability engage effectively in the exploration process. A DVD and work sheets were produced as part of the package. The advocacy group delivered 7 briefing sessions around the country to 152 staff and 119 service users from local advocacy groups who then completed the person centred exploration with service users engaged in the three sheltered work activities at local level.

In addition to this a separate briefing package was designed for the 31 mental health and physical and sensory disability locations. After briefings the process was facilitated at a local level by staff, service users and/or mental health advocacy groups.

#### **Organisations and Service Users**

The Case Management data reported 2,367 individuals attending the three work categories, provided by 57 organisations in 209 locations.



191 locations (91%) completed and returned individual service user views. 1,900 service users (80.5%) agreed to partake in the process and completed questionnaires.

## **Appendix 11**

### **Qualitative Research**

The sub group of the Priority Issues of Concern Project (POIC) team charged with responsibility for attending to the agreed work in relation to "Clarifying the Future Role of the HSE for Work and Employment Issues", undertook to arrange for the completion of Qualitative Research with Service Providers regarding models of work/employment for people with disabilities.

The subgroup agreed the process for requesting tenders and the evaluation of completed tender documents. The request for tender document outlined the main areas of work for inclusion in the research and the methodology to be deployed. The work was awarded to the Work Research Centre and was completed within the specifications outlined.

The methodology involved focus groups as the main data collection mechanism and a set of case studies of current practice.

It was decided to use an augmented focus group methodology as the main data collection mechanism for the study. Thus a questionnaire which asked quantitative and qualitative questions which addressed the main focus group issues were developed.

The questionnaires were issued to focus group participants one week prior to their taking part in the focus group and were collected from them no later than one week following the focus group. The analysis of the qualitative data was undertaken using content analysis methods which sought to identify the most frequently occurring responses. The quantitative data were compiled into rating tables comparing types of work.

The study undertook four focus groups with representatives of the target group, i.e. Day Care service providers. In all, 46 people were invited to take part in the study, of which 40 were able to take part. These were selected by the HSE to be representative of the various types of Day Care services.

During the course of the focus groups participants were asked to propose suggestions for a supportive policy framework to support mainstreaming. The process utilized was one of building on the outcomes from the first focus group held by adding to the development and completion of a framework during subsequent focus groups.

The organisations to be profiled within the case studies were selected by the HSE in consultation with the work/employment review sub-committee which included HSE, service providers and Health Research Board (HRB) representatives. The approach to gathering data for the case studies involved two stages. In the first stage the informants nominated by the organisations were provided with a short questionnaire which asked them to describe the programme type, duration, intensity in terms of hours per week and the nature and number of participants and to specify which activities in the list of 22 formed part of the programme.

The second stage questionnaire was customised to each informant based on the responses provided in the Stage 1 questionnaire. The main types of information sought in the Stage 2 case study questionnaire were programme staffing, facilities, funding, referral sources, eligibility assessment, programme values and intended outcomes.