# Quality and Standards in Human Services in Ireland: Disability Services

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## National Economic and Social Council

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National Economic & Social Council

# Quality and Standards in Human Services in Ireland: Disability Services

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## Abbreviations

**ANED**
Academic Network of European Disability Experts

**CARF**
Commission on Accreditation of Rehabilitation Facilities

**CBR**
Community Based Rehabilitation

**CEUD**
Centre for Excellence in Universal Design

**CIL**
West Limerick Centre for Independent Living

**CQL**
Centre on Quality and Leadership

**DESSA**
Disability Equality Specialist Support Agency

**DOH**
Department of Health

**DFI**
Disability Federation of Ireland

**EASPD**
European Association of Service Providers for Persons with a Disability

**ECHR**
European Convention for the Protection of Human Rights and Fundamental Freedoms

**EDS**
Enhancing Disability Services

**EFQM**
European Framework for Quality Management

**EIQA**
Excellence Ireland Quality Association

**EPR**
European Platform for Rehabilitation

**EPSEN**
Education of Persons with Special Educational Needs

**EQUASS**
Quality Assurance in Social Service Standard

**HIQA**
Health and Information Quality Authority

**HRB**
Health Research Board

**HSE**
Health Service Executive

**ICESCR**
International Covenant on Economic, Social & Cultural Rights

**ICT**
Information & Communications Technologies

**ISO**
International Organisation for Standardisation

**MHC**
Mental Health Commission

**NAC**
National Accreditation Committee

**NCI**
National Core Indicators

**NCSE**
National Council for Special Education

**NDA**
National Disability Authority

**NDS**
National Disability Strategy

**NFVB**
National Federation of Voluntary Bodies

**NGOs**
Non Governmental Organisations

**NIDAI**
National Intellectual Disability Advocacy Initiative

**NIDD**
National Intellectual Disability Database

**NPBA**
Not for Profit Business Association

**NPSDD**
National Physical and Sensory Disability Database

**NSAI**
National Standards Authority of Ireland

**NSDS**
Draft National Standards for Disability Services

**NTDi**
National Development Team for Inclusion

**POMs**
Personal Outcome Measures

**PQASSO**
Practical Quality Assurance System for Small Organisations

**PWDI**
People with Disabilities Ireland

**QSR**
Quality Service Review

**RADAR**
Results, Approach, Deployment, Assessment, Review

**SLAs**
Service Level Agreements

**SSGI**
Quality of Social Services of General Interest

**TQM**
Total Quality Management

**UN**
United Nations

**WCA**
Western Care Association

**WRD**
World Report on Disability

**VFMPR**
Value for Money and Policy Review

## Glossary of Terms

*Accessibility* is where people with disabilities have access, on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT), and other facilities and services.[1]

*Accountability* is being answerable to another person or organisation for decisions, behaviours and their consequences.[2]

A *Checklist* is a list of things to be done, used as a reminder. American surgeon, professor and writer Atul Gawande has written about 'The Checklist' as a tool to ensure consistency and completeness, while preventing mistakes and failure in accomplishing complex tasks involving a number of people.[3]

*Continuous improvement* is an ongoing process of review against accepted standards undertaken to (a) eliminate waste and inefficiencies; and (b) raise performance to produce quality outcomes.[4]

*Co-ordination* is the synchronisation of people, activities and services to ensure that resources are used most efficiently and effectively in the pursuit of quality outcomes. In the human services arena, the focus of co-ordination is on meeting the needs of service users in the most efficient and effective way possible.[5]

*Direct payments* are individualised cash payments made directly to people with disabilities instead of services usually provided or arranged by social care services (such as Personal Assistants).[6]

*Human services* are services that are publicly provided, funded or regulated with the purpose of promoting the well-being of citizens.

*Individualised supports* are a personal social service that includes a range of assistance and interventions required to enable the individual live a fully included life in the community.[7]

**Mainstreaming** means ensuring that people with disabilities are enabled to participate fully in society alongside their non-disabled peers. It also refers to the integration of policymaking, planning and service provision for people with and without disabilities, while ensuring that the services are tailored to the individual's needs (NDA, 2006c).

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[1] European Disability Strategy (2010–2020)

[2] Based on a definition used by the Health Information and Quality Association (HIQA).

[3] Based on dictionary definition and Gawande (2010).

[4] Based on dictionary definitions.

[5] Based on dictionary definitions.

[6] Expert Reference Group on Disability Policy, 2011

[7] Based on the National Federation of Voluntary Bodies http://www.fedvol.ie/_fileupload/Next%20Steps/Individualised%20Support%20for%20an%20Ordinary%20Life.pdf.

*Outcomes* are the effects on the individual of the services or supports received.[8]

*Performance* is the accomplishments of an organisation, service provider, programme or individual relative to stated goals and objectives, and/or pre-set standards.[9]

*Quality* is the extent to which service delivery and/or service outcomes are free from deficiencies or significant variations, adhere to agreed standards, and meet with the defined needs and informed expectations of the service user.[10]

*Quality Assurance* is defined as all those planned and systematic actions necessary to provide adequate confidence that a structure, system, component or procedure will perform satisfactorily and comply with agreed standards.[11]

*Quality Improvement* is the process that identifies problems, examines solutions to those problems, and regularly monitors the solutions implemented for improvement.[12]

*Quality Service Review* is a broad term for a set of processes and tools designed to review human-service systems.  It is based on an in-depth case-review method involving multiple stakeholders, and uses a performance-appraisal process to assess how service recipients benefit from services and how well service systems address their needs.

*Regulation* is a principle, rule or law designed to control or govern conduct.[13] It is often defined as rule making and rule enforcement.  It occurs when an external agency imposes standards or rules on the behaviour and actions of others and accompanied by enforcement provisions.[14]

*Rehabilitation* is a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with environments  (Carroll, 2012).

*Responsive Regulation* is a theoretical model that asserts that regulatory interventions are more likely to succeed if they are responsive to the context, culture and conduct of the regulated organisations. The model is encapsulated by a regulatory pyramid, which demonstrates an attempt to solve the puzzle of when to punish and when to persuade.[10]

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[8]  From the *VFMPR* (Department of Health, 2012a).

[9]  Based on dictionary definitions.

[10]  This definition is derived from definitions used by the NESF (2007) and standard dictionary definitions.

[11]  This definition is taken from the HSE website: http://www.hse.ie/eng/about/Who/Quality_and_Clinical_Care/medexpradiatonunit/Quality_Assurance_and_Quality_Control.html

[12]  From Mongan, 2011.

[13]  Based on dictionary definitions.

[14]  Based on definition by the Health and Social Care Regulatory Forum, 2009.

***Root Cause Analysis*** is a type of problem solving aimed at identifying the root causes of problems or incidents. The practice of root cause analysis is predicated on the belief that problems are best solved by attempting to address, correct or eliminate root causes, as opposed to merely addressing the immediately obvious symptoms. Root cause analysis is often viewed as an iterative process, and as a tool of continuous improvement.[15]

***Social regulation*** is a principle, rule or law designed to protect public interests and encourage behaviour deemed socially desirable in areas such as health, safety, welfare, working conditions, social cohesion, fairness and the environment.[16]

A ***Standard*** is an explicit agreed measure by which quality is judged. It sets out an expected or desired level of performance.[17] Outcome-oriented (or outcome-based) standards are statements of required outcomes for the user of a service or support.[18] They specify *what* is to be achieved, but often leave the *how* to the service provider.[19]

***Standardisation*** is the process of establishing or complying with a standard. It implies a degree of order, consistency and uniformity.[20] In the context of this report it is associated with standardising upwards in a process of continuous improvement, rather than confining innovation.

***Total Quality Management (TQM)*** is a comprehensive and structured approach to organisational management that seeks to improve the quality of products and services through ongoing refinements in response to continuous feedback.[21]

***Triple- Loop Learning*** is an advanced system of structured reporting and shared learning. The first loop of learning occurs when practitioners monitor their achievement and make adjustments to gain improved outcomes. The second loop occurs when this kind of practical learning is noted by managers who subsequently adjust their systems and routines to take note of this. And the third loop occurs when regulators and oversight authorities learn from monitoring the organisation's improved goals and revise their strategy for the entire field.[22]

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[15] Based on dictionary definitions.

[16] This definition is derived from a number of sources, including the OECD (1997), Sparrow (2000) and dictionary definitions.

[17] This definition is derived from definitions of standards used by the National Standards Authority and HIQA.

[18] NDA (2010b: 45).

[19] http://www.health.gov.bc.ca/library/publications/year/2008/Fact_sheet_outcome-based_standards_v3.pdf.

[20] Based on dictionary definitions.

[21] Based on dictionary definitions.

[22] This definition is derived from Parker (2002).

# Quality and Standards in Disability Services - Non-Technical Summary

This report focuses on quality and standards in disability services. It is one of eight reports from a NESC[23] project that looks at how quality processes, standards and regulations contribute to continuous improvement in delivery of services.[24] To inform this analysis, a NESC analyst spoke with individuals from stakeholders including service providers, policy makers, regulators, representative bodies, carers, service users and quality assurance specialists.

While most people with disabilities in Ireland access general health and social services, specialist services are delivered to only a small number. About 6 per cent (approximately 50,000) of people with physical, sensory and intellectual disabilities use a variety of these services, which costs the State €1.2 billion a year.[25] Although funded by the State, most are run by voluntary providers and community organisations. These services include 4,000 people living in congregated settings (residential care, mainly for people with intellectual disabilities).

Unlike other service sectors in Ireland, there is no State regulation of the disability sector. Specialist disability services are not inspected by a regulatory authority. Service providers are contracted by the HSE to provide services and complete a Service Level Agreement (SLAs) setting out their policies and procedures. Until recently, these varied in the extent to which they focused on quality measures so that some service providers have no quality assurance systems in place. However, others brought in their own quality assurance procedures in the absence of any State involvement and have gained international awards for excellence.

There is widespread recognition in the disability sector that the current model of provision for people with disabilities has to change. Both the Department of Health through the *Value for Money and Policy Review (VFMP*R) and the HSE have been developing policy in this area, which, when implemented, will bring dramatic shifts away from congregated settings towards individualised budgets, person-centred supports and a more inclusive approach to providing disability services in the community. At the same time, the disability sector is about to undergo a regulatory transition towards formal regulation of residential services, expected in 2013, and there remain uncertainties as to how this will impact on the disability sector and how to best achieve quality for all specialist services, at a time when resources are limited.

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[23]    NESC, the National Economic and Social Council, is an agency that analyses and reports to the Taoiseach on strategic issues relating to development of the economy, and social justice.

[24]    Other reports focus on an overview of concepts and practices: residential care for older people, end-of-life care, home care, the school system, policing and a synthesis report for the project.

[25]    HSE figures for 2009.

A number of particular **strengths** of the existing regulatory system were identified, including:

- Quality within the sector is being driven by many different factors including strong quality assurance practices among innovative service providers;

- There is a recognition that more needs to be done to protect vulnerable groups in the State's care through increased regulation of residential services by HIQA expected in 2013;

- Ambitious policy reviews and proposals from the Department of Health and the HSE have quality as a core concern;

- There are strong research, information and good-practice resources in the sector such as those provided by the National Disability Authority; the disability section of the Health Research Board; voluntary disability organisations such as the Disability Federation of Ireland and the National Federation of Voluntary Bodies; and

- Some voluntary disability organisations are providing innovative person-centred services and supports that help link people to move out of congregated settings and access mainstream services. These include less visible supports such as help lines, peer support groups and brokering to make links.

There are some **challenges** facing the disability sector in terms of quality and regulation, as follows:

- Since most of the services originated from local need and through voluntary and community organisations, they are not distributed evenly around the country, vary widely in terms of what they provide, and the quality of their services;

- There has been little formal regulation in the sector, with no inspections or compulsory standards, so that the services have been free to develop as 'independent republics', providing care as they see fit, with little protection for vulnerable groups;

- There has been a lack of focus on outcomes, with the exception of some service providers, and little accountability in terms of the quality of service delivered;

- The capacity to monitor, reflect, problem-solve and share the learning on what makes a quality service across the disability sector has not been developed; and

- More could be done to support people with disabilities to be the judges of quality, be centrally involved in regulation and have increased expectation of reaching their personal outcomes.

Given these strengths and challenges, the following are **possible directions for future policy development**:

- The importance of balance between formal regulation, **a focus on continuous improvement**, sharing of good practice, and effective monitoring and learning within the regulatory system;

- Connect the key actors (service providers, policy makers, regulators, service users) to develop a **forum** for discussion on responsive regulation practices, problem-solving strategies and review (e.g. Quality Services Forum). One emerging conclusion of this report is the value of building on existing good practice in the disability sector in relation to quality assurance, continuous improvement and outcomes, and such a forum would support this practice;

- More broadly, continue to tailor services to the needs of people with disabilities. Appropriate assessments of need, advocacy supports and defining goals and outcomes are therefore critically important elements of quality in service provision for people with disabilities; and

- Finally, this report shows how there are many cost-effective drivers of quality that improve disability services, many of which do not require additional resources, but rather involve a change of culture towards better performance, measuring and monitoring outcomes, devolving responsibility and service user involvement. These are already present in some service providers but this learning could be shares across the wider disability sector. Combined with regulation, inspection and standards, the disability sector could set the benchmark for good regulatory practice.

# Executive Summary

## General Context

This report examines how to drive standards and improve quality in disability services in Ireland, drawing from national and international literature and best practice, as well as from discussions with a number of key stakeholders. It is part of a series of NESC[26] reports on quality and standards in Irish human services. To inform this analysis, a NESC analyst spoke with individuals from stakeholders including service providers, policy makers, regulators, representative bodies, carers, service users and quality assurance specialists.

While the majority of people with disabilities in Ireland access general health and social services (mainstream provision), specialist services are delivered to 6 per cent (approximately 50,000) of people with physical, sensory and intellectual disabilities, which costs the State €1.2 billion a year.[27] Services are offered by both large and small service providers and can vary by region. Most of the disability services, although funded by the State, are run by voluntary providers and community organisations. One-sixth of provision is in the form of congregated settings (residential care, mainly for people with intellectual disabilities), a high proportion as compared with other European countries.

As for most service sectors, the 'regulatory system' is a composite of State, local, private, voluntary and community bodies, rather than one single regulator driving standards and improvements. While this is where many other jurisdictions are ending up, this is Ireland's starting position (NESC, 2011b: 76). The disability sector is a good example of this complex mesh of actors that is a potential strength, if part of a responsive regulatory system. It illustrates our earlier assertion that standards and quality are affected by a range of different organisations operating in a variety of different ways (NESC, 2011b).

Unlike other service sectors in Ireland, specialist disability services are not inspected by a regulatory authority and in broad terms, there is no State regulation of the disability sector. Many service providers have no quality assurance systems in place. Service providers are contracted by the Health Service Executive (HSE) to provide services and complete a Service Level Agreement (SLAs) setting out their policies and procedures, which, until recently, varied in the extent to which they focused on quality measures. This is one side of the disability sector story. However, another

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[26] NESC, the National Economic and Social Council, is an agency that analyses and reports to the Taoiseach on strategic issues relating to development of the economy, and social justice.

[27] HSE figures for 2009.

side exists, which shows the excellence and internationally recognised quality provision by some voluntary providers who have brought in their own quality assurance procedures in the absence of any State involvement. The active engagement of voluntary disability organisations is a distinguishing feature of the disability sector in terms of its regulatory system. While there is a move towards greater levels of formal regulation, the disability sector remains largely self-regulatory, varying from services that are demonstrating excellence, to ones where little is known about the quality of their service.

## Policy Context

In parallel to this uneven development on the ground, there have been high-level policy goals and strategies put in place such as the National Disability Strategy and the, as yet, unratified United Nations Convention on the Rights of Persons with Disabilities. Potentially, these strategies represent a complete re-orientation in terms of how people with disabilities are viewed in society, with paternalism giving way to person-centred services. There have been positive developments for the disability sector including increased State resources for services and actions taken from the implementation of sectoral plans, such as improved physical access to buildings. However, implementation has been very mixed and for many people with disabilities there have been few noticeable differences in the quality of their daily lives. There is, therefore, a gap between this top-level vision and the service reality on the ground that has created a complex sectoral landscape, characterised by unevenness in terms of the quality of care.

There is widespread recognition in the disability sector that the current model of provision for people with disabilities has to change toward a more equal and progressive system. Both the Department of Health and the HSE have been developing policy in this area, which, when implemented, will bring dramatic shifts away from congregated settings towards individualised budgets, person-centred supports and a more inclusive approach to providing disability services in the community. This transformation has been estimated to take approximately seven years, by the Expert Reference Group on Disability Policy and the Working Group on Congregated Setting, to move from congregated settings to person-centred, tailored provision.

It is likely that some parts of the regulatory system will emerge more quickly. For example, standards for residential services, developed by HIQA, the main regulatory body for the sector, are due to be made mandatory by 2013 for adults and children, along with the registration of service providers and inspections. In addition, the HSE has recently revised its SLAs to have a stronger quality focus, are developing standards for day services and are putting quality guidelines in place for all its services. In general terms, there is a need to pull all services upwards through continuous quality improvements and mandatory standards. However, tensions exist in the disability sector that reflect the challenge this will bring. For example, some stakeholders are fearful about the danger of services being brought down to a minimum level of quality and the potential loss of innovative practice, whereas others consider the commencement of mandatory standards to be the most critical and urgent first step to regulatory reform.

**Standards and Quality in the Disability Sector**

In considering the disability sector in this light, some observations can be made:

Firstly, as yet, the delivery of disability services has not been aligned with government policy. Since most of the services originated from local need and through voluntary and community organisation, they are not distributed evenly around the country, and vary widely in terms of what they provide and the quality of their services. This will change when the recommendations are implemented from the *Value for Money and Policy Review* (VFMPR) from the Department of Health. However, while high-level policy goals and strategies have been in place since 2004, and standards for disability services developed in 2004 and 2009, there has been considerable delay in progressing these fully.

Secondly, there has been little formal regulation in the sector, with a lack of mandatory standards, and no external oversight or inspections, so that the services have been free to develop as 'independent republics', providing care as they see fit. Standards would provide a necessary common foundation and could complement services' work on quality assurance and continuous improvement.

Thirdly, different organisations have uncovered distinct ways of achieving high standards of care, from the voluntary application of the Health, Information and Quality Authority (HIQA) standards, to the use of accredited quality assurance systems.[28] The report explains this development as underlining that there are 'multiple routes to quality'. This multiplicity can be seen as strength in regulatory terms, giving some formal role for the centre, and delegating application to the frontline (a meta-regulation approach). However, it has also meant a lack of consensus on what quality means for the sector and how it should be assured. To build an effective regulatory system, there would be value in endorsing this idea of 'many routes to quality' in some formal way but complementing it with the establishment of a quality forum that could elaborate on the essential elements of quality common to all providers. This would need to capture the cross-agency work of HIQA, the HSE, voluntary providers, service users and families, identify gaps and areas of overlap and tease out some of the inherent tensions in the disability sector as well as share innovative and effective practices. Such a 'quality forum' needs to be driven centrally, with clear accountability and governance for the achievement of stated outcomes.

Fourthly, there has been a lack of focus on outcomes, with the exception of some service providers and little accountability in terms of the quality of service delivered. International and national good practice point to the value of identifying and measuring outcomes in disability services and the *VFMPR* also emphasises their

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[28]   For example, the Personal Outcome Measures (POMs) from the Centre on Quality and Leadership (CQL),  the European Framework for Quality Management (EFQM) and the Practical Quality Assurance System for Small Organisations (PQASSO).

importance. There would be great value in developing a coherent and integrated set of outcome measures for disability services and policy.

Fifthly, the capacity to monitor, reflect, problem-solve and share the learning has not been developed and therefore the ability of the disability sector to self-regulate and exemplify learning within individual organisations is at best patchy, i.e. good in some areas but absent in others. Developing such a 'learning culture' that can reorder the practice of care is key to a successful regulatory system and has been highlighted by both the HSE and the *VFMPR* in relation to quality services. There are existing data systems that could be further enhanced to focus on outcomes and other quality aspects as well as considerable research expertise which can be drawn on for evidence-based practice. As the services change and develop, there will be valuable opportunities to reflect and learn about what *does* and *does not* work in both mainstream and tailored services, which could be exchanged between service providers and wider stakeholders.

Sixthly, service user involvement has increasingly been evidenced as being key to successful regulatory systems at all levels of service design, delivery, regulation and monitoring of outcomes and processes. Understanding what service users want and how they evaluate services is critical to the delivery of a quality service. Currently, the disability sector is open to criticism for providing services that are not always what people want, and that do not meet all needs. However, the most progressive and thoughtful service providers have taken a lead in criticising the limits of traditional congregated settings. A closer relationship with service users, their families and advocates, would keep services 'real' as needs and wants change over time.

Finally, this report shows how there are many cost-effective drivers of quality that improve disability services, many of which do not require additional resources, but rather involve a change of culture towards better performance, measuring and monitoring outcomes, and devolving responsibility and service user involvement. These are already present in some service providers but this learning could be shared across the wider disability sector. Combined with regulation, inspection and standards, the disability sector could set the benchmark for good regulatory practice.

## Conclusions

Given the disability sector is in flux and in the transition to a different model of provision, it is timely to consider what role regulation will play in the delivery of quality services in future. Quality within the sector is being driven by many different factors including the work of visionary voluntary providers, ambitious policy reviews and proposals, the pressing need for greater cost efficiencies and a recognition that more needs to be done to protect vulnerable groups in the State's care. There are enormous challenges in changing the model of provision, particularly when resources are limited, but there are a growing number of examples whereby service providers are moving towards more individualised supports for the same or fewer resources, while striving to achieve a high quality

service. Learning from this good practice could be valuable if shared across the disability sector to support the transition between service models. International evidence indicates that this is a journey worth making, but only if a strong focus on quality is at the heart of the transformation.

# Chapter 1
Introduction

This report examines issues of standards and quality in disability[29] services in Ireland, focusing primarily on specialist health and personal social services.[30] Given the considerable role of voluntary providers and community organisations in this area, the disability sector provides an interesting example of the strengths and limits of bottom-up approaches to quality in the absence of formal regulation.  The purpose of the report is to try to capture many of the quality successes and challenges across disability services and to highlight areas for potential learning for other sectors where possible.

While acknowledging the disability sector is undergoing considerable change, this report presents a profile of the current approach to quality and standards. The new policy model and emergent approaches to more individualised services and supports will be examined in Chapter 2, as these issues are at the forefront of debates in the sector at this time.  The structure of the report is as follows:

Chapter 1 introduces the project and its aims, and outlines the key questions posed in this report. It provides a short summary of the main approaches and concepts of quality and regulation used in the earlier report, *Quality and Standards in Human Services in Ireland: Overview of Concepts and Practice* (NESC, 2011b).

Chapter 2 provides an overview of the disability sector with regard to delivering quality services. It outlines the scale and variety of disability services, indicating the main types of provision and usage.  It then describes the existing legislative and policy context, both nationally and internationally, documenting the increasing policy shift towards mainstreaming services so that people with disabilities are supported to live in the community and achieve greater independence.  Also included is a brief introduction to the shifting landscape in international regulatory and quality initiatives and the proposed policy changes for disability services in Ireland.

Chapter 3 examines the current regulatory framework for disability services including the development of standards by the National Disability Authority (NDA)

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[29] 'Disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical,  sensory, mental health or intellectual impairment' (the Disability Act 2005). However, a social model as opposed to a medical model, considers disability  in broader terms.  For example (Murphy *et al*., 2007) outline how 'disability incorporates individual impairment, activity limitations and participation restrictions, all of which are influenced by the physical and social environment'.  See NESC, 2009 for a fuller analysis of definitions and approaches to disability as well as an overview of data.

[30] This report does not examine special needs education or mental health services.

and the Health and Information Quality Authority (HIQA) and their current status. As part of this chapter, the quality assessment tools currently used by service providers are presented.

Chapter 4 examines some of the key emerging quality and regulatory issues for the disability sector. To inform this analysis, a NESC analyst spoke with individual stakeholders including service providers, policy makers, regulators, representative bodies, carers, service users and quality assurance specialists. These took place in face-to-face meetings, in two workshops/forums and on the phone. In addition, NESC analysts attended disability conferences and events during 2011. Given the size of the sector, these consultations were by no means representative but have been invaluable in understanding the sector's response to quality.  The service providers consulted largely reflect a progressive approach to quality services so their views may not be representative of more traditional providers.  NESC would like to thank all those consulted for their time and expertise.

Chapter 5 reviews the regulatory system against key questions outlined in the earlier report*, Overview of Concepts and Practice* (NESC, 2011b) and presents the overall conclusions. The chapter examines the effectiveness of the current regulatory system for disability services and what strengths and challenges characterise this sector.  It outlines the potential of a quality forum for disability services.

## 1.1     Quality and Standards in Human Services in Ireland

This project is concerned with how quality processes, standards and regulation can best contribute to continuously improving human services.  The *Overview of Concepts and Practice,* set out the main approaches to standards, regulation and quality both in Ireland and internationally and this work will not be repeated here. Key concepts are defined either in the body of the report or in the Glossary.  Other reports from the project review different service areas including end-of-life care, eldercare, schools and policing.  A synthesis report draws together the conclusions of the overview and specific human-services reports to identify areas of commonality and difference and to identify future directions.

The *Overview of Concepts and Practice* set out a series of questions for human services in Ireland.  There are three overarching questions in relation to quality and standards to which Chapter 5 will return.

**Box 1.1          Three Overarching Aims for this Report**

- **To establish how convincing the regulatory, standards and quality assurance system is;**

- **To examine the extent to which the regulatory, standards and quality assurance system: (a) prevents the most serious harms/abuses; and (b) promotes quality improvement; and**

- **To identify elements in the regulatory, standards and quality assurance system that need to change to ensure the provision of a quality service; and to examine what they are and how they can be changed.**

In addition to exploring the aims as listed above, this report examines the specific questions presented in Box 1.2 as they apply to disability services.

**Box 1.2          Service Sector Questions**

1.     **Responsive Regulation and Standards**

To what extent is the regulatory, standards and quality improvement system driven from a command-and-control, self-regulatory, or responsive regulation perspective**?**

2.     **Involvement of Service Users**

To what extent, and in what way, are service users involved in the provision and/or regulation of services?

3.     **Cost-Effectiveness**

Have attempts been made to improve quality, while reducing costs?   If so, how?

What impact, if any, has this had on the quality of outcomes? Are there any barriers preventing implementation?

4.     **Devolution with Accountability**

Who are the main actors (State, local, private, voluntary providers) driving the regulatory, standards and quality improvement system, and what are their respective roles?

5.     **Monitoring and Learning**

What, if any, are the mechanisms for continuous learning?

### 1.1.1     Responsive Regulation

Quality services have been defined as the extent to which service delivery and/or service outcomes meet with the informed expectations and defined needs of the service user (NESF, 2007: 3). Human services provided in this way are often referred to as 'person-centred' services and services 'tailored' to meet service users' needs (NESC, 2005a).[31] The *VFMPR* of disability services outlines this further as:

> an organisation that is focused on quality uses the information gained from measuring progress against standards so as to continuously assess and improve the quality of life and outcomes of the individuals who receive services and supports (Department of Health, 2012a: 128).

Regulation is one of a number of 'quality enhancing interventions' that can improve the quality of services. It is often defined as rule making and rule enforcement. With many concepts and theories of regulation available, it would be tempting to find a 'fit' with the particular context of Irish human services, and, in particular, disability services. However, as we have argued, there is no single approach that functions effectively and efficiently in all circumstances (NESC, 2011b). Rather, 'it is the "nuanced application" of the most suitable approach appropriate to the circumstances that is required, in seeking to improve quality outcomes in human services' (Gunningham, 2010a: 141).

Regulation should not be considered here in its narrowest sense in terms of command and control, but rather as 'responsive regulation', which is more flexible in the approach taken and responsive to the context, culture and conduct of the regulated organisations (Ayres & Braithwaite, 1992). A 'regulatory system' can be effective with the involvement of multiple parties, which involves formal regulators, oversight bodies, campaigning groups, service users and concerned citizens (NESC, 2011b: 40).

In 'smart regulation', advocated by Gunningham & Grabosky, 1998, actions of third parties (such as professional organisations, trade unions, NGOs) are included in regulatory practice. The central argument of this approach is that, in most cases, the use of multiple—rather than single—policy instruments and a broader range of actors will produce better regulation (NESC, 2011b: 23). A related concept is meta-regulation, which is based on the idea that organisations should put in place systems of self-regulation and that regulators and overseers seek to assure themselves that these systems are adequate and being followed, i.e. it is the regulation of self-regulation.

In broad terms, it is useful to consider the three purposes of regulation of services: improving performance and quality; providing assurance that minimally acceptable standards are achieved; and providing accountability both for levels of performance

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[31]   This refers to tailored supports to mainstream services (NESC, 2005a: 172).

and value for money (Sutherland & Leatherman, 2006). These might not be always compatible in any one system (Expert Reference Group on Disability Policy, 2011).

Seddon usefully places the focus of regulation on increasing purpose and *performance* rather than compliance, and on involving frontline staff in driving improvements (Seddon, 2008). While supports from the bottom up are valuable, it is important not to forget the need for external oversight and regulation, for both public and private providers. As Brown, 2003: 132 argues with particular reference to private agencies:

> when care is provided by private agencies or NGOs, strong oversight from statutory funding bodies or regulators is necessary. What matters is that there are independent checks and balances and a variety of routes through which complaints can be routed.

As part of any regulatory system, standards can play a key role in setting out agreed criteria that all services have to meet, or be moving in that direction. The NDA outlines the value of standards and defines them as follows. 'Standards are statements that outline what level of service you can expect to be provided, and how it will be provided.'[32] The promised benefits for the service user include: telling them what they can expect from a service; giving them greater awareness of their rights and responsibilities; giving them confidence in the quality of services; and providing them with the opportunity to have a say in the development and review of services. For a service provider, the benefits include: improving outcomes for people who use a service; opportunities for staff to improve their skills; a way to use resources better; providing a tool to plan and improve processes and systems; and satisfying accountability requirements. Mandatory standards are also used in the registration and/or inspection of services (HIQA, 2010a).

There are divergent views about the relationship between standards and continuous improvement, and whether standards can be used to aid continuous improvement in the disability sector. While the literature presented in the *Overview of Concepts and Practice* (NESC, 2011b) shows the potential for performance standards 'pulled through the ceiling', another view is that minimum standards would at least 'push above a floor.'

The NDA points out that:

> the essential difference between minimum performance standards and outcome-oriented standards[33] is as follows: Minimum performance standards set out minimum actions to be taken or levels of performance to be achieved on the part of the provider of a service;

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[32] http://www.nda.ie/cntmgmtnew.nsf/0/17E9E062FE88E6FE80256C7B006CC2D1?OpenDocument

[33] These are referred to in this report as outcome-based standards. However, it is noted here that outcomes and standards are distinct concepts and many standards tend to refer to process or outputs, rather than outcomes.

and outcome-oriented standards are essentially statements of required
outcomes for the user of a service or support (NDA, 2010b: 45).

There can be an unnecessary and false dichotomy between standards and
continuous improvement, and many standards promote and reward innovation.[34]
As O'Donnell argues, a further challenge is 'to make the instruments and metrics
work as diagnostic standards. Standards that not only tell how things are, but also
how they can be improved, and so have to be specific, detailed and shared across
service providers' (O'Donnell, 2003: 33).

A further development of this argument is made by Kendrick who argues that:

> it is clearly worthwhile to be open to strategies of quality improvement
> that enable providers to be able to experiment with many promising
> quality enhancement methods, many of whose bias is towards optimal
> quality rather than achieving the barely adequate. This may make the
> difference between whether they can effectively use high yield versus
> low yield strategies in terms of quality.

He goes on to say that:

> this can be achieved by simply shifting the regulatory emphasis from
> prescribing the means of quality improvement to emphasising the
> nature of desired quality and allowing providers to self-select the use
> of approaches to quality (Kendrick, 2006: 4).

Skok notes that there is a tension in that 'the notion of standards implies clear-cut
criteria whereas the notion of continuous improvement implies a continual process
of self-examination and a never-ending search for improvement without a fixed
destination' (Skok, 2000: 11). She suggests that this tension between these
concepts (standards requiring certainty, and continuous quality improvement
requiring continual revision) is being resolved by the development of more flexible
and less prescriptive standards. A related aspect to this resolution is the
development of standards specifically requiring organisations to demonstrate
continuous improvement systems (NESC, 2011b: 43).

The *VFMPR* differentiates between quality standards and quality-of-life measures
and argues that both are necessary to ensure best outcomes are achieved for the
individual service user (Department of Health, 2012a: 128).

A final point is that there are inherent tensions in the regulation of services, for
instance, in relation to disability services, to balance greater control and safety with
increased independence and flexibility. The NDA in their international review of
disability services refer to this as the tension between choice and personal control
versus flexibility and safety. They argue that:

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[34] In correspondence with NESC.

challenges arise when services that facilitate people living independently intersect with efforts to ensure safety and quality through regulation, standardisation and accountability (NDA, 2010a: 21).

This points to the need for a flexible and nuanced approach to regulation.

### 1.1.2    Involvement of Service Users

As we outlined in the *Overview of Concepts and Practice*, an increasing trend in the provision of human services is a focus on how the *service user* receives the service. Thus, there is a growing reference to 'person-centred' services,[35] 'tailored services',[36] 'money following the patient/client', and so on. In this regard, there is a greater emphasis on taking into account the views of service users through consultation, ongoing engagement and, in some cases, the co-production of services and associated standards, for example, through student councils, patients' committees, residents' committees and joint policing committees. Associated with a greater emphasis on service users is an increasing focus on outcomes—for the service user, but also for the service providers, and the service system more widely (NESC, 2011b: 5). This approach, sometimes referred to as the *trilemma of standards*, understands that 'the centre' seeks accountability and assurances regarding standards, 'the local provider' seeks autonomy and the freedom to respond to local circumstances, while 'the client' seeks services 'tailored' to their needs (NESC, 2011b). One key question, therefore, posed in this report is 'to what extent, and in what way, are service users involved in the provision and/or regulation of services?'

Service user involvement is common at the inspection and monitoring levels of regulation as well as in the development of standards in other countries.

According to the NDA:

> Service users are increasingly used in the monitoring of standards as members of inspection teams, and visiting committees internationally. The UK in particular uses this approach involving people with intellectual disabilities in the monitoring of residential services for people with intellectual disabilities and we believe that such participation assists inspection committees in better identifying meaningful results and quality outcomes to the consumer population as opposed to simply processing inputs and outputs (NDA, in correspondence).

Another example is provided in the UK:

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[35]  Person-centredness is defined in the Draft National Standards for Disability Services as 'seeking to put the person first' (NDA & Department of Health and Children, 2004: 8).

[36]  See, for example, NESC's report on the Developmental Welfare State (NESC, 2005b).

The UK health and social care regulator, the Care Quality Commission, involves the public and service users extensively in its work. In addition to consultation exercises, it uses a range of other methods. It makes use of a national patient survey to provide it with feedback on patient experiences of health services. Surveys completed by users of services are also used during the Commission's inspection process for announced inspections. During announced and unannounced inspections, the Commission's inspector speaks to service users (Health and Social Care Regulatory Forum, 2009: 13).

The *World Report on Disability* argues that 'user involvement has become a criterion for judging the quality of service delivery' (WHO & Bank, 2011: 153). It refers to:

the European Quality in Social Services initiative which includes effective partnerships and participation among the principals governing its quality certification – a process complementary to national quality certification. Users can be involved in service delivery in different ways, including:

- In complaints procedures;

- During evaluation and feedback;

- As participants on management boards;

- As members of advisory groups of people with disabilities; and

- In making decisions for themselves (WHO & Bank, 2011: 154).

While increased service user involvement is part of current approaches to quality services, it does present challenges for service providers who want to have meaningful engagement, and not just tokenism. This engagement can occur at all levels of quality assurance and regulation from the planning of services, designing standards and regulatory tools, to inspections and ongoing quality assurance practices.

### 1.1.3     Devolution with Accountability

Devolving responsibility to service providers can be effective as part of a regulatory system but only with clear accountability mechanisms. The evidence presented in the *Overview of Concepts and Practice* report suggests that a fruitful approach is to set a broad regulatory framework or a small number of guiding principles 'at the centre' and then devolve their application to the local context.[37] The centre

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[37] Depending on the context, 'the centre' can be government, a government department, a regulator, etc. The important point is that power (to varying degrees) is devolved from a centre to the local or 'frontline' context.

continues to have an oversight role to ensure compliance but local providers have the opportunity, and in some cases, the incentive, to improve quality and performance.  The overriding priority is ensuring good governance that leads to achieving and improving outcomes for service users (NESC, 2011b: 72).

### 1.1.4       Monitoring and Learning

Seeking feedback on the delivery and quality of services is a key element of all quality assurance systems and is key to continuous improvement. The value of research, evidence gathering and monitoring of data is considerable as the foundation for quality work in services. Without knowing what works and why, improvements may be short-lived or *ad hoc.* The gathering of information in this systematic way is part of a learning culture, which, as we have argued in the *Overview of Concepts and Practice* report, is critical to a responsive regulation approach (NESC, 2011b). Ideally, learning should take place at a number of levels: the level at which the service is delivered; at regional or sectoral level; and at the level of regulator or at national level. This approach is sometimes referred to as 'triple-loop learning'. Diagnostic monitoring and other service review approaches, at the highest level, focus on asking why in a systematic way and share any learning to change systems. This approach is fairly new in Ireland and to develop it fully would involve a strengthening in capacity from organisational to policy levels.

What is needed is a mechanism for practitioners to learn from their practice and monitoring on an ongoing basis to ensure that review and learning, which can be described and demonstrated, are a constant feature of what people at a local service delivery level do (NESC, 2011b; Sabel, 1994). Part of such a culture is the sharing of good practice and information, an example of which is found in the 'Learning Hub', the HSE's development website where evidence and practice issues are shared with staff and interested parties.[38] Another (UK) organisation worth noting here is the National Development Team for Inclusion (NTDi),[39] a non-profit organisation that works to promote inclusive lives for those most at risk of exclusion. This provides a focal point to share best practice and focus on social inclusion, across all service sectors.

According to Kendrick, monitoring and evaluation can point to the need for changes in service models:

> [review and monitoring] are not in themselves capable of assuring quality, unless they are subsequently combined with feasible measures to improve service practice and models (Kendrick, 2006: 3).

Developing a diagnostic monitoring approach is key to effective regulatory practice, as it essentially 'digs deeper' to identify problem areas and then shares the learning

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[38]   http://www.hseland.ie/tohm/default.asp.

[39]   http://www.ndti.org.uk/about-ndti/.

across the service sector.  One example of such an approach is Quality Service Review (QSR) (Noonan *et al.,* 2009). QSR is a broad term for a set of processes and tools designed to review human services systems. It is based on an in-depth case-review method involving multiple stakeholders, and uses a performance-appraisal process to assess how service recipients benefit from services and how well service systems address their needs.

The QSR approach has several advantages. It shows practitioners that a monitoring system can be used to showcase strengths and achievements. But it also forces reviewers and frontline workers to articulate why standards were operationalised in the way that they were. And it can be used as a tool of systemic reform if certain patterns are shown to reoccur (NESC, 2011b).

There is not always consensus about what kinds of data are needed. Within the health and social service system there are different levels of measurement, for example, frontline managers might value one type and national directors another. It is not always clear what to measure and for what purpose. International best practice shows the value of indicators that are developed with stakeholders including service users to agree measures that capture outcomes at service user level, service level and nationally.

Closer to home, NESC identified indicators of well-being and provided a structured way of assessing the status of health and well-being of people with disabilities in Ireland, drawing on the NDA's previous work in developing indicators (NDA, 2005; NESC, 2009). Three distinct types of indicators are of value here, as outlined in the NESC 2009 report on well-being: diagnostic indicators that establish who, why, where, what, how; baseline indicators for setting baseline positions; and performance measures to assess performance, using quantitative and qualitative evaluations, case studies and other methodological instruments, as appropriate. Finally, outcomes can be assessed through the use of systemic indicators. They can assess how Ireland is faring in an international context and can measure change over time (NESC, 2009).

From evidence gathered by the NESF, performance indicators work best where both quantitative and qualitative data are collected from service users and providers, and benchmarked against best practice (NESF, 2007). Such an approach enables continuous learning and improvement, both within the organisation and potentially more widely across the sector, and at national level (NESC, 2011b).

The potential value of systematic monitoring and learning within disability services is immense. In a recent review of quality-of-life measures for people with intellectual disabilities, Townsend-White *et al.* have argued that measurement systems are central to quality:

> Routine outcome measurement systems constitute an important part of a quality system and can promote effective evidence-based policy and service development, planning and delivery. Comprehensive outcome data include individual and population outcomes, service level outcomes including levels of service utilisation, efficiency, effectiveness, accessibility, equity and appropriateness, and economic

> data including resource use and costs at the level of individual users, their families and community (Townsend-White *et al.*, 2012: 271).

However, they caution that there is no universally gold-standard instrument for assessing quality of life for people with intellectual disabilities and that even if there was, it should not be the sole focus of outcome measurement systems. Rather, it should be one of a raft of measures that make up a comprehensive measurement system (Townsend-White *et al.*, 2012: 281).

### 1.1.5    Cost-Effectiveness

In the current economic climate, cost is to the forefront of any debate in providing public services. While the evidence is limited, as outlined in the *Overview of Concepts and Practice* report, it is plausible, though not proven, that as quality improves, the costs of provision can be reduced. This can be achieved, for instance, by cutting out waste, and changing the way things are done to make services more efficient and effective, and by taking a person-centred approach (for example, by supporting a person with disabilities to live in the community rather than a congregated setting). However, it may also be the case that, in the context of budget reductions, specific measures might be needed if quality is not to be jeopardised, i.e. if services are not to deteriorate when there are budget reductions (NESC, 2011b: 5).

Further details on costs for the disability sector will be examined in Chapter 2 (Department of Health, 2012a).

## 1.2    Conclusions

While the regulatory system will be examined fully in Chapter 3, it is worth noting that this is a time of potentially seismic change for disability services and this will present considerable challenges for service users, service providers, policy makers, funders and regulators. The Comptroller and Auditor General argued in 2005 that:

> delivering change in the disability sector is a particularly complex undertaking because the delivery system is multifaceted,  involves multiple stakeholders, including non-profit organisations, impacted upon by a variety of environmental factors, multi-layered and multi-tasked (Comptroller and Auditor General, 2005: 36).

However, despite this change, the focus on better regulation and quality for disability services is not likely to diminish. It has long been argued that better regulations are needed 'to assure that people with disabilities are enabled to lead fully independent lives, can participate in all aspects of life, and are offered real choices in terms of service provision' (NDA, 2002).

# Chapter 2
# Context of Disability Services in Ireland

## 2.1        Introduction

This chapter sets out the particular context in which disability services are being delivered, to whom and by whom. In addition, there are policies and legislation, both national and international, which continue to shape services and these are further examined here.

While services provided for people with disabilities are the specific focus of this report, it is clear there will be overlap with other sectors examined in this project such as eldercare, policing, schools and end-of-life care. This project recognises the cross-over from sector to sector and will provide a more holistic analysis in a report synthesising the key lessons from all the sectoral reports.

## 2.2        Users of Disability Services

As the World Health Organization (WHO & Bank, 2011) outlined, disability is complex, dynamic, multi-dimensional and contested. In Ireland, information on disability has generally been sparse and incomplete (NESC, 2009: 21). According to the National Disability Survey's broad definition of disability (CSO, 2008; Watson & Nolan, 2011),[40] some 18.5 per cent (749,100) of the population, that is approximately one in five of the population, have a long-term disability (or disabilities). The *WRD* estimates a global level of 15 per cent (WHO & Bank, 2011).

Most people with disabilities access mainstream services, such as through primary-care teams and community health, with only a small percentage, approximately 6 per cent, using specialist disability provision. In this way, the focus of this report is on services that most people with disabilities do not use but that are provided only for a minority. However, it is anticipated that there will be increasing demand for disability services into the future with a growing ageing population (Expert Reference Group on Disability Policy, 2010; Doyle *et al.*, 2009). The Value for Money and Policy Review (VFMPR) confirms this and outlines that it expects the increase in

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[40]    However, estimates vary for methodological reasons (CSO, 2008; Watson & Nolan, 2011). The NDA recently reported a study showing 14 per cent had a disability (NDA, 2011b).

the level of demand for disability services will continue for the medium term (Department of Health, 2012a: 30).

There are two databases, administered by the Health Research Board, which provide a statistical overview of disability service provision in Ireland: one focuses on people with intellectual disabilities, the National Intellectual Disability Database (NIDD); and the other, the National Physical and Sensory Disability Database (NPSDD), focuses on those with physical and sensory disabilities. In terms of these specialist disability services,[41] 55,559 people receive these, of which 26,484 have intellectual disabilities and 29.075[42] have physical (such as mobility) and/or sensory (such as sight, speech or hearing) disabilities (HRB, 2010b; 2010a). 31.2 per cent of those with an intellectual disability were in receipt of full-time residential services. This rate of residential care is high, when compared internationally.

One study compared residential rates and found Ireland had a prevalence estimate of 122 persons per 100,000 population residing in institutionalised care settings nationwide, as compared with the UK rate of 110 per 100,000 population while Sweden, having completed the deinstitutionalisation process, reported a zero estimate (Mansell *et al*., 2007). However, this prevalence is changing with an increase of more than 60 per cent in the number of people with intellectual disability living full-time in community group settings from 1996 to 2008. Currently, close to 4,000 adults with disabilities continue to reside in large congregated settings (Working Group on Congregated Settings, 2011).[43]

The HSE report *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* from the Working Group on Congregated Settings (Working Group on Congregated Settings, 2011)[44] showed that most of the residents of congregated settings, with similar proportions of men and women, are middle-aged and have been living in a congregated setting for over fifteen years. The vast majority, 93 per cent of residents, have an intellectual disability but many have other conditions as well, such as mental health difficulties, challenging behaviour or a physical/sensory disability. Over half of those with intellectual disabilities are described as at a severe or profound level. In terms of quality of life, over a quarter of residents in congregated settings have either a limited or no programme of activities and about the same number have only annual contact with family or friends, with an additional 11 per cent having no contact at all. Many of the

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[41]   These databases are limited as they are voluntary in nature; consent is sought before someone is registered. In addition, they represent only those who use or need specialist disability services and so are not epidemiological databases. They do not include any evaluation of services.

[42]   The figure includes all age groups. However, the analysis in the report excludes anyone who was aged 66 or over at the time of reporting as responsibility for the provision of services for this group lies within the Office for Older People in the Department of Health (DOH) and the Health Service Executive (HSE) rather than within the Office for Disability and Mental Health. The lesser figure, excluding those aged 66 and over, is 25,191 (HRB, 2011: 13).

[43]   This has reduced to 3,600 since the Working Group completed their work on Congregated Settings (Department of Health, 2012a).

[44]   This report was commissioned by the HSE to examine the role of congregated settings for people with disabilities.

residential centres are physically isolated thus making contact with the wider community more challenging for any resident.

In broad terms, people with disabilities experience significantly greater inequality and lower participation rates in Irish society than people without disabilities (NDA, 2005). There is some evidence to suggest also that attitudes towards people with disabilities have hardened in recent years. The NDA notes that 'of particular concern are the less positive attitudes towards children with disabilities in mainstream education, which challenges the improvements that were achieved between 2001 and 2006' (NDA, 2011b: 4). Adults with a disability are also disadvantaged in terms of labour market, social class and living standards (Watson *et al.*, 2012: 96).  It is also the case that many people with disabilities experience social isolation and need help to strengthen their natural supports in terms of family, friends and people in the local community. Some of the barriers that people face in their daily lives include:

- Inadequate policies and standards;

- Negative attitudes;

- Lack of provision of services;

- Poorly coordinated services;

- Inadequate funding;

- Lack of accessibility;

- Lack of consultation and involvement; and

- Lack of data and evidence (WHO & Bank, 2011: 262).

Another recent report, *Growing Older with an Intellectual Disability in Ireland*, documents the lives and demographics of a nationally representative sample of 753 older people with an intellectual disability (IDS-Tilda, 2011). It found that many people with an intellectual disability are not actively engaged with their communities, and while they have some family contact, they have fewer members in their social network than the wider population. The majority reported that they have limited choice in relation to how they live their lives, with 75.4 per cent reporting they have no choice in where they lived and 85.5 per cent reporting that they have no choice in relation to whom they live with.

Presenting a social portrait of people with disabilities, Watson and Nolan report that 13 per cent of people with a disability use one or more specific services such as day care, respite services, meal or drop-in services, supported housing and long-stay care. A further 8 per cent of people with a disability who live in private households needed, but did not use, some of these care services (Watson & Nolan, 2011: 53).

They conclude that 'improvements to the accessibility of public transport or services more generally, could benefit up to one in four people with a disability'.

## 2.3     Health and Personal Social Disability Services

Most specialist health and personal social disability services are provided by voluntary disability organisations under arrangements with the Health Service Executive (HSE). The HSE has a dual role, providing service directly and funding services from voluntary bodies. This includes 90 per cent of specialist intellectual disability services and 60 per cent of specialist physical and sensory disability services (Expert Reference Group on Disability Policy, 2011).

Services provided by, or on behalf of the HSE, are broad-ranging and include the following: early childhood/family support services; day services; sheltered workshops; rehabilitative training; residential care; home support services; aids and appliances; home adaptations, nursing and medical community supports; and respite care. Service provision is rendered more complex again by the fact that the providers vary from county to county and cater for very different needs through services provided in people's homes, in day services and residential centres.  The *VFMPR* outlines:

> the complexities of disability service provision, which is not a single, homogeneous and easily measured programme, but rather a multiplicity of service types and agency types serving a varied client population with widely differing needs (Department of Health, 2012a: xxii).

Broadly, the sector can be described as the following:

- Services are delivered by voluntary providers, funded by the State with minimum formal oversight and regulation;

- There are varied contexts and service histories for different disability types;

- There is still unmet need for which no services have yet been developed or for which funding has not been available.

- Services have sprung out of local need and therefore are not evenly provided around the country. There are social and historical factors that underpin the development of services for people with intellectual disabilities, with many of the longer-established services, in keeping with the practice of segregation, located away from urban centres (Eastern Regional Health Authority, 2003). The widespread use of voluntary organisations to provide services has resulted in an unequal, or variable, distribution of services geographically, with some families moving to areas with better services (Quin & Redmond, 2003: 154). A qualitative study of intellectual disability services found that service provision was ad hoc geographically and poorly integrated across the country (Power,

2009). Some voluntary providers are working together through umbrella groups, for example, the National Federation of Voluntary Bodies (NFVB), runs a series of master classes to share good practice. However, there is no overall network or system for collaborating on service delivery or ensuring that all need is met;

- Most people with disabilities live at home, and only a small minority live in residential services. However, residential services, mostly for people with intellectual disabilities, absorb about half of the specialist disability service budget (NDA, 2010b);

- More than half of people with a disability acquire it during their working life. For many people, a return to work is desirable, if the right supports are available. The WRD emphasises the key role of rehabilitative services in this regard (WHO & Bank, 2011);

- Some voluntary disability organisations exist as large organisations with many national sites, providing congregated settings and other services (and following innovative and traditional models of practice), while others are small, tailored services specific to one local area or disability type (e.g. supporting people with sight or hearing disabilities). Individual providers may operate a variety of services ranging from traditional institutions to innovative community services and supports (NDA, 2010b);

- There has been movement towards a social approach to disability[45] in policy and in newer service models, but this has been slower to change in the way services are delivered in many of the older, more institutional settings. (See the report, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* [Working Group on Congregated Settings, 2011], for additional details). A further study on outcomes, conducted as part of the *VFMPR*, found that while most service users decided on decisions that affect their daily lives, some still had no choice, for example,  in terms of mealtimes, getting up times or bedtimes (Department of Health, 2012a: 154);

- There is no national standard methodology for assessing client need or for linking those needs with target outcomes (Department of Health, 2012a); and

- There is no nationally agreed means of predicting the amount of resources an individual is likely to require or for calculating the amount of resources an individual actually consumes (Department of Health, 2012a: xxii).

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[45] This recognises that people with disabilities are prevented from achieving their full potential by societal attitudes, as well as environmental obstacles such as restrictions in their access to public transport, entertainment and public places, and in education and employment.
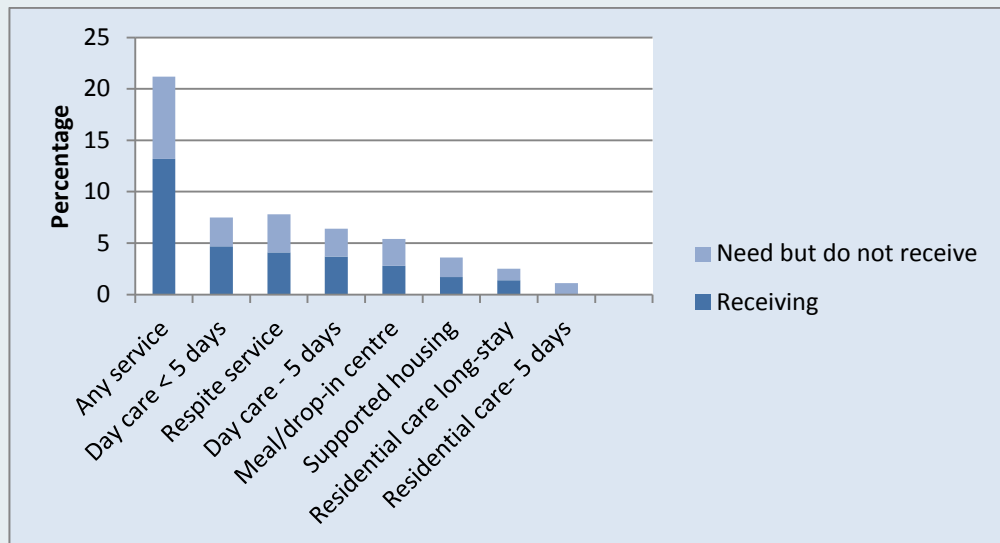
The current economic context and reduced expenditure on service provision and supports have added additional pressures to the disability sector, people with disabilities and their families, particularly difficult in a time of changing service models. The *VFMPR* argues that the current model of service delivery is not providing a sufficient quality and quantity of services at an affordable price (Department of Health, 2012a: 22). It concludes that the emerging trend toward the delivery of supports rather than services will produce a more effective service at a more reasonable cost (*ibid*.: 23).

Current disability provision has not, to date, been operating as part of a unified system and, as such, is not guided by an overall aim. As Deming pointed out, 'a system must have an aim. Without an aim, there is no system' (Deming, 1994: 98). As one service provider commented in the *Final Report on Consultation: Value for Money and Policy Review* ,'there is no clear "vision statement" to guide the service provision.  This is needed to ensure a values-driven service approach on the back of which quality person-centred services can be designed and delivered' (Department of Health and Children, 2010: 22). This ties in well with the international trends towards such a value-driven service as outlined by the NDA in Chapter 1. However, as discussed later in this report, there is no guarantee that high-level goals and visions alone may necessarily lead to improvements on the ground.  Any such vision or policy aim needs a careful implementation strategy to deliver change.

Figure 2.1 shows the percentage of people with disabilities who use care services, and also those who stated they need these services but are not actually receiving them. Overall, 13 per cent of people with disabilities use one or more of these services (Watson & Nolan, 2011). People are generally assigned to a specific disability service provider in their locality (NDA, 2010b) rather than having a choice of provider or  model of service.

In terms of mainstream services, there is some research evidence to show that difficulties can be faced including physical, communication and attitudinal barriers, as well as exclusion from preventative services and inadequate provision of therapy services (D'Eath *et al.*, 2005).

**Figure 2.1    Services Required by People with a Disability**

### 2.3.1    Delivery and Funding of Disability Services

Voluntary providers have, in recent years, received block funding for services, which is not specifically calibrated either to the levels of need of service users or to achievement of quality standards (NDA, 2010b).

Table 2.1 shows the funding[46] provided by the HSE for disability services in 2009 (this excludes those run by the HSE).[47] This shows that:

> 280 service providers in the voluntary sector received funding from the HSE amounting to €1.2bn. Twenty-three agencies received an average of €24m each and 68 agencies averaged €1-10m (Expert Reference Group on Disability Policy, 2011: 27).

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[46]    For 2010, the total investment in specialist disability services, as outlined in the HSE National Service Plan 2010–2014, was €1.476 billion. This represents 10.5 per cent of the €14 billion health budget (Expert Reference Group on Disability Policy, 2011: 26).

[47]    Home care packages from the HSE are used primarily to help older people with high support needs remain at home; they have also been used by some younger people with disabilities, but it is not clear how many. Our report, *Home Care for Older People,* gives a full account of the regulatory aspects of home care.

In addition to HSE funding of specialist disability services, some additional funding for these services is drawn from other public sources (e.g. FÁS-funded staff), from fundraising, and from contributions by those in residential services from their Disability Allowance (NDA, 2010b: 16).

Three quarters of the budget for disability services goes on services for the 9,000 people in residential services[48] and the 25,000 people receiving adult day services (NDA, 2010b).[49] About 80 per cent of the specialist disability budget consists of staff costs. This staffing, particularly in residential centres, consists of nursing and other health or social care professionals, a degree of professionalisation (and medicalisation) which, the NDA argues, is out of line with international norms (NDA, 2010b).

**Table 2.1**    **Allocation to Disability Service Providers 2009 (Expert Reference Group on Disability Policy, 2011)**

| Agencies in receipt of € | Number of Primary Service Providers/Agencies | % of Agencies | Total Received € | % of Total Received € |
|---|---|---|---|---|
| Over €100m | 3 | 1 | 408m | 33 |
| €10–€100m | 20 | 7 | 607m | 50 |
| €5–€10m | 11 | 4 | 77m | 6 |
| €1–5m | 38 | 14 | 99m | 8 |
| €1m–€500k | 19 | 7 | 14m | 1 |
| €500k–€250k | 25 | 9 | 9m | 1 |
| Under €250k | 164 | 59 | 7m | 1 |
| Grand Total | 280 | 100 | 1,221m | |

**Source**    HSE/ DOH, 2011

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[48] Only 50 per cent of Irish adults with intellectual disability live in a home setting as compared to 82 per cent in the United States and 74 per cent in England (NDA, 2010:35).

[49] In 2008, 81 organisations provided day services to 25,302 service users in 817 locations(HSE, 2012a: 39).

Unit costs were calculated for services as part of the *VFMPR*. They were found to vary considerably and the review concluded this was not due to some agencies, sectors or geographical areas being more or less efficient than others overall, but rather that the variation existed within agencies so that they were efficient for some of their services, but not for others (Department of Health, 2012a: 98). A UK study by Emerson also found this, noting that few studies have satisfactorily accounted for the wide variation in costs, but one finding is that higher service costs are related to greater user needs (Emerson *et al.*, 1999) One example of the variation in Irish residential support services for people with intellectual disabilities is the unit cost per place of €126,264 in one service to €177,388 in another, 42 per cent higher. They found no obvious reasons why this should be the case (Department of Health, 2012a: 101). They also found no clear pattern to explain cost differences between services in the statutory or non-statutory sectors.

The *VFMPR* identifies the wide variation in how services use current expenditure, and what can be done to achieve greater cost efficiencies. It contains an analysis of expenditure that was gathered by hand. Table 2.1 shows that 8 per cent of agencies receive 83 per cent of the allocation to providers (Expert Reference Group on Disability Policy, 2011).

The Competition Authority has argued in relation to the funding of disability services that:

> Services for people with a disability are currently contracted to service providers with no tendering mechanisms for what often turns out to be infinite contract length. This means that service providers face little incentive to honour their contracts in a satisfactory fashion. There is no clear mechanism to allow new service providers to access funding, which means that it is extremely difficult for new service providers to offer services – potentially, more innovative services (The Competition Authority, 2005).

### *Quality and Costs: Towards Person-Centred Services*

Within the disability sector, there is some limited evidence to suggest that adopting a person-centred model and moving away from congregated settings can be achieved for the same and potentially lower cost in the long term while also providing a better quality of life for the person with a disability (Working Group on Congregated Settings, 2011). Community-based services can be cost effective for the vast majority of service users, that is, the same, or less cost for better outcomes (Expert Reference Group on Disability Policy, 2011; Mansell *et al.*, 2007; Working Group on Congregated Settings, 2011). The HSE Service Plan 2012 envisages that progression towards the new model of service provision would help to achieve efficiencies:

> There is evidence that an accelerated move towards a new model of individualised, person-centred service provision in the community can help to achieve efficiencies, particularly in relation to services for those with mild or moderate intellectual disability (HSE, 2012b: 8).

However, going for the smallest unit size may not necessarily be the cheapest option. In their analysis of expenditure, the *VFMPR* found that the least costly service unit size contains 11–25 residents for residential high-support services for people with intellectual disability. In this type of provision, the smallest unit size was not the most cost effective. The *VFMPR* concludes that this finding must be 'viewed in the context of quality of life issues, cost effectiveness, the recommendations of the Report of the Working Group on Congregated Settings and the UN Convention on the Rights of Persons with Disabilities' (Department of Health, 2012a: 109).

Research evidence suggests that where institutional living seems more cost effective, it can be because of inadequate staffing and quality of life in the institutions (Mansell *et al.*, 2007). A study by Emerson *et al.* in 2000, cited in the *VFMPR*, found weak associations between costs and quality for participants with service and complex disabilities. The NDA has also concluded that indicators of basic resources have little or no association with quality (NDA, 2007). More important factors are supportive staff and the climate of the organisation. Mansell argues that for people with severe and profound disabilities, less staff support is likely to mean poorer quality of life (Mansell & Beadle-Brown, 2009).

## 2.4     Organisational Context of Disability Services

### 2.4.1     Voluntary Disability Organisations

As with most human services in Ireland, voluntary disability and community organisations have had a major role in creating and providing a wide range of services for people with disabilities as well as providing supports and information beyond a service-provider role.[50] While this is not unique to disability services, there has been a particularly heavy reliance on voluntary and community organisations to provide disability services, growing out of local need and often emerging in the absence of State provision. As outlined above, much of the funding is directed to large service providers. Some of the big service providers include Rehab, St Michael's House, Central Remedial Clinic, Sunbeam House, Daughters of Charity Services and the Brothers of Charity Services. There are many smaller organisations providing tailored services to local communities. Some of the newer organisations have been created and driven by people with disabilities (and family members) (DFI, 2011b). Many are represented by one or more umbrella organisations, which include:

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[50]   Voluntary organisations have been providing services for persons with an intellectual disability in Ireland since 1869.

- The Disability Federation of Ireland (DFI), which is a national support agency for voluntary organisations in Ireland, representing over one hundred and fifty voluntary disability organisations and groups;

- Inclusion Ireland, the National Association for People with an Intellectual Disability, with over one hundred and sixty members;

- The National Federation of Voluntary Bodies (NFVB), with sixty two member organisations working with people with intellectual disabilities;

- The Not for Profit Business Association (NPBA), primarily representing agencies working with people with sensory and physical disabilities;

- People with Disabilities Ireland (PWDI), a cross-disability organisation that has recently disbanded; and

- The Wheel, which represents a wide cross-section of community and voluntary organisations, including those providing services to people with disabilities.

The disability sector is also informed by research and evaluation work undertaken by the National Disability Authority (NDA), which has a statutory function in relation to research, by university departments and units that are contributing to work in this area, some of which receive statutory, philanthropic and private funding. These include:

- The Centre for Disability Law and Policy in the National University of Ireland, Galway, whose recent work includes: a comparative work on national disability strategies internationally; analysis of the UN Convention and the legal implications for Ireland; and a comparative study of models of support for people with disabilities;

- The National Institute for Intellectual Disability at Trinity College Dublin promotes inclusion for people with intellectual disability through education, research and advocacy;

- Other research on aspects of disability has been funded through grants provided by the Health Research Board (HRB) and the NDA;

- The HRB also maintains the two databases on disability service provision outlined earlier; and

- The CDLP, (National University of Ireland Galway); Centre for Disability Studies (University College Dublin); Centre for Intellectual & Developmental Disabilities (University of Ulster); National Institute for Intellectual disabilities (Trinity College Dublin) and Disability Action (Northern Ireland) publish some related research and are in the process of forming the Disability Studies Association of Ireland.

### 2.4.2    Institutional Actors and Responsibilities

The NDA was established as an independent statutory body in June 2000, under the National Disability Authority Act 1999, to inform government on policy and practice in relation to people with disabilities. It advises and supports the implementation of the National Disability Strategy, offers advice on quality and standards for services, and undertakes research. The Office for Mental Health and Disability in the Department of Health was established in 2008 to develop cross-sectoral engagement. One of its functions is 'to advise the Minister on appropriate standards for services for persons with disabilities' (Section 8 (2) (c)). The NDA also monitors the progress of the National Disability Strategy and develops guidelines and codes of practice.

The Health Information and Quality Authority (HIQA) is the statutory Authority, established under the Health Act 2007, with responsibility for setting standards for health and social care services, and ensuring that the standards are being met.[51] HIQA is responsible for the registration and inspection of 'designated centres', that is, residential services for children, older people and people with disabilities, although so far this has applied only to older people. HIQA's statutory responsibilities include developing standards for health and social care services in Ireland, monitoring and implementing continuous quality assurance programmes as well as registration and inspection of residential homes for people with disabilities. Standards concerning services for adults and children with disabilities in residential services have been developed by the social services directorate within HIQA, but are not yet mandatory. This will be examined in detail in Chapter 3.

HIQA and the NDA share a focus on standards in their remit but with different areas of emphasis. HIQA is the regulatory body in this sector and will be the inspectorate for services once the standards are statutory, while the NDA provides an advisory role to government on standards and quality. The NDA outlines on its website that it has an 'important statutory remit to develop standards and codes of practice and to monitor the implementation of standards and codes in programmes and services for people with disabilities'.[52]

The role of the Patient Quality and Safety Directorate of the HSE is to support the organisation in delivering on its objective of providing high quality and safe services to patients and service users. It aims to determine recommended practices (within the context of the National Standards on Better Healthcare) and systems required for quality and safe care based on best evidence; build capacity within the organisation to deliver on the quality improvements; use data and evidence to

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[51] While mental health is included as a disability in relation to the National Disability Strategy, the mental health service sector has a different regulatory body, the Mental Health Commission (MHC). The MHC maintains a register of approved centres and codes of practice for people working in the mental health sector. The Commission also published the *Quality Framework for Mental Health Services* in 2007. This work is complemented by the Inspectorate of Mental Health Services, which visits and inspects every approved centre annually.

[52] www.nda.ie

monitor service quality; sponsor patient focus and service user participation; improve the sharing of information, the management of, and learning from, incidents to avoid reoccurrence and to undertake healthcare audits to provide organisational assurance (HSE, 2012c). It is currently preparing quality and risk guidelines for all HSE services.

The National Standards Authority of Ireland (NSAI), the official standards body in Ireland, operates under the National Standards Authority of Ireland Act 1996. It works to agree minimum Irish standards for goods and services, benchmarked against international best practice to ensure fair trade nationally and globally.[53] The NSAI established the Standards Consultative Committee along with the NDA and the Centre for Excellence in Universal Design (CEUD). The work of this committee is particularly focused on appropriate standards in the use of technical aids and systems that might support people with disabilities. CEUD focuses on enabling the design of environments that can be accessed, understood and used regardless of age, size and ability.

The National Accreditation Committee (NAC) operated between 1996 and 2007 to accredit specialist vocational training, and, in later years, rehabilitative training, but was disbanded by the HSE as part of its National Review of Day Services (HSE, 2012a).

## 2.5    Disability Policy and Legislative Context

There have been many developments in the disability sector in terms of policy and legislation in recent years.[54] Table 2.2 presents the key policies and legislation that underpin the sector, not all of which are examined in detail here. In relation to service provision, the direction of policy over the last twenty years has been a slow move towards a rights-based approach (but which is not in place), support for independent living, expansion of provision of personal assistance, providing new residential care places within the mainstream community and, in broad terms, increased funding for residential services. However, there are no explicitly stated national objectives for disability services funded by the HSE (Department of Health, 2012a: 15).

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[53]   www.nsai.ie

[54]   See Doyle, 2003; Quin & Redmond, 2003 for a full account of the development of disability policy in Ireland.

## Table 2.2       Key Policies and Legislation[55]

**Key Policies and Strategies**

Quality and Fairness: A Health System for You (Department of Health and Children, 2001).

National Disability Strategy (Government of Ireland, 2004).

Towards 2016 (Government of Ireland, 2006).

National Action Plan for Social Inclusion (2007–2016) (Government of Ireland, 2007).

National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011–2015 (Department of Health, 2011a).

National Housing Strategy for People with a Disability 2011–2016 (Department of the Environment, 2011) and National Implementation Framework (Department of the Environment, Community and Local Government & Health, 2012).

Time to Move on from Congregated Settings: A Strategy for Community Inclusion (Working Group on Congregated Settings, 2011).

New Directions: Review of HSE Day Services and Implementation Plan 2012–2016 (HSE, 2012a).

National Review of Autism Services (Irish Hospice Foundation *et al.*, 2011; HSE, 2012e).

Value for Money and Policy Review for Disability Services (Department of Health, 2012a).

The National Carers' Strategy (Department of Health, 2012b).

**Key Legislation**

Equal Status Acts (2000/2004).

Education for Persons with Special Educational Needs (EPSEN) Act (2004).

Disability Act (2005).

Health Act (2007).

Citizens Information Act (2007).

The Charities Act (2009).

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[55] This list does not include the Buildings Regulation 1997 and 2000, which include regulations on access to buildings for people with disabilities.

Within the framework of *Towards 2016; Ten-Year Framework Social Partnership Agreement 2006–2015*, the high level objectives of the disability services funded from the HSE are:

- To provide the individual with a disability, to the greatest extent possible, the opportunity to live a full and independent life with their family and as part of their local community;

- To support the individual with a disability as far as possible to participate in work and in society and to maximise their potential;

- To ensure that the individual with a disability would, consistent with their needs and abilities, have access to appropriate health and personal social services; and

- To support and acknowledge the role of carers in their caring role (Department of Health and Children, 2009).

There was more than a decade of policy focus that began with the report of the Commission on the Status of People with Disabilities (Commission of the Status of People with Disabilities, 1996). *A Strategy for Equality* was a wide-ranging, comprehensive report, which made many recommendations on legislative change, new structures and new ways of providing services. It was recommended that services for people with disabilities would be provided in the mainstream, with appropriate supports, a policy later referred to as mainstreaming (Expert Reference Group on Disability Policy, 2011: 31).[56] This was followed by the Irish Disability Bill, 2001, but this was withdrawn following negative reaction from disability groups. Extensive consultation with disability groups led to the development of the National Disability Strategy.

### *The National Disability Strategy*

A cornerstone of policy in this area, the National Disability Strategy (NDS), was introduced in 2004 with the overall aim of improving the participation of people with disabilities in society. It sets out a direction for public policy, services and facilities to underpin the participation of people with disabilities (Department of Justice, Equality and Law Reform, 2004). Furthermore, it is a programme of co-ordinated action plans across government departments to further integrate people with disabilities into mainstream society. While the strategy does not regulate services or provide standards, it does include a focus on making services more accessible.  The strategy provides for equal access to buildings and services, employment of people with disabilities in the public sector, individual assessment of needs and detailed sectoral plans for selected government departments. It

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[56]  Three particular elements of any mainstreaming policy are to try to ensure that (i) people with disabilities can take their place in mainstream society; (ii) mainstream public services include people with disabilities and (iii) the impact on people with disability of mainstream public policies (Barron, 2009).

represents a significant milestone in recognising the place of persons with disabilities in Irish society and of the State's responsibilities in ensuring they participate on an equal basis with other citizens (NESC, 2005c). It sets out a vision of tailored services to meet the needs of people with disabilities as part of mainstream provision and as a move away from separate and institutionalised care. The Programme for Government includes a commitment to publish an implementation plan for the NDS (Government of Ireland, 2011).[57]

The Strategy's main legislative structure is the Disability Act 2005, which requires that every public body considers people with disabilities and disability issues as part of their core work in mainstreaming their services. After the protracted and contentious debates of the previous decade, a central provision of the Act was the right of people with disabilities to an assessment of need. This was in contrast to the 2001 Bill, which had been criticised for not recognising the rights of people with disabilities. The Disability Act 2005, includes a statutory obligation on public service providers to support access to services and facilities for people with disabilities and to appoint at least one access officer to support customers with disabilities in accessing their services.  Under the Act (if fully commenced), people with disabilities would be entitled to:

- Have their health and educational needs assessed;

- Have individual service statements drawn up, setting out what services they should get;

- Access independent complaints and appeals procedures; and

- Access public buildings and public service employment.

Part 2 of the Act, concerning Individual Assessments of Need, was commenced for children under five on 1 June 2007. The remainder of Part 2 has been deferred with the result that adults and older children are not currently entitled, under the Act, to an individual assessment of their needs. The Act also gives the Ombudsman and Information Commissioner powers to investigate complaints. In summary, the Disability Act's main aims are to provide for:

- Independent assessment of health and education needs of people with disabilities;

- Provision of resources to meet those needs;

- Making of plans for services;

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[57]   This was also emphasised in *Towards 2016* and the *National Action Plan for Social Inclusion* (NAPS 2007–2016; Government of Ireland, 2006, 2007).

- Complaints and appeals procedures;

- Access to public buildings, services and public service employment; and

- Restrictions on genetic testing.

In addition, the Citizens Information Act 2007 provides for the establishment of a comprehensive advocacy service to support people with disabilities who seek to enforce their legal entitlements to services. While not a statutory service, the National Advocacy Service was commenced in 2011 and is run by the Citizens Information Board.[58]

The third legislative arm of the Strategy is the Education for Persons with Special Educational Needs (EPSEN) Act 2004, which aims to enhance the rights of children with disabilities to avail of, and benefit from, an appropriate education with individual education plans for all children with special educational needs. EPSEN has not been fully enacted. Under the Act, the National Council for Special Education was established and published *Implementation Report: Plan for the Phased Implementation of the EPSEN Act 2004.* The report sets out how the Act can be implemented (National Council for Special Education, 2006).

Under the Strategy, a number of sectoral plans were drawn up (a programme of measures, including targets and timescales) by six government departments covering communications, employment, environment, health, social welfare and transport.

Another key element of the Strategy includes the provision for the CEUD, which focuses on universal design of buildings, products, services and Information and Communications Technologies (ICT), and is based in the NDA.

### *Implementation of the Disability Act and the National Disability Strategy*

While some key elements of the Strategy have been activated, other aspects of the Strategy and associated legislation have been put on hold for economic reasons (e.g. EPSEN).

The Department of Justice and Equality has lead responsibility for the co-ordination of the National Disability Strategy and the UN Convention on the Rights of People with Disabilities. In terms of monitoring the strategy, until the end of 2010, departments reported twice yearly to the National Disability Strategy Stakeholder Monitoring Group.[59] (For a full overview of the structure and process of monitoring of the Strategy see (Centre for Disability Law and Policy, 2010; Van Lieshout, 2010).

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[58] The background to this service is outlined in *Developing an Advocacy Service for People with Disabilities* (Comhairle, 2004)˙

[59] This group includes six disability organisations, the NDA, senior officials from ten government departments, the HSE, the National Council for Special Education (NCSE) and representatives from the social partners.

More recently, the National Disability Strategy Implementation Group was established by the Department of Health in 2011 and chaired by the Minister of State at the Department of Justice and Equality to develop an implementation plan for the National Disability Strategy and new arrangements for reporting are in place.

Although the National Disability Strategy has provided the policy and legal framework for mainstreaming disability services, it has little role in relation to the regulation of services *per se*. However, through sectoral plans it is a driver for key departments to provide equality of access to services and facilities, and places greater emphasis on quality-of-life issues for people with disabilities. The value of its co-ordination role, seeing how different programmes match up cross-sectorally, is acknowledged but it is not clear what impact they have on service users.

While there has been some progress achieved in relation to the accessibility of public buildings, access to services and specific actions (under sectoral plans of departments, for example), it is less clear how this strategic vision has impacted directly on service quality, regulation or delivery. In other words, how has the Strategy and its actions materialised into change on the ground for people with disabilities?

One aspect, the assessments of need, which come under implementation of Section 2 of the Disability Act, have posed significant challenges in meeting statutory deadlines for processes under the Act (assessments, service statements and reviews). For example, in 2010, only 30 per cent of assessments were completed within specified timelines (Department of Health, 2011b).[60] Chapter 3 discusses this further.

Originally considered one of the most progressive pieces of legislation in Europe (Irish Times, 22 September 2004), the Disability Act seemed to confirm Ireland's reputation as a frontrunner in the international battle for the inclusion and recognition of disabled people (De Wispelaere & Walsh, 2007; Doyle, 2003). In this way, there are critics of the Strategy and the Disability Act who argue that they have not yet lived up to the high expectations that grew out of the extensive process of consultation that preceded its enactment.

As DFI argues (DFI, 2011a: 4):

> Ireland has a National Disability Strategy (NDS); it has goals that government and civic society have agreed to achieve, namely people with disabilities living as full citizens. It has mechanisms with which to marshal progress. Nonetheless all is not well with the Strategy. On the one hand, there is no coherent picture of how Ireland is progressing towards the agreed goals; information about what outcomes have been achieved is very sketchy.

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[60] Following a High Court decision, statutory assessments of need extend to children who were aged under 5 in June 2007.

*Other Relevant Legislation*

As well as the National Disability Strategy, key legislation of relevance here includes:

- The Health Act 2007 which brings a statutory obligation for the registration and inspection of residential services for people with disabilities. This piece of the legislation has not yet been commenced but it is likely in 2013;

- The 2001 Health Strategy, *Quality and Fairness: A Health System for You,* made a commitment to mainstreaming which states that 'specific services for people with disabilities should be the responsibility of those government departments and State agencies which provide services for the general public' (Department of Health and Children, 2001: 141). Included in the 2001 Strategy was the prioritisation of national standards for residential care of people with disabilities (Expert Reference Group on Disability Policy, 2011: 31);

- The Equal Status Acts 2000 and 2004 promote equality and prohibit discrimination against people with disabilities in relation to the provision of goods, facilities and services available to the public generally. A person selling goods or providing services must do all that is reasonable to accommodate the needs of a person with a disability;[61] and

- The Charities Act 2009 aims to provide for greater accountability and transparency in the charity sector and to protect against abuse. It is not yet commenced but the main provisions of the Act include a new Charities Regulatory Authority, which will be set up to secure compliance and encourage better administration of charities. It will have investigative powers. There will also be a Register of Charities, on which all charities must register.

## 2.5.1     Recent Policies and Strategies

*Time to Move on from Congregated Settings*

The HSE strategy for the closure of congregated settings, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (Working Group on Congregated Settings, 2011) provides a rare picture of the lives of close to 4,000 people with disabilities living in groups of ten or more. Accommodating people in these settings, with shared facilities and very little personal independence, runs counter to the current State policy of inclusion an full citizenship (Working Group on Congregated Settings, 2011: 10). In its recommendations, this report presents a new model of accommodation and support in the community where people are moved from congregated settings to dispersed housing in ordinary neighbourhoods with individualised supports.

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[61] Access and inclusion to mainstream services for people with disabilities is underpinned by this important legislation.

The proposed closure of these congregated institutions is in line with recent Department of Health policy proposals for person-centred services. The report makes the case clearly from existing evidence that community living, that is living in dispersed houses in ordinary neighbourhoods, is better in terms of health, social supports, personal skills development and overall life satisfaction. But the Working Group makes the point that in addition to the change of accommodation, it is necessary to change the kind of staff support provided in order to make a difference to outcomes. The Working Group report concludes that while the evidence they review shows that community-based models may not necessarily be cheaper than institutional care, they will bring about better outcomes for people. The report outlines the support frameworks necessary for residents to make the transition to the community, including advocacy, person-centred planning and in-home supports. On a strategic level, the report further provides the implementation steps necessary to move all residents out of congregated settings within seven years, including change management, national protocols and strengthening access to community health services. However, it would not be an easy process for residents or staff and will bring considerable challenges to implementation.

The HSE is developing an action plan to implement the report.

### New Directions: Report of the National Working Group

*New Directions*, HSE Review of Adult Day Services, was conducted by a National Working Group established in 2007 and published in 2012 (HSE, 2012a). This review included examining the reconfiguration and modernisation of existing adult day services with a view to adopting best practice and getting value for money; and achieving better outcomes for service users and in line with relevant legislation and national standards (Department of Health and Children, 2007).

The resulting report, *New Directions: Personal Support Services for Adults with Disabilities,* proposes a radical change in the provision of day services so that 'supports will be tailored to individual need and will be flexible, responsive and person-centred' (HSE, 2012a: Foreword). According to the HSE, these supports will be outcomes-based and will need to be delivered within a culture of person-centredness where the users of a service will play a key role in the development, planning, delivery and evaluation of their service. The wider policy focus on mainstreaming of services will require collaborative working at a local level supported by the national structure for the co-ordination of the National Disability Strategy's sectoral plans. The Strategy identifies the National Disability Strategy's formal structures for cross-departmental co-operation as valuable for building links between specialist and mainstream services so that 'individuals can have the benefit of the seamless continuum of services to which New Directions aspires' (HSE, 2012a). In addition, there is an intention to develop integrated information on disability to monitor services more effectively, reporting on key performance information and with links to financial systems.

As part of implementing *New Directions*, the National Working Group outline the importance of a quality assurance system (for service providers in all disability services) as a foundation for national and organisational change planning and

translates the principles of New Directions into programme indicators (HSE, 2012a). This will incorporate guidelines for service providers in respect of New Directions and will include an audit tool to assist with self-evaluation, internal monitoring and continuous improvement. The system will 'form the basis of a quality framework which will be used to approve service providers, enter into service agreements and monitor service delivery by HSE funded services on an on-going basis.' Service providers will be expected to 'build the guidelines into their internal quality assurance, quality control and accreditation systems' (*ibid*. p.136). As part of the development of this system, the report recommends that a process should set out how the framework links with the responsibility of other bodies with responsibilities in relation to quality standards such as HIQA, the Mental Health Commission and the National Qualifications Authority of Ireland. The HSE's Patient Quality and Safety Directorate is developing a policy document on the management of quality and risk and is due to be published later in 2012. This is likely to include further details on quality assurance processes and systems. In addition, a sub-group of the National Implementation Group for New Directions is focusing on national standards for day services.

### *National Housing Strategy for People with a Disability*

The *National Housing Strategy for People with a Disability 2011–2016* (Department of the Environment, 2011:7) focuses on the housing needs of people with disabilities by seeking

> to facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living.

One key element of this Strategy will be to develop a framework to facilitate housing in the community for those moving out of congregated settings:

> This framework will be supported by the development of specific guidance to assist housing authorities to manage the assessment and allocation process for people leaving congregated settings on a regional or national basis  (: 10).

It outlines the context of housing provision for people with intellectual disabilities to date and how the strategy is supporting mainstreaming of services:

> Historically, in Ireland, most people with intellectual disabilities have had all their services provided by one organisation. This would include accommodation needs and medical and social services or, where they live in a private home, day services and medical and social services. Service providers receive funding from the HSE to provide all a person's various needs and the individual had very little, if any, influence on how this allocation was spent. This has had the effect of tying the person to a particular service provider, often from early childhood, leaving the person with few options for changing aspects of their care. (Department of the Environment, 2011: 130).

This strategy includes for the first time an entitlement that all people with a disability, regardless of their current housing situation, should receive an assessment of their housing need from the local authority. This is a new departure as previously those who were in institutional care or in group homes were not included in any housing-need assessments.

The *National Implementation Framework* includes a strong focus on multi-agency collaboration, specific assessment and allocations policies and will reflect individual choice and living preferences. It includes a recommended action of developing and implementing good-practice models to support people with disabilities within communities (Department of the Environment Community and Local Government & Health, 2012). This will include a pilot programme to test good practice informed by the current work of Genio.

### National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015

Published in 2011 by the Department of Health, the *National Neuro-Rehabilitation Strategy* set out the development of a national policy and strategy for the provision of neuro-rehabilitation services. This includes the mandatory compliance to protocols across the delivery system, and will require the integration of services, among other areas.

While this section has provided a brief overview of the current policy landscape, there are policy developments underway, with the Department of Health currently circulating the *VFMPR* for disability services, and prior to that, the Expert Reference Group on Disability Policy report. Both propose a model of individualised supports, underpinned by mainstreaming of all public services. These proposals will be examined in more detail in the next section.

### The National Review of Autism Services

The National Review of Autism Services identifies the core principles of service delivery and standards of practice that will guide national autism services in the future. It set sets out clear and consistent pathways for access to services for children with autism. It found that, to date, 'geographically, current services can vary from robust, comprehensive and integrative to isolated, patchy and ineffective' (HSE, 2012e: 7).[62]

### The National Carers' Strategy

*The National Carers' Strategy* sets out a vision for the support of carers in Ireland:

> Carers will be recognised and respected as key care partners. They will
> be supported to maintain their own health and well-being and to care

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[62] http://debates.oireachtas.ie/dail/2011/11/08/00008.asp.

with confidence. They will be empowered to participate as fully as possible in economic and social life (Department of Health, 2012b: 9).

It includes a focus on providing relevant and accessible carer-training opportunities for carers as 'where carers have the necessary care skills, the quality of care provided will be better, the physical impact of caring will be lessened and their quality of life enhanced' (Department of Health, 2012b: 16).

It also refers to the role of standards in home care as part of protecting the physical and mental well-being of carers by aiming to

> progress the development and implementation of national standards for home support services, which will be subject to inspection by the Health and Information Quality Authority (HIQA) (Department of Health, 2012b: 22).

## 2.6      Recent Irish Policy Developments

Recent policy developments are likely to have considerable impact on the disability sector. The most significant document is the recently published Department of Health's *VFMPR* which evaluates the efficiency and effectiveness of services for people with intellectual, physical or sensory disabilities, funded by the HSE, including the statutory and non-statutory sectors (Department of Health, 2012a). This review will provide 'the framework for the development of effective and accountable services' for the Department of Health.[63] Prior to its publication, the Expert Reference Group on Disability Policy reported their draft policy proposals in 2011 (Expert Reference Group on Disability Policy, 2011), which was influential in shaping the policy vision in the *VFMPR* but also has value as a commentary on current disability services and policy.  These reports will be examined here, and again briefly in Chapter 5, in relation to their approach to quality and regulation.

### 2.6.1      Value for Money and Policy Review

The *VFMPR* proposes a fundamental change in approach to the governance, funding and focus of disability services, towards a model of person-centred and individually chosen supports. The achievement of measurable outcomes and quality for service users, at the most economically viable cost, underpins its recommendations. It also recommends that a new model of community-based supports should be put in place for people moving from congregated settings (Department of Health, 2012a: 210).

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[63] Department of Health Press Release: http://www.dohc.ie/press/releases/2012/20120720.html

It recommends the following vision statement for the revised Disability Services Programme:

> To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being (Department of Health, 2012a: 164).

It also recommends that it should be underpinned by the following goals:

- Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community; and

- The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities (Department of Health, 2012a: 164).

The *VFMPR* argues that the current approach to disability services is not sustainable for many reasons, primarily because: the high costs of delivering services; current expenditure cannot be maintained at current levels; resources are not allocated according to assessed need nor funding linked to outcomes (Department of Health, 2012a: 160). It further outlines how the current system no longer meets the changing aspirations and needs of people with disabilities and there is a need to improve the degree of fit between the delivery of services and supports and the UN Convention on the Rights of Persons with Disabilities (Department of Health, 2012a: 173).

It states that agencies that receive funding from the State for the delivery of services and supports should be accountable for that funding. It recommends strengthening the role of the HSE to have a central directional role in funding, shaping and driving disability services and to use the Service Level Agreements (SLAs) to 'drive migration towards a person-centred model of services and supports' (Department of Health, 2012a: xviii). Further actions in relation to reshaping commissioning and procurement, resource allocation and information infrastructure are also outlined.

The *VFMPR* concludes with some implementation priorities and immediate actions for the HSE, the Department of Health and other stakeholders. It argues that demonstration projects should be initiated by service providers, which show how the person-centred model of service can be delivered. While the value of such projects is not in doubt, both the *VFMPR* and this report have identified some innovative good practice already going on in the disability sector. What would seem of great value, therefore, is the prompt dissemination of this good practice across the system, to provide a faster route towards the new model of service delivery, outlined in the *VFMPR*.

Aspects of the *VFMPR* that concern quality and regulation are discussed in Chapter 3.

### 2.6.2    Expert Reference Group on Disability Policy

The Expert Reference Group report outlines some of the evidence and concepts that underpin the *VFMPR*. It is worth briefly outlining some of these here.

Mainstreaming is presented as the central mechanism to realise the new policy vision (Expert Reference Group on Disability Policy, 2011, 2010) with individualised supports.[64] This is not new but it has been a policy goal, as yet not fully implemented, to provide mainstreaming of services with person-centred supports rather than specialist disability services (NESC, 2005a; Expert Reference Group on Disability Policy, 2010).

Table 2.3 outlines the proposed change in service provision towards individualised supports and mainstream services as part of the Expert Reference Group's vision, drawing on NESC's work on tailored universalism as part of the Developmental Welfare State (NESC, 2005a).

**Table 2.3    Summary of Proposed Change from Current Provision to Individualised Supports and Mainstream Services**

| Current disability provision | Individualised supports and mainstream services |
|---|---|
| *From* ... service defined by agency | *To* ... service jointly defined by service user and family, commissioning authority (e.g. HSE and government) |
| *From* ... service deliverer accountable for inputs and compliance | *To* ... service deliverer accountable for outputs and quality |
| *From* ... compliance with rules | *To* ... attainment of outcome-based standards and demonstrated commitment to continuous quality improvement |
| *From* ... provides categorical services | *To* ... provides integrated services |
| *From* ... service delivered through credentialed professionals | *To* ... services and supports delivered through professionals, non-professionals and service user representatives |
| *From* ... funds isolated projects | *To* ... levers local innovations into improvements in mainstream services |
| *From* ... one size fits all | *To* ... assumption of need for diversity |

**Source**    Expert Reference Group on Disability Policy (2011)

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64  Submissions by the Centre for Disability Law and Policy, NUIG, and Citizens Information Board to the Expert Reference Group on Disability Policy both emphasise that while mainstreaming of services is the way forward, it is important to provide services for some people with disabilities who have high-level support needs.

A key part of the proposed approach to services in both the Expert Reference Group report and the *VFMPR* is allocating resources based on need. This is outlined as comprising an independent assessment of need, the allocation of an individualised budget, with input from service users and families as to how to spend it. This could include direct payments

> where the person administers the budget themselves, or a broker system, where the person has the same amount of input into 'designing' their supports and services, but uses the broker to administer the budget and to commission supports and services on their behalf (Expert Reference Group on Disability Policy, 2011: 18; Department of Health, 2012a).

The new model for service provision focuses on building on community and natural supports for service users, helping them to access mainstream services. This is creating a need for a new type of role in the disability sector, that of a community connector, lifestyle facilitator or broker. Mainstreaming services requires these supports to be active. DFI argues that Expert Reference Group's report values mainstreaming but leaves the main tasks of achieving it to others.

This point reflects a wider concern about the lack of any systematic evaluation of mainstreaming as a policy for the disability sector, so that it is not clear where it is working well and what areas of support still need to be developed. Further research in this area would be valuable. One qualitative study on access to health services by people with disabilities in 2005 found:

> For many people with disabilities interviewed in this study the degree of fit between themselves and the health service is a poor one. To compensate for the poor fit a range of adaptations is brought into play. In this research it was found that the system is generally rendered accessible only with considerable support from friends and relatives and from the informal goodwill of individual health workers who try to personally compensate for the deficiencies, inefficiencies and injustices of the system. "Society" acts as a buffer to compensate for a health service that is too rigid to be person-centred (D'Eath *et al.*, 2005: 4).

The *VFMPR* notes that the effects of the proposed policy approach for service users presented in the Expert Reference Group report have not yet been fully examined, and that a further detailed appraisal will be needed. Service providers will also be affected and the market will need to be shaped and developed, a function that falls to the HSE's National Disability Unit.

When the final policy proposals are implemented, the disability sector will undergo unprecedented change as the model of service provision changes to a tailored, individualised service with supports. This move to tailored services is not unique to the disability sector but is occurring in other health and social services areas and in no sphere has it been successfully achieved as yet. It is a complex task to develop the range of appropriate supports needed to make tailoring effective, where people with disabilities are at the helm of choosing what services they need and are resourced by the State to make these choices. Such tailoring requires resources and

professional brokers and advocates. It is hard to fully comprehend the level of change required for service users, their families, service providers, regulators and the State, in moving to a self-directed model of mainstream provision with supports. Increased service user involvement is a vital part of progressing effective quality services, particularly in periods of profound change.

Capacity building and circles of support are needed for service users and their families to help them gain confidence in having more control of a new way of life. Ongoing consultation by the HSE in the National Consultative Fora and what HIQA has done in the recent past in relation to the development of standards play an important role.

### 2.6.3     HSE Disability Policy Developments

Forthcoming HSE policy developments are outlined in the current HSE *Service Plan 2012* (HSE, 2012b) and include the implementation of *New Directions*, introduced in the previous section. This makes reference to a total system reconfiguration of service provision through the implementation of a number of programmes and reviews. The Service Plan outlines the emerging approach to disability service provision that 'will include a robust implementation plan which will be developed through the National Consultative Fora and will include a monitoring and evaluation framework' (*ibid*: 53). The Service Plan also outlines the intention to support organisations in the delivery of high quality and safe services, in preparation for the commencement of a system of registration and inspection of residential services for adults and children with disabilities.

It also includes reference to the following programmes and reviews:

- Reconfiguring residential services as recommended in *Time to Move on from Congregated Settings* (see Section 2.5.1);

- The Programme for Progressing Disability Services for Children and Young People aims to establish one clear pathway for all children with disabilities at primary-care level if they can be met there or through a Disability Team if required.  It is rolling out nationally involving a partnership approach to delivering services. It follows from recommendations of the National Reference Group on Multidisciplinary Services for Children 5–18 (HSE, 2009);

- The National Neuro-Rehabilitation Strategy (See Section 2.5.1) sets out the development of a national policy and strategy for the provision of neuro-rehabilitation services (Department of Health, 2011a); and

- Another policy initiative is the development of a Comprehensive Employment Strategy for people with disabilities which is slowly being progressed in a Cross Sectoral Group Department of Education and Skills and the Department of

Health. The Department of Social Protection, FÁS and the HSE are also represented on the group. A key issue is appropriate provision for people with disabilities requiring ongoing employment supports.[65]

## 2.7    International Policy and Legislative Context

There has been increasing focus internationally on the rights of people with disabilities to access services and information and this focus is impacting on Ireland.

### European Convention for the Protection of Human Rights and Fundamental Freedoms 1953 (ECHR)

Ireland is a party to international human rights treaties, notably, the European Convention for the Protection of Human Rights and Fundamental Freedoms 1953 (ECHR). The ECHR is part of Irish law by virtue of the European Convention on Human Rights Act 2003. Also, the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1979) is a multilateral treaty ratified in Ireland in 1989, and which commits its parties to work towards the granting of economic, social and cultural rights. These treaties provide an international context for Ireland's legislation and policies in relation to disability services.

### United Nations Convention on the Rights of Persons with Disabilities 2008 (Disability Convention)

Most recently, the United Nations Convention on the Rights of Persons with Disabilities 2008 (Disability Convention) has been adopted by the EU.  It has not been ratified in Ireland so it is not in force here yet. However, in signing the Convention, Ireland has committed to maintain a policy in line with it. Its aim is to include all those actions that each country needs to do in order to ensure that people with disabilities can enjoy their rights, on an equal basis with all others. As noted in an earlier NESC report, 'it marks a shift in thinking about disability from a medical and welfare concern to a human rights and equality issue' (NESC, 2009: 239).

Article 16 of the Convention is of particular relevance here. It calls, inter alia, for independent monitoring of services for people with disabilities. Article 16 (3) states:

> in order to prevent the occurrence of all forms of violence, exploitation and abuse, States parties shall ensure that all facilities and programmes designed to service people with disabilities are effectively monitored by independent authorities (UN, 2008).

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[65] Speech by Minister of State for Disability, Equality, Mental Health and Older People at a National Disability Authority Employment Seminar Series 2011 on a Comprehensive Employment Strategy for People with Disabilities.

States who ratify the Convention will undertake the obligation to have measures that promote the human rights of persons with disabilities without discrimination (Secretariat for the Convention on the Rights of Persons with Disabilities, 2007). The Convention will therefore have implications for disability services when Ireland ratifies it (European Foundation Centre, 2010).  However, the Convention allows States to progressively achieve rights that require resources. While its impact may not be immediate, past experience of other conventions, such as the UN Convention of the Rights of the Child, shows that they can bring about lasting legislative and policy changes such as the development of the National Children's Strategy. The National Disability Strategy has led to some progress in line with the Convention, for example, in the area of accessibility of public buildings. However, greater focus will be needed to meet the requirements of the Convention in future (Flynn, 2010a, 2010b; Barron, 2009)[66] and legislation will be needed in relation to mental capacity (Quinn, 2011). The government has stated its intention to ratify the UN Convention soon but will bring in required legislation before doing so, in particular, the forthcoming Mental Capacity Bill 2012.

### European Disability Strategy 2010–2020

The other key international strategy is at EU level, the *European Disability Strategy 2010–2020,* which aims to empower people with disabilities so that they can enjoy their rights and participate fully in society (European Commission, 2010).[67] The strategy focuses on eliminating barriers across eight main areas: accessibility,[68] participation, equality, employment, education and training, social protection, health and external action. These will be tackled through awareness-raising, financial support, data-monitoring, and the governance framework required under the UN Convention including involvement of people with disabilities.

The UN Convention and, to a lesser extent, the European Disability Strategy, have significance for their emphasis on rights for people with disabilities, but are also noted as important in terms of governance and how they present new ways of regulating policy across Member States.  The UN Convention contains some novel dimensions as a form of regulation containing a number of 'experimentalist characteristics' as outlined by de Burca[69] in her paper from 2010 (and detailed more

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[66] The Zero Project run by the Essl Foundation compares how countries are implementing the UN Convention using social indicators, and selects examples of good practices and good policies and works towards zero barriers.  Ireland receives criticism for its guardianship legislation, which is at odds with the supported decision-making model enshrined in the Convention, and also in relation to a lack of safeguards in institutions, and limited financial support for inclusion in the community. Positive areas noted included the statistics and data collection (such as the HRB disability databases), accessibility of new buildings and the right for people with disabilities to marry, have and raise children.

[67] This follows from the EU Disability Action Plan (2003–2010).

[68] A new EU initiative, the Access City Award, sets out to showcase and reward cities with over 50,000 inhabitants that take exemplary initiatives to improve accessibility in the urban environment.

[69] The key characteristics of interest here are the discretion that State actors have to implement the rights outlined, the flexible nature of many of the provisions, and the key role of periodic reporting and monitoring. In addition, the central role accorded to stakeholders, notably disability NGOs, played 'in all aspects of the Convention's drafting, implementation, monitoring and operation' is significant (de Burca, 2010: 3).

generally by Sabel and Zeitlin as 'experimentalist architecture' (Sabel & Zeitlin, 2011).

While the UN Convention on the Rights of Persons with Disabilities includes the need for independent monitoring of services under Article 16, it is not yet clear how it will impact on Member States in relation to quality. One possibility is that EU-level indicators and outcomes might emerge for people with disabilities, in the spirit of the Open Method of Co-ordination used in other areas across the EU.[70] This approach fosters greater self-regulation toward agreed outcomes, leaving the routes and processes to achieving those outcomes to Member States, with the possibility of being delegated in turn to a regulator or to service providers themselves.

Finally, it is worth noting that a comparative study of national disability strategies identified ten critical success factors to make a strategy work, including detailed measurement and monitoring of outcomes. Dr Eilinóir Flynn of the Centre for Disability Law and Policy at NUI Galway identified eight factors related to three central themes – consultation and participation of people with disabilities, implementation and reporting on progress, and independent monitoring and review (Flynn, 2010b). One key element of successful strategies was where a culture of the 'learning organisation' was promoted for those implementing the strategy. There was a focus on the need to measure progress in advancing NDS and measure the impact on the lives of people with disabilities.

## 2.8     International Perspectives on Quality Disability Services

The importance of regulation is supported  by the World Health Organization, which argued recently in the WRD (WHO & Bank, 2011: 151) that to ensure quality services Member States should 'regulate service provision by introducing service standards and by monitoring and enforcing compliance'.  It goes on to state that:

> in countries where NGOs, assisted by foreign aid and local philanthropy, have been the main providers of support services, stable public regulatory frameworks and funding are needed to sustain and build on the services. Regulatory frameworks should cover: quality standards, contracting and funding procedures, an assessment system and allocation of resources.

> In establishing regulatory frameworks, in whatever setting, people with disabilities and their families should be included, and service users

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[70]     In conversation with Prof. Gerard Quinn, NUIG.

should help in evaluating services. Service outcomes can improve when
providers are accountable to consumers.

The WRD recommends key measures that will improve the quality of formal
assistance and support services for people with disability (WHO & Bank, 2011: 159).
These identify the need to:

- Develop sound and fair disability assessment criteria and procedures, focusing
on support needs to maintain and improve functioning;

- Develop clear eligibility criteria for assistance and support services and
transparent decision-making processes;

- Encourage the monitoring of service quality by disabled people's organisations
and other NGOs;

- Set standards for services, enforce them, and monitor compliance;

- Introduce mechanisms to detect and prevent physical and sexual abuse in both
residential and community settings;

- Monitor service provision. Keep updated records of users, providers and
services provided;

- Ensure co-ordination across different government agencies and service
providers, possibly through introducing case management, referral systems, and
electronic record-keeping;

- Establish complaints mechanisms; and

- Ensure that support staff have appropriate training, proper levels of pay, status
and working conditions.

While the last four measures would apply to any quality public service, the first five
are of direct relevance to disability services and this report, and will be considered
throughout.

A broader point to reflect on in this report is that the quality question does not only
focus on the quality of delivery, but also of access and outcomes. There is no single
regulatory tool or mechanism that will be appropriate to all elements of quality
services, so that every stage of a comprehensive quality approach will need its own
battery of instruments.

Of value in a wider context is the international review of disability services
conducted by the NDA[71] in 2010 for the *VFMPR*. In terms of regulation, the NDA
note that registration and standards systems are in place across the jurisdictions

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[71]    The NDA informs government on policy and practice in relation to people with disabilities.

they examined.[72] Key issues emerging include a move from minimum performance standards to the development of outcome measures; and standards and indicators that measure the long-term impact of services. They report that the quality agenda is moving beyond services to the impact on people's lives, in terms of quality-of-life outcomes.

The NDA outlines evidence that establishing a vision is important to informing outcomes, as well as the system design and clear implementation plans to ensure service delivery:

> Creating a vision was an important part of developing new frameworks for disability services with opportunities for contributions by stakeholders, including policy makers, staff and service users and their families. As well as contributing to better service design, participation can increase support for service development (NDA, 2010a: 9).

This points to the value of involving service users and service providers from the outset of any regulatory system, so that they actively participate in the system as key stakeholders.

Also important is engaging users in the development of services, better data collection and monitoring outcomes for people with disabilities. These are an integral part of disability service and programme development internationally. Successful implementation internationally has been underpinned by effective change management, staff training, monitoring outcomes and leadership, as well as government commitment and clarity (NDA, 2010b).

A final and important finding from international evidence is the value of a broader focus on quality, which includes formal regulation but also other elements, including wider stakeholder engagement. This is referred to by some as a quality framework.

The NDA argues that, drawing from international best practice:

> in order to be fully effective, standards and regulations need to be developed and implemented as part of a comprehensive, interoperable, overall quality framework, copper-fastened by robust, ongoing surveillance activities at national level, based on agreed indicators (NDA, 2010a: 92).

Such a framework would:

> set out the various interlocking elements of a comprehensive quality approach, which includes standards and external oversight along with capacity development initiatives, strong legislative underpinning and

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[72] Victoria (Australia), New Zealand, England, Scotland, the Netherlands and Norway.

perhaps most importantly, service user involvement in the design, implementation and monitoring of standards.[73]

A key element of such a framework as outlined in an Australian Disability Services Commission report is to:

- Think about the dimensions of quality over and above those associated with quality assurance;

- Understand the role of quality and its impact at all levels within the funded disability sector; and

- Take a 'helicopter view' about how all the elements come together to form an operating framework (KPMG, 2006: 32).

The value of a quality framework is outlined in the *VFMPR*, discussed further in Chapter 3. For a more detailed account of the international developments in quality and regulatory systems for disability services, please see Appendix A.

### 2.8.1      European Quality Initiatives

Service providers and interest groups have been working towards an EU framework for quality in disability services. The European Association of Service Providers for Persons with a Disability (EASPD), based in Brussels, has been working to focus the EU on the quality of services for people with disabilities. In 2006, they produced a memorandum proposing a European Quality Principles Framework on the quality-of-life principles for quality services that would be effective at the EU level. In their view:

> A valid model of service quality must not be based on static or minimum standards. Quality is a journey, not a fixed abode. Therefore, such a model must be dynamic and developmental. A valid model of service quality must enable organisations to pinpoint what needs to be improved. Furthermore, it must provide organisations with guidance on how to achieve improvement. The model must be able to demonstrate whether such improvement has been achieved or not (EASPD, 2006: 3).

Such a model should contain a statement of values (dignity, equal opportunities, independent living, participation in and contribution to society); quality-of-life domains (including well-being, social inclusion) and subjective, objective and organisational quality indicators.

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[73]   Correspondence with NESC.

Alongside this initiative, the Disability High Level Group, made up of representatives of all the Member States under the Commission presidency, produced a report in 2007, *Quality of the Social Services of General Interest (SSGI)* from the viewpoint of disability (Disability High Level Group, 2007). Following this, the Voluntary European Quality Framework for Social Services was established in 2010 by the Social Protection Committee. This framework includes quality principles, monitoring and evaluation criteria.

## 2.9     Conclusions

This chapter has profiled the users of disability services, the types of services provided, expenditure on the provision of disability services and the current policy and legislative context both nationally and internationally.

The legislative and policy context is important in setting the scene for regulation, quality and standards in the sector. The Disability Act 2005, while not directly concerned with quality and standards, does provide the wider context for mainstreaming, equality of access and the right to services which underpins a quality approach to service delivery. The National Disability Strategy has had an impact on policy and practice in relation to disability services both directly and indirectly in a number of ways: through a cross-sectoral focus on disability issues; an established Office for Disability and Mental Health; some limited funding for representative groups; assessment of need for children under five years; a more coherent focus on housing; and improved accessibility to buildings and services. The development of an implementation plan for the strategy this year is likely to push forward the impact of the strategy on the ground.

Part 2 of the Disability Act 2005, relating to the assessment of need for older children and adults with disabilities, is not yet operational. As outlined in the WRD, such an assessment is a vital first step in accessing quality tailored services as it provides a clear path for both the individual, the State and service providers to follow in how it supports the individual in their daily lives (WHO & Bank, 2011).

The changes in international policy, as outlined by the UN Convention, will be important in positioning people with disabilities centre-stage in directing their own lives, once it is ratified. This represents a progression in attitude that places the service user as the key reference point for quality concerns. This sea-change in the disability sector brings its own challenges for service users, their families and voluntary disability organisations, as will be outlined later.  If the provision of quality services starts with asking what a service user needs and wants, this will bring a choice and responsibility to service users and their families that has not been there before. It may also bring challenges to the capacity of service providers and the State to provide services and supports for people with disabilities in this way.

As yet, the delivery of disability services has not been aligned with government policy. Since most of the services originated from local need and through voluntary

and community organisations, they are not distributed evenly around the country, and vary widely in terms of what they provide and the quality of their services.

This inconsistency is expected to change with the implementation of the *VFMPR* by the Department of Health. However, while high-level policy goals and strategies have been in place since 2004, and standards for disability services developed in 2004 and 2009, there has been considerable delay in progressing these fully. While the *VFMPR* sets out a policy vision towards individualised supports and person-centred care, it does not examine how this transition will occur. It advocates pilot studies to test out the concept, while also recognising that such innovative practice is already underway with many organisations already providing care in this way.

Two important implications for services arise from the information examined so far. Firstly, mainstream services are the main service providers for people with disabilities, and are likely to be increasingly so, with greater support (e.g. advocacy, information) services likely to be needed for effective access. Secondly, it is a small minority of people with disabilities, for the most part, who use specialist services, and may require particular supports to achieve a quality service. The way these services are delivered is likely to change in line with national and international policy developments, so that people with disabilities will have more choice and control in how they access services. With that will come a change in how quality is maintained, regulated and monitored, so that personal outcomes are delivered as part of a more person-centred regulatory system. Later discussions will capture some of the concerns and rewards of these changes and how they might impact on the question of quality.

Another key point is the enormous change-management process that will be needed to bring the Department of Health's and the HSE's policy visions into action. This will be particularly challenging at a time of limited resources. For those service providers already moving in that direction, it is more likely to be a welcome but difficult process. However, more supports will be needed for those providers who may not embrace the new model of service provision and may view the traditional model of service as still appropriate for them.

This chapter has provided a snapshot of the likely future plans for disability service provision, drawing on international best practice and current working proposals. It identifies the key role of standards, regulation and inspection in other international jurisdictions, which work alongside a focus on outcomes, continuous improvement and service user involvement. The NDA's research on international comparisons provides valuable evidence for best practice in quality and regulation in this sector. Alongside this work, there are other examples of quality initiatives in Europe, such as the potential for development of an EU framework for quality in disability services, and which could be influential here. The work of the Expert Reference Group on Disability Policy articulates this best practice in an Irish context and outlines what a more person-centred policy focus would entail. However, these remain high-level goals and aspirations without further implementation plans and delivery mechanisms in place, but they have moved a step closer to realisation with the publication of the *VFMPR*.

The proposed move from institutionalisation to person-centred services is not new but signalled already in the Disability Act 2005, for example, in relation to the independent assessment of need. However, this assessment has yet to be implemented for older children and adults. There are acknowledged ongoing challenges in bringing a person-centred focus to the delivery of services (DFI, 2006). These are noted as including capacity-building in mainstream services, staff training, tackling a resistance to change and the need for a collaborative approach across services (NDA, 2006a). In addition, the proposed movement towards individualised budgets adds a further complexity. There is extensive cultural and organisational change needed to bring services as a whole to be more closely aligned to policy directions. There is, in addition, a transitional cost element in relation to the closure of congregated settings.

Ireland has not yet developed research into the effectiveness of person-centred services. Nevertheless, there is some work underway by Genio, a non-profit organisation, on comparative costs and potential benefits of this model, drawing on pilot projects.[74]

What are less well understood, at this relatively early stage in their development, are the regulatory and quality implications of this individualised approach. Improved quality and regulation are a key part of the proposals for more effective services, notably in the registration and inspection of residential services. However, less is known about any plans for regulating more person-centred models of service provision and individualised supports. These will need to be examined carefully to achieve a balance between formal regulation, external oversight and self-regulation, if this aspect of governance and regulation is to stay in line with international best practice described as flexible and responsive regulation and quality assurance systems (NDA, 2010a).  The NDA argues that new policy initiatives will require robust systems to support the delivery of quality services and to measure its implementation (NDA, 2010b).

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[74] Genio seeks to scale up innovative projects and works with the public, private and non-profit sector to stimulate and support social innovation http://www.genio.ie/research.

# Chapter 3
# Quality, Standards and Regulation in Disability Services

## 3.1    Introduction

The previous chapter outlined the policy and legislative context for disability services, showing that it is a large, diverse sector, with voluntary disability organisations playing a key role. This chapter focuses directly on the regulation of the disability sector to examine the following questions:  What are the main drivers of quality in the disability sector? What standards have been developed and are in use? How is quality assessed in the sector and what systems and approaches are being used?

To help answer these questions it is useful to take a broad look at the drivers of quality in the sector, from the more formal development of standards to the influence of international policy and legislation. It is important to bear in mind, from the outset, that national governance and accountability (and regulatory) structures for disability services are in a state of transition (Department of Health, 2012a).

## 3.2    What are the Main Drivers of Quality?

Some of the key instruments that have driven quality in the sector, albeit to varying degrees, include the following:

- Standards, Guidelines and Codes of Practice;

- Governance and Service Level Agreements (SLAs);

- Quality Assurance Systems  and Innovative Practice;

- Research and Monitoring; and

- Policy Developments and Service User Involvement.

The current lack of mandatory standards means that there are a range of drivers operating that impact on quality and not just a single formal regulatory system. These will each be examined in turn. The views of stakeholders on many of these will be examined in Chapter 4.

## 3.3      Standards, Guidelines and Codes of Practice

In Chapter 2 we noted that HIQA had responsibility for setting standards for health and social care services, and ensuring that the standards are being met. Standards for residential services, *Quality Standards: Residential Services for People with Disabilities,* were developed in 2009. These are not yet mandatory and HIQA does not inspect any disability services against these standards.

The lack of mandatory standards in the disability sector was noted as a theme in the Department of Health's consultation document produced as part of the *VFMPR*. The *Final Report on Consultation: Value for Money and Policy Review* noted that 'respondents commented on the need to introduce standards and measure performance against those standards. Many highlighted the need to have quality assurance systems, and to evaluate the outcomes for service users' (Department of Health and Children, 2010: 24).

A Voluntary Service Provider cited in that report said:

> The range or variety of services are not user driven but service provider driven.   A lack of enforcement of standards (including HIQA standards on residential services for people with disabilities) and inspection of services means that the quality of services has fallen.  We believe that a standard for community services for people with disabilities is urgently required and should be put on a statutory basis. The lack of user directing and leading of services has a negative impact on quality of life outcomes   (Department of Health and Children, 2010: 49).

The absence of mandatory standards has been also been raised repeatedly by umbrella organisations, such as Inclusion Ireland and the National Disability Authority (NDA) as posing a potential risk for people with intellectual disabilities. As the NDA noted in relation to the 4,000 people living in congregated settings, the absence of standards makes this group in particular very vulnerable (NDA, 2010b: 44).

### 3.3.1      Development of Standards in the Disability Sector

The development of standards in the disability sector grew out of a debate on the importance of social, economic and cultural rights for people with disabilities that began in the mid-1990s (O'Donnell, 2003; Conroy, 2010). While beyond the scope of this report, it is worth noting that a number of different pushes for quality in human services have developed in the last decade, with a drive for quality improvements in public services, public sector reform and equal rights having their own influences and narrative. Pillinger outlines some of these developments in relation to disability, in her 2002 working paper, *Disability and the Quality of Services*, where she

identifies a growing approach 'to establish certain minimum standards in services and minimum entitlements to them, as well as rights to active citizenship' (Pillinger, 2002: 5).

As part of their statutory remit, the NDA began the process of developing standards for all disability services in 2002, establishing a Standards Advisory Committee, followed by a national consultation process, resulting in more than 500 submissions. Draft general standards were issued in 2003, after more consultation. Further work continued on the assessment of these standards through the use of an audit tool tested in a pilot study of twenty providers, working with an independent assessment body and this was then evaluated. A final round of consultation took place in 2004 including a review by international experts, resulting in the *Draft National Standards for Disability Services* (NSDS) (NDA & Department of Health and Children, 2004) and an audit tool. Despite the extensive consultation and the pilot process, the standards have not been widely used and more recent HIQA standards are more commonly used.

Once established, HIQA began a wide consultation process on developing standards for residential services for people with disabilities in 2008 and set up a Standards Advisory Group, including the NDA and service users. In this regard, the development of standards for residential disability services has been very consultative. However, the resulting standards, *Quality Standards: Residential Services for People with Disabilities in 2009* have yet to be established on a statutory basis.

In this way, both the NDA and HIQA have produced sets of standards, developed over many months with widespread consultation. This engagement in itself, despite the lack of statutory footing to the resulting standards, has provided some direction to the disability sector in terms of quality.

Recent research as part of the Department of Health's *VFMPR* suggests that there are increasing numbers of service providers using the HIQA standards for residential services on a voluntary basis. According to the umbrella organisations Disability Federation of Ireland (DFI) and the National Federation of Voluntary Bodies (NFVB), many of their members are either using the standards, adopting their own quality system or applying an external system such as POMs/CQL or PQASSO.[75]

This voluntary use is likely to change soon. Following a government commitment to 'put the National Standards for Residential Services for People with Disabilities on a statutory footing and ensure that services are inspected by the Health Information and Quality Authority' (Government of Ireland, 2011), Minister Lynch announced there would be full regulation of residential services by 2013. HIQA is currently reviewing them to develop a single set of standards for children and adults residing in residential centres for people with disabilities, and regulations and inspections will follow in 2013. According to the *VFMPR*, 'given the complex nature of

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[75]   These are discussed more fully later in this chapter.

residential provision for people with disabilities, careful consideration is being given to designing the most appropriate regulatory model'(: 130).

### 3.3.2     Current Standards

Only one set of standards[76] has been officially adopted on a statutory basis for people with disabilities to date. These are the Standards for the assessment of need process Under Part 2 of the Disability Act 2005 for children under five. The other statutory instrument under the Disability Act is the Code of Practice on Accessibility of Public Services and Information Provided by Public Bodies (NDA, 2006).

There are other standards, guidelines and codes of practice that are of relevance and used on a voluntary basis by disability organisations. Appendix D has a further list, which includes guidelines for transport, person-centred planning and early intervention for children's services, which have been developed in recent years to improve access, design or delivery of services for people with disabilities. Some of these guidelines have been introduced out of commitments from sectoral plans from the National Disability Strategy.   Table 3.1 sets out the main standards for the disability sector.

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[76]   Broadly, standards can vary in terms of their official status, from mandatory to voluntary, and their scope, from minimum standards to performance standards. Guidelines, frameworks and guidance are also used to improve quality and their titles are not always helpful in establishing their role and function. When standards become mandatory, they include (legally binding) regulations as well as suggested standards and criteria.

**Table 3.1        Current Standards and Codes of Practice**

| Standards and Guidelines | Key Function | Status |
|---|---|---|
| Assessment of Need for Children under 5 (HIQA & DOHC, 2007) | An assessment of health and educational needs for children with a disability under the age of 5. | Mandatory under the Disability Act 2005, but not currently monitored by HIQA or the HSE. |
| Quality Standards: Residential Services for People with Disabilities (HIQA, 2009b) | Residential services for adults with disabilities (see below). Draft National Standards for Residential Centres for People with Disabilities, is being considered by stakeholders. | Not yet mandatory. Used by some service providers on a voluntary basis. Expected to be put on a statutory footing soon. |
| Code of Practice on Accessibility of Public Services and Information provided by Public Bodies [77] (NDA, 2006b) | Public bodies to make their services and information accessible[78] to people with disabilities (Part 3 of the Disability Act). | Mandatory, monitored by the NDA. There are a range of measures to ensure that customer services and information provided by public bodies are responsive to service users with disabilities. |
| National Standards for Safer Better Healthcare (HIQA, 2012b) | These have been developed to describe quality and safety requirements for healthcare service providers (except mental health services). They will promote a consistent level in the safety and quality of healthcare across services. | Not yet mandatory. Used by some service providers on a voluntary basis. They will form the basis for future licensing of all healthcare facilities in Ireland. |

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[77]   Built environment standards are accredited by organisations such as the International Organisation for Standardisation (ISO). The Accessibility for All Standards Consultative Committee, which is run by the National Standards Authority of Ireland, has had an input into EU and national standards concerning the built environment, wheelchairs, information technology and other areas. While not central to this report, it is worth noting that the Building Regulations 1997–2000, Part M, focuses on accessibility regulations for people with disabilities for all new public buildings and major extensions to old ones.  This was broadened to extend to private housing with the Building Regulations (2000). These regulations set a minimum standard.

[78]'  Accessibility' is defined in the European Disability Strategy (2010) as  people with disabilities having access, on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT), and other facilities and services. There are still barriers to access in these areas. For example, on average in the EU, only 5 per cent of public websites comply fully with web accessibility standards, though more are partially accessible. Many television broadcasters still provide few subtitled and audio-described programmes (European Commission, 2010)·

| | | |
|---|---|---|
| **Draft National Quality Standards for Residential and Foster Care Services for Children and Young People (HIQA, 2010b)** | **Residential services for children and young people in residential services and foster care. There are 21 standards across seven areas, including: quality of life; rights and governance.** | **Not yet mandatory. Used by some service providers on a voluntary basis. These standards are currently being reviewed by HIQA.** |
| **National Standards for the Protection and Welfare of Children (HIQA, 2012a)** | **Standards to support continuous improvements in the care and protection of children in receipt of HSE child protection and welfare services. Although these are mainstream services, they do receive referrals of children with disabilities.** | **Mandatory. HIQA will monitor the current HSE Children and Family Services, the future Child and Family Agency's, compliance with the Standards and will assess how the HSE undertakes its statutory function under the law and its implementation of Children First – the national guidance for the protection and welfare of children.** |
| **Standards for Residential Services for Older People (HIQA, 2009a)** | **Sets out the appropriate standard of care in residential care settings.** | **Mandatory. Regulates and inspects nursing homes. Some of the residents are younger and have disabilities.** |

The first three of these will be examined in greater detail in the sections below.

### *Assessment of Need for Children under 5 (HIQA & DOHC, 2007)*

As outlined in Chapter 2, the EPSEN Act 2004 and the Disability Act 2005 set out a new approach to assessing the needs of eligible persons with disabilities and/or special educational needs for health and/or educational services. These standards were developed by a special sub-group of the Departments of Health and Children and Education and Science in 2007 and included consultation with service providers and service users. The standards for the assessment include Garda clearance for the person making the assessment, the provision of clear and accessible information to applicants and the handling of confidential information. They are organised around six key areas:

i.     Person-centred approach;

ii.    Information;

iii.   Access to the assessment of need;

iv.     Involving appropriate education and health staff;

v.      Co-ordination of the assessment of need; and

vi.     Monitoring and review.

Currently, they are administered by the HSE with support from the National Council for Special Education (NCSE) in relation to children under five years. HIQA later approved the standards. However, there is no public monitoring of these standards by HIQA but the HSE is required to keep records of them. The assessment of need is carried out or arranged by assessment officers who are independent officers of the HSE. They are required to be aware of the standards and undertake to adhere to them (Department of Health, 2012a: 17). After the assessment, a service statement is drawn up by a liaison officer. There is independent complaints and appeals machinery for people who are dissatisfied with the assessment, the service statement or with the subsequent provision of services.

Problems have been reported in the overall assessment of need process in terms of the delay in getting an assessment and access to services. In accordance with the Disability Act 2005, the HSE is required to prepare an annual report for the Minister on the data collected from the assessment process. The 2010 report highlighted the challenge presented by the definition of needs in terms of desired outcomes for children but the report required under the Act is on inputs. This creates a difference in focus on the monitoring of this process (HSE, 2011b). In addition, the NDA conducted an examination of the assessment of need process and the experience of both personnel doing the assessments and the parents of service users. Some of their findings include:

- Many assessors remain unclear as to what is required of them under Part 2 the Disability Act 2005;

- The assessment of need is being used as means to expedite special education assessments in the absence of the commencement of the EPSEN Act 2004;

- There is a great deal of variation in how long assessors take to conduct statutory assessments of need; and

- While parents are mostly positive about their experience of the statutory assessment of need process, their satisfaction is related to whether their child received services or enhanced services after the statutory assessment of need process was completed (NDA, 2011c).

The NDA did not focus on compliance with the HIQA standards for assessment of need standards as an audit of compliance was underway at the time. However, their interviews indicated that it was not playing as strong a role as it should do.

The NDA concludes:

Interviewees for this project were asked about the role the Standards played in shaping their approach to statutory assessments of need. Many interviewees indicated that they were not aware of the content of the Standards, while others indicated that the Standards were too general to have much practical application on how statutory assessments of need were conducted (NDA, 2011c: 66).

### *National Quality Standards: Residential Services for People with Disabilities*

Some residential services have been using the 2009 *National Quality Standards: Residential Services for People with Disabilities* on a voluntary basis. In addition, the HSE has been piloting the voluntary use of these standards by way of self-assessment for organisations.

The *National Quality Standards: Residential Services for People with Disabilities* developed in 2009 are underpinned by the following principles: quality of life; safety; rights; anti-discrimination; person-centredness; community integration and responsive services (HIQA, 2009b). There are seven dimensions to a quality service as outlined in the standards. Each dimension has a number of standards, amounting to nineteen standards in total.  Each standard in turn comprises a number of criteria. Box 3.1 shows one of the standards under the Section Governance and Management, by way of example, and one of the criteria that underpins it. This particular standard is presented here because of its focus on continuous improvement. This supports the argument, made in Chapter 1 and in the report *Quality and Standards in Residential Care for Older People*, that standards can foster continuous improvement.

**Box 3.1    Quality Standards: Residential Services Example**

**Standard 17**

**The residential service is governed and managed in a manner that supports the creation and continuous improvement of a person-centres service that meets the needs of each individual and achieve outcomes for him/her consistent with his/her plans and aspirations**

$\Updownarrow$

**17.15 Service planning is directed towards delivering on the individuals personal plans and preferred options in life.**

**Source**    HIQA 2009

The standard statements set out what is expected in terms of the service provided to the person living in the residential service. The criteria can best be described as supporting statements that set out how a service may be judged as to whether the

standard is being met, or not. These criteria are meant to be indicative, not prescriptive.

- ***Draft National Standards for Residential Centres for People with Disabilities***

The new (October 2012) draft national Standards for care centres providing residential services to adults and children with disabilities are currently being reviewed by stakeholders, as part of a consultation process. The standards are outlined in two separate sections for adults and children but under the same themes of: person-centred services; effective services; safe services; health and development; leadership, governance and management; use of resources; workforce; and use of information.

### Code of Practice on Accessibility of Public Services and Information

The other statutory instrument that acts as quality driver is the *Code of Practice on Accessibility of Public Services and Information*. As outlined above, the NDA has a function to monitor compliance with the code of practice on accessibility of public services and Information among public bodies (National Disability Authority Act, 1999).  The code brings into practice obligations under Part 3 of the Disability Act 2005, which places significant responsibilities on public bodies to make their services accessible to people with disabilities, including the following:

- Under Section 26, public bodies are required to ensure that their services are accessible for people with disabilities by providing integrated access to mainstream services where practicable and appropriate; and

- Under Section 27, public bodies are required to ensure that the goods or services they provide are accessible, unless it would not be practicable or justifiable on cost grounds or would result in an unreasonable delay (NDA, 2006b).

According to the NDA, this statutory code is complemented by a monitoring process that they developed in national consultation with public bodies and government departments. The 2008 monitoring report found examples of best practice in relation to some particular organisations and actions but also found  areas of under-achievement, including that less than half of survey respondents reported having policies and procedures in place to ensure that goods and services supplied by them are accessible to people with disabilities (NDA, 2008).

There is, to conclude this section, an absence of mandatory standards for disability services, but also some good examples of standards, guidelines and codes of practice that are used to varying degrees voluntarily by service providers. With increasing focus on person-centred services, personal social supports and independent living, there is a notable absence of any standards for home care or personal social supports. While not mandatory, there has been considerable focus on the development of home care standards for older people, as discussed in another report from this project, *Home Care for Older People.*

A submission by the Centre for Disability Law and Policy in NUI Galway made to the *VFMPR* argues that standards are needed in services provided at home, but that great care is needed in how they are delivered:

> It is important that standards to be applied in people's own homes be respectful of people's rights, dignity and privacy and that monitoring or inspection be undertaken in a manner which fully recognizes the private nature of people's homes. Standards must be applied, both to systems and policies of in-home support providers, and to the outcomes achieved by users of their services (Centre for Disability Law and Policy, 2011: 16).

However, while this gives a clear indication of 'what' is needed, it does not outline 'how' it would work. Work of the Law Reform Commission (2012) *Legal Aspects of Professional Homecare* provides a detailed account of what legislation is required before such standards can be developed for home care services, which would include provision for people with disabilities. It recommends that:

> HIQA should be empowered to regulate and monitor undertakings that provide professional home care (whether public sector or private sector, and whether for-profit or not-for-profit); and while the main beneficiaries of the proposed new HIQA regulation would be likely to be those over 65, the proposed system should apply to professional home care provided to any adult over the age of 18 in their own home (Law Reform Commission, 2012: 4).

Finally, in relation to day services, the HSE is developing standards as part of *New Directions*. These will focus on the key elements needed to implement the new model. Organisations will be required to use the standards to develop action plans as part of the SLA process, and new initiatives will be measured against the standards.[79]

## 3.4      Service Level Agreements and Governance

An important potential driver of quality is the service contract between the State and the service provider. Of interest here is the potential role that the HSE has in relation to driving quality through its direct provision of services and through its contractual arrangement with voluntary bodies. The strength of the role of voluntary  providers has been recognised in recent years by the use of formal contracts, called Service Level Agreements (SLAs) with the HSE, rather than the more informal arrangements that characterised early provision (Quin & Redmond, 2003). The disability sector is moving towards a more commercial, contract-based

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[79]  Information supplied by the HSE to the Secretariat.

relationship with the HSE, through the introduction of competitive tendering (DFI, 2011c). The most recent SLAs include reference to quality assurance information and to the requirements of regulatory bodies such as HIQA. The *VFMPR* outlines that service providers are 'required to have systems in place to assess quality and standards, and to specify the actions being taken to maintain and monitor quality and service standards' (Department of Health, 2012a: 35). There is variation in the degree of monitoring of SLAs, depending on the size of the service provider, and the relationship with the Local Health Office.

Quality issues have not in the past played a strong role in SLAs between the HSE and service providers. The following quote is from a family member/carer taken from the *Final Report on Consultation* as part of the *VFMPR*. It expresses well the concerning quality issues to date for service providers in the disability sector.

> There is very little examination of the quality and range of services before and after funding is given. The Comptroller and Auditor General's report in 2005 would support that. It is necessary for funding sources to have a philosophy as to what the 'best outcomes' means if that is to be achieved. Monitoring of all services is also a requirement (Department of Health and Children, 2010: 24).

In terms of governance and accountability, as outlined in the Comptroller and Auditor General's (2005) report, the HSE is responsible for

> ensuring a consistent national approach to the delivery of health services (including disability services) and with ensuring that best practices within the existing health service delivery structures are replicated across the country (Comptroller and Auditor General, 2005: 14).

The Comptroller and Auditor General were critical of the lack of co-ordinated data for the monitoring of non-profit disability services funded by the HSE. They found that the SLAs lacked a statement of outcomes so that it was difficult to evaluate to what extent they were providing the service as required. The report recommended (without outlining what these would contain) that:

> Performance management systems should be developed to facilitate evaluation of the achievement of strategic aims and objectives of the services.  (Comptroller and Auditor General, 2005: 35).

The report concluded that

> there is a need for greater accountability, transparency and governance within this sector as well as further clarity around the relationship between the State and those organisations it funds (Comptroller and Auditor General, 2005: 41).

According to the HSE, a comprehensive framework was recently developed for the purpose of planning, managing and overseeing the governance of health and personal social services funded by the HSE. This included a review of current

documentation, including SLAs, to include a focus on quality and standards and performance monitoring, such as more quality assurance information and checks, such as referring to meeting standards that HIQA might require as a regulatory body.

For example, Schedule 2 of the current Service Arrangement (under Section 39 of the Health Act 2004) for community agencies states:

> The Provider shall have in place appropriate mechanisms to assess quality and standards of the delivery of Services in line with best practice, as agreed with the Executive. The Provider will conduct Service User experience surveys or use qualitative methods of obtaining Service User input and have systems in place to provide routine monitoring and evaluation of Services.

> The Provider shall comply with legislation relating to quality and standards and such other appropriate requirements as may be stipulated by recognised standard setting bodies, HIQA, the Minister and/or the Executive (HSE, 2012d: 24).

It seems unlikely, particularly in the current economic climate, that the HSE will have the resources to check or monitor the implementation of these requirements to any great extent. Further work is ongoing in the HSE to put in place a quality assurance framework as part of the implementation of *New Directions*, the review of day services, outlined in Chapter 2.

With the current developments in SLAs, many of the problems previously identified should be reduced. According to the NDA:

> the Service-level Agreements now being implemented across the disability services should address many of the issues around the accountability and transparency of non-profit disability services raised by the Comptroller and Auditor General in his 2006 report  (NDA, 2010b: 51).

The *VFMPR* recommends that:

> Agencies that receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding and the necessary systems and protocols should be put in place by the HSE to ensure full accountability and transparency on a standardised basis (Department of Health, 2012a: 42).

Many voluntary providers are also putting in place codes of governance to improve their accountability and processes on a voluntary basis. The Wheel, an umbrella organisation, has developed a voluntary code of corporate governance called the Governance Code (developed by a working group that includes the Disability Federation of Ireland). With the Charities Act 2009 coming into force in the next few years, charitable organisations are working towards self-governance before it becomes formally regulated.

Other developments in relation to governance include increased consultation planned by the HSE for service user engagement, and tailored disability advocacy services. National Consultative Fora have been established by the HSE to enable people with disabilities to actively and effectively participate in the development of policy, practice and organisational strategies (DFI, 2011c).

### Cost-Effectiveness and Quality

It is hard to quantify the value of an effective regulatory system. Undoubtedly, the introduction of formal regulation and HIQA's role as inspector of residential services will require additional initial expenditure by the State and by service providers, but it will also introduce valuable public scrutiny and safeguarding of service provision that is long awaited by many in the disability sector, in particular, service users and their families.

The Comptroller and Auditor General have noted this:

> the achievement of standards and organisational competencies may have resources and other implications for non-profit organisations involved in the delivery of services to people with disabilities, and for the relationships between such bodies and the State in relation to these services (Comptroller and Auditor General, 2005: 38).

With little information available on quality and costs for disability services, it is of interest that in relation to residential services for older people, research from the United States shows that the costs of providing high quality care can be reduced through use of best practice management and care processes. Sharing best practice on these processes could therefore help to reduce the costs of quality improvement (NESC, 2012c: x). The report, *Residential Care for Older People,* found that while implementation of the HIQA standards had taken time and resources, stakeholders welcomed the increased confidence that the standards provided and that the cost of implementing these standards yields business benefits as well as wider economic and social benefits for older people and their families (NESC, 2012c: xv).

With the future timing and nature of regulation of home care as yet unclear for the disability sector, the report *Home Care for Older People* identifies some cost-saving strategies and outlines some of the cost issues around regulating home care for private, voluntary and public providers. Contracting out home care services in the UK has led to increased regulation and this may follow here (NESC, 2012b). The recommendations of the Law Reform Commission (2011) provide a blueprint on how to regulate in this area.

The elements outlined in the reports from this project, and their emphasis on a learning, reflective system, will not necessarily require new resources, but rather a change of focus and work practices at a service provider level as well as at national planning and delivery level. If implemented and regularly reviewed, these measures are likely to reduce duplication, waste and poor practice.

### 3.4.1    Redress

There is a complaints procedure outlined under the  Disability Act 2005 in relation to the assessment of need for people with disabilities (Part 2 of the Act) and with regard to access to buildings, services and information (Part 3 of the Act). Complaints can be made on any of these areas to Inquiry Officers in government departments. If this is not satisfactory, the Office of the Ombudsman has statutory responsibility under the Disability Act as well as under the Ombudsman Act (Health Complaints).[80]

The independent complaints and appeals procedure in place for the assessment of need process is accessed via the Disability Complaints Officer in the HSE in the first instance, and appeals can be made to the Disability Appeals Officer.

Another route for making a complaint concerning the operations of the HSE and non-statutory service providers comes under Part 9 of the Health Act 2004. There is a twelve-month time limit for making a complaint, running from the time of the cause of complaint.  Complaints may only relate to actions concerning fair and sound administration and the person concerned must have been adversely affected by the action giving rise to the complaint (Department of Health, 2012a: A62). Data is gathered on these complaints but not for other HSE complaints.

## 3.5    Quality assurance Systems and Innovative Practice

A major driver of quality services is a focus on quality assurance, either through the application of external systems or through the development of systems in-house.[81] Such quality assurance systems are used by some service providers, particularly by voluntary disability organisations.

Some of the main systems in use in the disability sector include Practical Quality assurance System for Small Organisations (PQASSO), European Framework for Quality Management (EFQM) and Personal Outcome Measures from the Council on Quality and Leadership (POMs/CQL), presented in Table 3.2.[82]

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[80]   http://www.healthcomplaints.ie/disability-services/complaints-under-the-disability-act/.

[81]   It should also be noted that although outside the remit of this project, there has been considerable standardisation work in relation to assistive products and universal design. For example, ISO 9999:2011 establishes a classification of assistive products specially produced, or generally available, for persons with disability. ISO 9000 is a series of quality management systems. The Centre for Excellence in Universal Design outlines the current legislative and policy context for universal design in Ireland.

[82]   The use of private quality assurance systems in HSE services is not widespread. The HSE has developed standards and guidance for service delivery to support implementation of the National Standards for Safer Better Healthcare and other relevant quality and safety programmes.

**Table 3.2        Examples of Quality Assurance Systems**

| Quality Assurance Systems and Awards | |
|---|---|
| PQASSO (Practical Quality Assurance System for Small Organisations) | A quality assurance system that offers a practical step-by-step approach to self-assessment by organisations against twelve quality standards. They award a PQASSO Quality Mark. |
| Personal Outcome Measures (POMs) from the Council on Quality and Leadership (CQL) | Personal Outcomes Measures is a person-centred quality system that was developed in the United States by the Council on Quality and Leadership (CQL). It emphasises responsiveness to individual needs, rather than compliance with standards.     An outcomes focus encourages the service to identify the individual outcomes for each person served. Accreditation every 3 years. |
| Q Mark for Quality Management Systems | Quality Management Systems Standard and annual assessment applied to wide range of business and non-profit organisations administered in Ireland by Excellence Ireland Quality Association (EIQA). |
| Quality Assurance in Social Services Standard (EQUASS) | An initiative of the European Platform for Rehabilitation (EPR), EQUASS is a certification system for quality assurance and quality control specifically in social services. It sets out a framework for social services that are person-centred with an approach that focuses on quality, excellence and best practice. |
| IS0 9000 | International Organisation for Standardisation (ISO) is a network of the national standards institutes of 162 countries. The IS0 9000 is a series of standards for quality management systems. |
| Commission on Accreditation of Rehabilitation Facilities (CARF) | Founded in 1966, CARF International is an independent, non-profit accreditor of health and human services including visual rehabilitation and behavioural health. |
| ABLE Business Excellence Awards | A national award for accessibility levels in organisations. |
| The European Framework for Quality Management (EFQM) | EFQM is a non-profit quality membership foundation that sets out a framework to support continuous learning, review and a strong emphasis on setting measurable results.     Assessors give certification, administered here by EIQA. Uses RADAR (Results, Approach, Deployment, Assessment, Review) scoring methodology. |

These quality assurance systems are supplied and monitored by private and non-profit organisations that promote and assess quality and standards in services and businesses. Some offer consultation, accreditation, training and certification services to human organisations and systems and assess quality and standards in services and businesses. The Disability Federation of Ireland provides support to voluntary organisations to reflect on quality and governance issues and to put in place quality assurance programmes, notably the PQASSO. In tandem, the National Federation for Voluntary Bodies has supported its members (voluntary organisations providing services for people with intellectual disabilities) in the use of POMs. Rehab's training services, delivered by the National Learning Network, were awarded the EQUASS Excellence Award in 2011 and were the first Irish organisation to be so awarded. Another example of a system being used successfully is that of Enable Ireland, who have used the EFQM model since 2001 for continuous improvement, and apply the RADAR approach to reflect on services (used as a form of diagnostic monitoring).

One of the CQL's approaches, POMs, is detailed in Box 3.2.

We can gain some idea of the prevalence of these quality assurance systems from provisional data gathered as part of the *VFMPR* (Expert Reference Group on Disability Policy, 2011).  Research examined the outcomes and effectiveness of residential disability services. As part of this, a questionnaire survey was conducted, including a question on quality measures. Table 4.1 presents the provisional results from a survey of physical, sensory and intellectual disability services (at a service centre/unit level so not service providers *per se*) conducted as part of the *VFMPR* by the Department of Health.

**Box 3.2          Case Study: Personal Outcome Measures**

The CQL started in the United States in the 1960s as an effort to stop abuse in large institutions. CQL was first introduced to Ireland in 1997 by Western Care and others.

CQL helped to develop national standards for services for people with intellectual disabilities. In the 1990s they moved emphasis from compliance to performance and person-centred approaches and introduced the POMs. POMs is a person-centred quality system that was developed and validated on outcomes that people with disabilities want from their support or services. The 21 POMs are organised in three factors:

My Self: Who I am as a result of my unique heredity, life experiences and decisions.
My World: Where I work, live, socialise, belong or connect.
My Dreams: How I want my life (self and world) to be.

They are examined in terms of their presence in the person's life at the time, supports in place to help the person achieve them and the person's priority outcomes.  Scores for each outcome are given by a service user in collaboration with a service provider and the scores are calculated on the outcomes present or achieved, the supports present (to  meet that outcome) and the extent to which the outcome is a priority. Appendix E presents a graphic example of this data aggregated for one service centre.

More recent work emphasises social capital and community life, placing a person-centred approach within the context of community. CQL argues that quality has to be placed in the context of community inclusion. Organisations have a role to connect people with resources and social networks in their communities, beyond their services.

The Council has produced a guide to person-centred excellence for disability services, What Really Matters (CQL, 2010). This guide outlines 8 factors and 34 success indicators for services that should be evaluated. These factors include person-centred planning, supports and services, community connection, governance, and quality and accountability. Examples of the success indicators include that there should be measurement of the quality of supports and that participants, families and advocates should be part of any evaluation of supports and providers. According to CQL, organisations have an obligation to organise and deliver supports that facilitate outcomes.

It further outlines that 'quality must be examined from each person's point of view', so that people provide their own definition of quality. The concern for quality is found in the design of responsive systems that can identify barriers to quality for the individual, alleviate those barriers and activate efforts to improve quality. In addition, data collection and analysis contribute to further understanding of what is happening, 'to monitor movement towards outcomes that the person values and to identify areas in need of further attention'  (p. 26). Given the difficulty of comparing individual definitions of quality, it is worth noting that it is the movement towards outcomes that is quantified and monitored.

The POMs involve a change in the focus of how services are delivered from a fixed, programme-focused, group-oriented approach to a focus of: one-person-at-a-time; holistic view of the person; and flexible, responsive supports. It encourages organisations to be more person-centred and flexible in their delivery, as well as sharing the learning and spreading good practice.

CQL keeps a database of over 7,000 POMs interviews. An analysis of 3,630 interviews from 552 organisations, between 1997 and 2002 showed an increase in outcome scores, especially those associated with choice and rights (Gardner & Carran, 2005).

**Source**     http://www.thecouncil.org/

**Table 3.3      Quality Assurance Systems used by Physical, Sensory and Intellectual Disability Services (N=180)**

| Quality Assurance Systems | |
|---|---|
| HIQA standards | 79 |
| POMs/CQL | 49 |
| EFQM | 13 |
| Nothing | 4 |

**Source**    Department of Health (2011).  Data provisional and incomplete

Data from the HSE National Working Group on Day Services (2012a), *New Directions*, reported that 61 per cent of organisations (providing day services) are using a quality system and have been accredited or are in the process of achieving accreditation from awarding bodies.  But they note that many providers have no quality systems (HSE, 2012a: 134).

Separate from this survey, according to DFI, currently 25 organisations have or are going through the PQASSO system, but not all apply to be accredited, so use the system informally.  Some use the approach as a way of redirecting emphasis towards an individual and their quality of life.

Do quality assurance systems increase the quality of services? There is no systematic review of the impact of quality practices and self-assessments in relation to quality of services in Ireland. While anecdotally, organisations are more in tune with quality issues as a result of the process of external accreditation and putting in place quality assurance systems, there is scarce documentation on how this process, and subsequent accreditation, impacts on the quality of service being delivered in Ireland.

A review of quality assurance systems used in Ireland, as part of the *VFMPR* concluded that:

> There is little evidence in the literature in relation to their effectiveness, but each system contains elements of both quality assurance and quality improvement and all systems would be useful for disability services who wish to assess quality and identify both strengths and areas for improvement (Mongan, 2011: 20).

Western Care Association, (WCA) provides supports and services to people with intellectual disabilities in Co. Mayo. It outlines how, with POMs, people with disabilities become the focus of the quality enhancement process. Services and supports are then developed to address the person's unique, individual outcomes. It has also been a leader in the provision of individualised supports and services. In the last three years, WCA has supported seventeen people to move from group homes into more independent living settings.

**Box 3.3          Case Study: Western Care Association**

**Western Care Association is a registered charity and voluntary agency founded in 1966 that provides supports and services to over 750 people with intellectual disabilities in Co. Mayo and is funded by the HSE. Part of its mission is to support service users in making choices. Its services include supporting service users to live in the community, in group homes as well as offering respite and day services. For children, it offers shared care and respite services, family supports and school age services as well as autism supports. It is accredited by the CQL using POMs and was the first organisation to use that approach in Ireland. It has been developing its approach to quality over the last thirty years, starting with a framework for self-assessment in the 1980s by adapting UK models of good practice. Trying other initiatives, it attended a conference in 1996 organised by the Brothers of Charity, and a network emerged. In 1997 it held its own conference and brought CQL over to Ireland.  For Western Care, CQL's focus on outcomes that are personally defined was the main draw. As Tom Hughes, Head of Evaluation and Training, commented, 'Once you go there it is hard to come back. It is a powerful experience.'**

**With other organisations, including St Michael's House and the Brothers of Charity, it set up the Outcomes Network in Ireland in 1999. This group continues to meet to share the learning and experiences of the CQL approach.**

**Western Care has not developed any group homes in 6 years and its service users are living according to their own housing needs.**

**Source**    http://www.westerncare.com/

There are other examples of good practice in disability services that have a strong focus on quality or quality systems in place. Genio, with funding from Atlantic Philanthropies, the Department of Health and Children and the HSE (Genio, 2009) has begun to identify good practice in disability services and build capacity through funding and sharing the learning. Genio is funding fifty disability projects, including those providing person-centred services and support services for independent living. Good practice will be used by the HSE to help implement the report from the Working Group on Congregated Settings.

This innovative practice is linked into a research project, run by the University of Ulster, to examine quality-of-life measures, to evaluate this work and identify the costs of personalised services. Genio provides documentation of services that are 'person-centered, encouraging self-determination and operating in a sustainable,

cost-effective way' (Genio, 2009: 7). (For examples, see Western Care Association or the West Limerick Centre for Independent Living (CIL), detailed below.) Genio concludes that services which provide opportunities for inclusion and participation, as well as encouraging self-determination, 'not only achieve good outcomes for the individual, but do this cost-effectively' (Genio, 2009: 6).

Some of the services listed as good practice include those that provide individualised supports and services. According to Genio, these new support arrangements have been provided at a lower cost per person than the per capita rate used for the National Funding formula (the average cost of a residential place). The quality of life experienced by those in these new support arrangements has also improved (Genio, 2009: 38). It is important to bear in mind that this is only one small study and that further work funded by Genio will examine the comparative costs of individualised services.

Another example cited by Genio is the Wes Limerick Centre for Independent Living (CIL), a provider of personal assistance services to people in the Mid-West. According to Genio, this service has a very strong emphasis on quality with a well-developed 'customer charter', which gives a detailed description of what each service user should expect from their service in terms of courtesy and respect, fairness, clarity, accessibility, timeliness and responsiveness (Genio, 2009: 39).

A further example is Cheshire Homes, a service provider that uses the CQL approach. Their Service Quality Manager described the role of quality in their work to NESC: 'It's about holding quality in hearts and minds. Standards you can meet, but you are not going to meet quality of life with them alone.'

Cheshire Homes adopted an innovative service design model drawing from Kendrick's approach of social role valorisation, which essentially emphasises valued social roles for people and how to strengthen these (Kendrick, 2010). They gave information to staff on values and assurances on how to place the person at the centre of service delivery, and report that they focus on delivering outcomes and quality of life for each individual. They have brought services together to learn from one another and continue to share good practice.

A final example is KARE, which provides supports to people with an intellectual disability (See Box 3.4).

**Box 3.4        Case Study: KARE**

KARE promotes inclusion for people with intellectual disabilities in Kildare, east Offaly and west Wicklow and was started in 1967 by parents and friends. The organisation developed its quality assurance systems in 2004, and used the EFQM as it felt it was robust and emphasised organisational issues such as the structures that underpin a total business approach. EFQM is overseen by EIQA. KARE won the Overall National Quality and Excellence Q Mark Award in 2008. It is an independent validation and gives international recognition.

The EFQM Excellence Model is used as a basis for self-assessment, an exercise in which an organisation grades itself against the nine criteria. These are: leadership; strategy; people; partnerships and resources; processes, products and services; customer results; people results; society results and key results. This exercise helps to identify current strengths and areas for improvement against strategic goals.

Following an assessment against the EFQM conducted by Excellence Ireland in October 2010, KARE were awarded 'Recognised for Excellence Level 4'. The assessors noted: 'KARE has a truly exceptional people-centred approach to the provision of services with the strategy and measures in place aligned with achieving the needs and aspirations of the service users. This fully reflects the vision, mission and values which KARE strive to achieve.' KARE has also been certified in the EQUASS.  EQUASS is a European certification system for quality assurance and quality control in social services. It focuses on the provision of quality services to service users and other stakeholders.

**Source**    http://www.kare.ie/

*Innovative Services*

Another driver of quality is the funding of supports for innovative services. The Department of Health and the HSE, with innovation health funds, have supported projects through the work of Genio. Another example of such supports for innovation was provided through the Pobal Enhancing Disability Services (EDS) programme, which produced a *Guide to the Enhancing Disability Services Programme* (Pobal, 2010).[83] This aimed at promoting collaboration and innovation across the disability sector The thirty-four projects funded included innovative pilots such as:

- The Brothers of Charity in Galway, who offer a community-based respite service for children and adults with an intellectual disability;

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[83]    The programme was funded over a six-year period from 2005 to 2010. With a budget of approximately €15 million the programme supported once-off projects that demonstrate an innovative cost-effective approach to, and promote collaboration in, the provision of services to people with disabilities.

- SOS Kilkenny, who enable people with intellectual disabilities to act as advocates for themselves in local policy-making levels of their organisations;

- The Assistance Dog Programme for Families of Children with Autism, run by the Irish Guide Dogs for the Blind; and

- The Brothers of Charity Services, Roscommon Transitions to Socially Inclusive Living Project. This project included action research on ways to support the changing accommodation needs of people with an intellectual disability with forty-six participants over fifteen months. The project helped to develop best practice in supporting people to live in a place of their choice. A key finding was that:

> Block funding presents a barrier to person-centred planning. Person-centred services are often no more expensive than block-funded services, but people remain in expensive, unsuitable services because resources do not follow the people who receive the services (Pobal, 2010: 85).

An implication from this is that a 'money follows the service user' approach seems to be key to moving effectively to more person-centred approaches to service delivery.

### The VFMPR and Expert Reference Group on Regulation and Governance

The *VFMPR* recommends that greater transparency and accountability should become an integral part of the delivery and funding of services and supports (Department of Health, 2012a: 161). A focus on outcomes is considered to be an essential part of a service delivery framework and that funding should be linked to outcomes at individual, programme and organisational levels, with performance indicators developed to measure outcomes at a national basis (: xxiv).

In terms of quality and regulation, the Review recommends that:

> Guidelines for a national quality framework should be established to address standards, inspection or audit, quality assurance, person-centred planning and outcome measurement. Agencies should be encouraged to engage in continuous quality assessment and improvement, preferably by means of an internationally accepted methodology (Department of Health, 2012a: 131).

It recommends that agencies should be *encouraged* to engage in continuous assessment and improvement. However, without requiring them to do this, it is unclear how those who have not already put such systems into place will be persuaded to do so.

The *VFMPR* recommends that from 2013 onwards, through the SLA process, agencies should identify relevant demonstration or pilot projects and prepare plans for their implementation. The *VFMPR* recommends that it should be the

responsibility of the HSE to monitor the results of the HIQA inspections of residential centres and that adherence to HIQA standards should be incorporated into the SLA funding and monitoring process (Department of Health, 2012a: 145). It further adds that in the absence of day-service standards, the HSE should establish a framework whereby they can satisfy themselves within the context of the SLA process, of the quality of day services provided and outcomes achieved, through dissemination of quality assurance guidelines, self-evaluation and continuous quality improvement protocols (Department of Health, 2012a: 131).

It advocates strengthening of the HSE to include a greater focus on the identification and dissemination of good practice as well as research, development and implementation of innovative interventions (Department of Health, 2012a: 39). This is important to the learning and review element of responsive regulation, further examined in the following section. The newly formed Quality and Patient Safety Directorate of the HSE and its focus on supporting the HSE as a learning organisation could be valuable in this regard.

The preceding report from the Expert Reference Group on Disability Policy views having a 'light touch regulation' system to be of value, with some flexibility included. This approach is also outlined by Braithwaite (2008) in relation to his 'pyramids' of responsive regulation, detailed in the NESC report, *Overview of Concepts and Practice* (NESC, 2011a). The Expert Reference Group argues that a 'gradation of governance' would be appropriate for the disability sector, with lighter regulation for services for people with less complex needs, and more rigorous regulation for the most vulnerable service users using non-family settings provided by voluntary disability organisations. However, such an approach would require the regulator to adopt a risk-assessment approach that identified poorer performers and targeted action on those. In effect, this is likely to increase focus on minimum performance and compliance, and neglect best practice and excellence. It is unclear how the learning regarding the best performers would be passed on to the weakest, or if a two-tier system of regulation would then emerge. Also, how are the middle group of performers encouraged to improve with this approach? Care would be needed in developing such a gradation approach not to target attention solely on the worst performers. Drawing from existing good practice and the very best performers is central to an effective regulatory system.

The Expert Reference Group argues that what is needed are 'ambitious standards and targets which can be used to challenge the system and help organisations identify areas for development' (Expert Reference Group on Disability Policy, 2011: 139). While ambitious standards are welcome in that they will drive continuous improvement, setting unrealistic standards could be counter-productive. Without providing supports, guidance, incentives and rewards, it may be difficult to achieve targets of this kind.

Along this gradation of governance, outlined above, the Expert Reference Group indicates that home services would not be inspected in the same way as residential services. However, as discussed in Section 3.3.2, it is not yet clear how such regulation of personal support services, home care and community services would be best approached and how the necessary flexibility would be adopted.

## 3.6       Research, Monitoring and Review

The data available in the disability sector does not generally focus on the outcomes for service users nor on quality directly. Existing data sets have been provided by the HSE for the *VFMPR*. The HSE also collects data on a regular basis to inform service provision planning but they recognise the potential value of an integrated system of information in relation to the disability sector. The HSE National Service Plan outlines that it will 'review the current information systems and information needs for disability services and make recommendations for future planning' (HSE, 2012b: 54).

In terms of monitoring, the disability databases administered by the Health Research Board (HRB) on behalf of the Department of Health, mentioned in Chapter 2, provide data annually on the specialised health services currently used or needed by people with both intellectual disability and physical/sensory disability. Although they do not evaluate services, they provide information on service need and usage.[84] The databases inform the regional and national planning of these services by providing information on trends in demographics, current service use and future service need to the HSE.  The data is gathered by voluntary disability organisations and HSE staff, with support from the HRB. Customised software to facilitate the collection and reporting of data is used.

The HRB National Physical and Sensory Disability Database (NPSDD) disability database provides the HSE with planning information on service level need and also has a small focus on performance measures (see Box 3.5).

**Box 3.5        HRB Database Measuring Activity and Participation (MAP)**

**Additional questions were used in a special module of the National Physical and Sensory Disability Database (NPSDD) in 2004 which looked at participation in terms of any restrictions in education, employment, socialising, shopping and family life; barriers and challenges in relation to social-environmental factors that can restrict participation; and the World Health Organization Disability Assessment Schedule (WHODAS) II, which measures the difficulty a person has in performing daily activities. One of its findings was that access to personal assistance services impacted positively on participation. Other data gathered focuses on whether the client has a written person-centred plan and if they were involved in the completion of the form. These questions could be developed further and have potential as outcome data (O'Donovan & Doyle, 2006).**

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[84]  There are reservations noted in Chapter 2 on the representativeness of these databases as they are based on self-defined need and not fully comprehensive. See the *VFMPR* for further analysis of this data.

The NDA developed a suite of outcome indicators for the National Disability Strategy linked to each of the high-level goals for disability in *Towards 2016*, and is doing further work on developing outcome indicators in the context of the National Disability Strategy Implementation Plan. This data consists of published data (e.g. Census 2006, Quarterly National Household Survey, EU-Survey on Income and Living Conditions); special cross-tabulations conducted by the Central Statistics Office and disability specific data (e.g. the national disability databases managed by the Health Research Board [Van Lieshout, 2010; NDA, 2011a]). The strategy has been criticised for a lack of transparency in its implementation and progress and it does not have the in-built tools for continuous improvement and reflective practice. In a comparison of international disability strategies, transparent processes are one of the key ingredients of a successful strategy (Flynn, 2011). While such transparency is effective only when there is data available to share, there has, to date, been little public reflection as to the progress of the strategy.

In terms of the key role of service user outcomes for quality services, the *VFMPR* argues that the achievement of measurable outcomes and quality for service users should be of paramount importance and should be an ongoing process, subject to regular review and audit. It recommends that funding should be allocated on the basis of measurable service user outcomes. It also set out new performance indicators and suggested outcomes for disability services. It also recommends that data quality standards be developed and enforced by the HSE to ensure that the information base is fully reliable and validated (Department of Health, 2012a: 193). The HSE has scheduled a review of performance indicators to be completed by 2012 (*ibid*.: 87).

There is clearly potential value in collecting outcome-based data that can be examined for individuals, services and nationally across disability services as outlined in the report of the review of disability services (Expert Reference Group on Disability Policy, 2011). The *National Disability Survey* and census data on people with disabilities (CSO, 2008) contain considerable information, although not directly related to quality.

Small sets of data are being gathered by voluntary disability organisations, which have greater potential value if shared. For example, Sunbeam House has been using their CQL/POMs data to monitor their performance in terms of meeting the needs of their service users over time. They can also compare their performance with international data to provide a benchmark for the quality of their service. This is tied to a wider question about how the wider system for any service area uses and absorbs such locally rich service data. The range and depth of data that could be usefully shared at a national level needs further exploration.

Other service providers using CQL/POMs have been working on developing the reach of CQL in Ireland and in using outcome data on a wider basis. The POBAL

*Delivering Outcomes to People Project*[85] (National Outcomes Network of Ireland 2006–2008) was funded by the Department of Justice, Equality and Law Reform to support  smaller agencies in the disability sector to train staff in Personal Outcomes measuring; develop a national baseline of data from agencies using personal outcomes; and disseminate good practice in outcomes delivery. The project included seminars, national conferences, and a guide, *Implementing Personal Outcomes: A Good Practice Guide* (Pobal, 2008: 2). The guide emphasises the value of flexibility in service delivery:

> Service boundaries are man-made. People's lives don't stop at 4 in the afternoon. So, to help someone have a better quality of life, we have to be more flexible in how we deliver services.

The project represents the kind of innovative and collaborative practice that can widen and deepen the quality of services. The project also produced a research report on the quality of life of people with disabilities, which used the POMs as research questions (McCormack & Farrell, 2007). The Quality of Life of People with Disabilities in Ireland survey focused on people supported by specialist disability agencies. It used the CQL's POMs to assess people's quality of life. It had a sample of 300 service users from 27 service providers. Six out of the 27 service providers who took part were accredited by the CQL, and perhaps not surprisingly, those service users scored higher on outcomes and supports.  Nevertheless, the study is not representative of people with disabilities (NESC, 2009) but is based on a specific sample of people who have used specialist disability services. However, in the absence of other information, the results are presented to provide an indication of a model that can be used to access the quality of life of people with disabilities in Ireland. It does show the rich research potential of POMs/CQL data and the developing action-research capacity within service providers who use the approach.

The absence of any critical review process across the sector is a weakness for regulatory purposes. A process such as Quality Service Review (QSR), administered as a mechanism for digging deeper and sharing the learning across the system, would be of great value (Kershaw *et al.*, 2002). Once HIQA has a role in the regulating of some disability services, such a process could be piloted to inform practice. This is a point we will return to in Chapter 5.

## 3.7    Service User Involvement

Good communication between the State, the voluntary and community sector and service users is key to quality in services.  A lack of communication from service providers to service users, as well as between agencies, emerged as a theme in the

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[85] This was funded by the Department of Justice, Equality and Law Reform, under Enhancing Disability Services (EDS) and was managed by Pobal.  It came out of a proposal for EDS funding by the Outcomes Network of Ireland, a network of service providers in Ireland using Personal Outcome Measures.

*Final Report on Consultation: Value for Money and Policy Review* (Department of Health and Children, 2010). Respondents stated that communication needs to be improved on a number of levels. Of central concern was that service users and their families/carers should be listened to, consulted and involved.  Others mentioned the need for better communication between agencies and more cross-agency co-operation.

Service users are increasingly used in the monitoring of standards as members of inspection teams and visiting committees.  This is increasingly the case in the monitoring of disability services internationally.  The UK, in particular, uses this approach involving people with intellectual disabilities in the monitoring of residential services for people with intellectual disabilities.  Such participation assists inspection committees in better identifying meaningful results and quality outcomes to the service user.

Consultation processes are not always accessible to people with disabilities. The NDA has produced a guide to help service providers and policy makers engage meaningfully with service users, *Ask Me: Guidelines for Effective Consultation with People with Disabilities* (NDA, 2002).

The *Framework for Public & Service User Involvement in Health and Social Care Regulation in Ireland* (Health and Social Care Regulatory Forum, 2009) details the level of consultation carried out by HIQA before publishing its draft *National Quality Standards: Residential Services for People with Disabilities* (HIQA, 2009b):

> Members of the general public and other interested parties submitted feedback on published draft standards. In addition, focus groups were conducted with staff, service users and the families of service users at various locations throughout the country. Individual interviews were also held with service users for whom participation in a focus group was not a realistic option (Health and Social Care Regulatory Forum, 2009: 10).

In Ireland, people with disabilities and their representatives have been involved in the development of standards for disability services, by the NDA and HIQA. In addition, a wide range of stakeholders were consulted by both organisations and changes made as a result of this process. It is not clear to what extent this engagement will continue once the HIQA standards for residential services are made mandatory, but it is likely further engagement will continue in the early stages of implementation as HIQA consults widely in relation to residential centres for older people.

In terms of future policy development, the *VFMPR* has recommended that the future delivery of services should acknowledge the views of stakeholders, that

choice, control, independence and community inclusion are the keys to an effective, person-centred service (Department of Health, 2012a: 154).[86]

Although people with disabilities and representative organisations have engaged fully in relation to policy proposals and reviews, they have had a lower profile in terms of advocating for change, particularly in relation to greater State oversight into disability services. There has not been a unified voice from the disability sector in relation to service delivery more broadly or quality and standards specifically, as different umbrella groups and representative bodies have different perspectives. However, in this sense, people with disabilities are becoming more visible and vocal in relation to policy development. Recent work funded by Genio outlines the value of a National Intellectual Disability Advocacy Initiative (NIDAI) that would strengthen the voice of those with intellectual disabilities through self-advocacy (Keenan & Keogh, 2011).

One issue is the ambivalence expressed by some service users about greater regulation for disability services, which they fear could lead to greater restrictions for them. However, as in the case of residential centres for older people, some of the improvements as required by HIQA in inspection reports have led to more activity and choice for residents. The ambivalence has also been evident in voluntary disability organisations, many of whom have been operating independently and developing their own quality guidelines and service directions and who have not always been in agreement about the best next step in establishing a regulatory system.  Chapter 4 will explore some of these views in detail.

The importance of the service user's perspective is a key part of evaluating quality services. How a service user knows about and gets access to services, and what makes a quality service for them, are key questions. In considering new models of disability services, the Citizens Information Board has advised the Department of Health that:

> There is a need to put in place at the outset clear protocols as to how the experiences and perspectives of service users are to be captured and issues addressed. Of particular importance here is how the system takes on board issues identified by users who experience difficulties or inequities and/or make valid complaints about the way their needs are assessed or about their ability to access the services required (Citizens Information Board, 2011: 8).

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[86] A recent review of international approaches to involving service users in standard development and inspection has been completed by the National Institute for Intellectual Disability in Trinity College Dublin, with funding from HIQA. The unpublished report, C*ritiquing the Involvement of Service Users in Standard Development and Monitoring/Inspection*, includes a strategy for user involvement in Ireland.

***Networking and Collaborative Working***

Good practice in services has not been as widely shared as it could have been. Genio is working with one group of providers to find ways of spreading out their learning and capturing good practice. There are also examples of good practice being shared by voluntary disability organisations and through support from organisations like DFI, National Federation of Voluntary Bodies (NFVB) and Genio. Both DFI and the NFVB run workshops and master classes for their member organisations on salient issues. As identified in the NESDO Futures Ireland project, confronted with difficult problems, adaptive people search outside their immediate context for approaches and partners that can help them (NESDO, 2009).  This was also found in disability services in the work of Cheshire Homes, Western Care, The Children's Sunshine Home and others where good practice and research were sought out both nationally and internationally to help fix a particular problem in quality.

The person-centred vision, as outlined in *New Directions*, the review of adult day services conducted by the HSE, identifies the need for more integrated working between different service providers, regulators and government departments.  It is hard to see how effective quality and social regulation processes can be enhanced without greater collaborative engagement and a culture of transparency and openness in terms of service delivery.

Finally, the media has been a driver in creating awareness of the lives of people with disabilities through television programmes such as Prime Time Investigates, and articles in the print media. However, unlike the changes in policy and practice that arose after the Leas Cross review in the eldercare sector, the media has not had such a strong impact as an advocate for change for people with disabilities, despite producing some investigate programmes on residential care.

### 3.7.1    Community Connectors

Some voluntary disability organisations are providing supports that would help link people to mainstream services, such as help lines, peer support groups and brokering to make these links. These supports are not visible to the wider community but are an important part of offering person-centred services (DFI, 2011b). This type of networking and searching is an example of the 'sociological citizen' (Silbey *et al.*, 2008; NESC, 2011b). A sociological citizen (networking individual) is one who sees their work and themselves as a link in a complex web of interactions and processes, and, by trial and error, tries to connect organisations and arrangements, through experiments and  a problem-solving approach (NESC, 2011: 15). Interestingly, there are examples internationally where personal support networks have been fostered through initiatives such as the BC Personal Supports Network in British Columbia, a network of community organisations to help people access personal supports in their community; and an online community, Tyze, which helps build circles of support for people with disabilities  (Harrington, 2010). While the role of broker or community connector has commonalities with community development, it may have unique elements in the Irish context, which needs to be developed through professional training and qualifications.

## 3.8     Other Practices and Initiatives

Within voluntary providers more broadly, there has been the development of networks, and running of conferences and seminars, as well as *ad hoc* projects to support quality services. One current initiative being rolled out by the Wheel is a good practice guide, *Knowing and Showing Your Outcomes and Impacts,* which help voluntary non-profit organisations develop, implement and monitor a strategy to advance outcomes (The Wheel, 2012).

The Citizens Information Board runs the National Advocacy Service for People with Disabilities which has provided a service for people with disabilities since 2011. The new service has taken over the work of the 46 pilot advocacy projects, with a particular remit for more vulnerable people with disabilities. More staff will also be trained in general advocacy across all Citizens Information Board centres.

Other related initiatives include the promotion of disability awareness courses and impact assessments. These aim to ensure that the specific needs of people with disabilities are included from the beginning in the development and delivery of all structures, policies and practices in local authorities. One example of this approach is Monaghan Local Authorities Disability Proofing Template (Monaghan Local Authority, 2008). Another is DESSA,[87] which runs training courses in Disability Equality Proofing.

## 3.9     Conclusions

This report has so far profiled the context for the delivery of disability services and provided the background to the current quality and regulatory system. It shows that organisational diversity, coupled with the range of services delivered for different types of disability plus the social, political and historical context, makes the disability sector a complex one to examine.

This chapter has examined the key drivers of quality in the disability sectors including standards, codes of practice, quality assurance systems and SLAs. In broad terms, the predominant driver of quality comes from the sector itself, through quality assurance systems. While standards have been developed, and are used to some extent on a voluntary basis, they are not mandatory and no inspections are carried out. While the HSE has SLAs on a contractual basis with private and voluntary service providers, the quality elements of these have not been routinely monitored.  It is clear there has been slow progress towards formal regulation for disability services, despite extensive consultation and policy developments, thus leaving the disability sector to its own devices in terms of delivering a quality

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[87]   Disability Equality Specialist Support Agency (DESSA) is a national State-funded organisation working to develop and deliver social inclusion initiatives to people with disabilities and their families.

service. In the meantime, there has been considerable self-governance with voluntary disability organisations looking to private domestic and international quality assurance systems to provide guidance and accreditation for their services and processes.

This quality assurance activity, which can be seen as an example of self-regulation practice, has operated alongside a set of high-level policy and legislative frameworks. These have set out goals for the improvement of access for people with disabilities to buildings, information and services (such as the NDS), and more generally to improve equality and inclusion for all socially excluded groups (such as the *National Action Plan for Social Inclusion* Government of Ireland, 2007). However, these strategies have been criticised for not being fully implemented, which means that sufficient change has not yet been achieved in the lives of people with disabilities, in terms of improved access to quality services. At the very least, it would be reasonable to observe that there is a disconnection between policy aspirations and the reality on the ground. As the NDA (2010) argues in its submission to the *VFMPR* on Disability Services, there has been

> The NDA advises that the central task of the Value for Money and Policy Review of Disability Services should be to design a framework which ensures that disability services and the funding mechanisms which support them deliver on these values (NDA, 2010: 9).

The overall impact of this has been a bubbling up of quality in some services, and not others, and in the absence of formal standards or regulations, the creation of a very uneven service landscape. However, change is underway on many fronts, notably in the following areas. Firstly, the regulator, HIQA, is expected to register and inspect residential services in the next year and this is likely to have a considerable impact on the disability sector. Secondly, the HSE has developed more rigorous SLAs with a greater emphasis on quality measures so that all funded organisations are expected to have quality assurance processes in place. Thirdly, and reflecting wider international commitments to the UN Convention on Rights of Persons with Disabilities, the Department of Health's *VFMPR* includes policy proposals for a more person-centred approach to service delivery. Fourthly, the sector is moving towards individualised services, direct payments and the closure of congregated settings, which will bring regulatory and governance challenges.

New regulatory structures will need to be put in place to regulate the necessary personal assistance and support services to underpin this model. The challenges of this include the balance between institutional versus person-centred services; the priority given to safety and risk versus greater independence; and the possibility of over-regulating people's homes and lives.

This chapter has shown the grass-roots nature of quality in the disability sector. There is uncertainty and expectation as to what formal regulation will be like and Chapter 4 explores this further. What is lacking in the sector is formal arrangements for, and coherence in, regulation and quality assurance, so that much of what is going on is localised. Good practice is not shared as much as it could be. Much of the other quality 'work' is in pockets, too, such as networking, shared learning, monitoring of data and setting plans for service outcomes. The next chapter

examines some of these issues raised by stakeholders regarding the quality and regulation of disability services.

# Chapter 4
# Emerging Quality Issues

## 4.1     Introduction

So far this report has outlined the current context and details of the regulation and quality assurance system within the disability sector. Chapter 3 identified some of the key drivers of quality. This chapter will first review available research evidence and documentation on the quality processes within disability services. It will then identify some of the key quality issues raised by stakeholders directly. It attempts to bring together what is known, and to draw on the experience and insights of stakeholders in the disability sector as to the key issues that are of concern, as well as areas of strength. It remains a partial review, given the size and breadth of the sector, but one that hopefully will add value to the ongoing debate even if only from a distance. Its value will be more evident in the capturing of quality initiatives, drivers and challenges for a broader debate on quality, standards and regulation in Ireland. The final chapter will draw some broad conclusions concerning quality, standards and regulation in disability services.

While a list of stakeholder organisations consulted is available in Appendix F, all quotations have been anonymised to preserve confidentiality as much as possible. It is difficult to give weight to some of the issues raised in terms of their representativeness, so some caution is advised in their interpretation. Nevertheless, the discussions do help us begin to understand issues of quality from varied perspectives of the disability sector itself.

## 4.2     To What Extent are Quality Services Being Delivered?

Research by the Department of Health and the HSE provides some insight into the perceived quality of current services. The recent consultation process linked to the *Value for Money and Policy Review (VFMPR) of Disability Services* was outlined in the *Final Report on Consultation* (Department of Health and Children, 2010). Almost 200 stakeholders completed an online questionnaire or made a written submission. Just one in three respondents (31 per cent, 54 of 176) reported that they were satisfied or very satisfied with the quality of services being provided. 42.7 per cent of respondents were dissatisfied (61 of 176) or very dissatisfied (14 of 176). However, 40.1 per cent of respondents reported a positive change in the quality of services provided in recent years. Some 79 per cent of respondents felt there were

measures that could be taken to improve effectiveness, by taking greater account of service user needs and a greater focus on achieving value for money.

Those who made submissions gave detailed comments on the efficiency of current services and there was particular mention of the need for standards and measuring of performance. One organisation commented:

> While the range of services has increased, the quantity and quality of services has remained the same due to inadequate funding and a lack of quality assurance and national standardised protocols and procedures (Department of Health and Children, 2010: 24).

Other comments centred on the need for implementation of quality measurement systems and linking funding to outcomes. Some respondents mentioned that although they have their own quality standards, there should be a national standard and a quality assessment or inspection programme put in place. The lack of implemented disability standards and inspection/review was considered to be a significant barrier to achieving quality services. In relation to service providers operating their own quality measures, some respondents felt that these quality evaluations were manipulated to look good (Department of Health and Children, 2010). These views suggest that there is a need for a comprehensive national framework for standards and inspection.

The overall picture of quality is unclear in places, with much not known about the extent of quality in some of the less transparent residential settings, apart from the experiences documented in published reports such as *Time to Move on from Congregated Settings* (Working Group on Congregated Settings, 2011). This outlines the lack of facilities and quality in some of the services provided in congregated settings:

> The survey also gathered detailed information on the nature of physical facilities and levels of access to personal privacy. The survey found that there are significant issues around lack of privacy and dignity, as demonstrated in the data on shared bedrooms and bathroom facilities, people being changed in communal areas and situations where people have no personal belongings or where their personal belongings are communal property**.**

> Just over half of residents had a single bedroom. A quarter of residents were living with 4 or more to a bedroom, while one in 10 were living with 12 or more people to a bedroom.

> 20 older people with severe disability with one accessible shower and two wash basins. People wait their turn to be washed and have their teeth cleaned (Project Manager's observations).

> A ward with 10 beds side by side with minimal space between, and no curtain dividing them (Project Manager's observations).

The report also documented that

for a significant minority of residents, there are no activities or very limited day activities. 11 per cent had no structured day programme with a further 18 per cent having a limited day programme in the ward or sleeping/living area (Working Group on Congregated Settings, 2011: 54–56).

A further issue was that services tended to be organised around the availability of staff, rather than service users' needs, for example, what time they wanted to go to bed. This places the emphasis on fitting the needs of service users around staff working hours, rather than providing what the service user needs, when they need it.

The services being offered in some cases were not what people wanted. As outlined by the Department of Health and Children (2010: 2) people want 'flexible supports to suit individual needs'; 'to use local services – do ordinary things in ordinary places'; and they want more opportunities for families to 'play their part in supporting their family member'. People were also dissatisfied with the limited choice they have over the service received from service providers and the majority wanted to choose to get different elements from different providers. In this sense, the current model of service provision might be of good quality but because service users expect and want a different model, what is on offer currently falls short, regardless of quality *per se*. It is therefore a complex picture of service provision, which, by its nature, is not easily captured in quality terms. Not all service users will want to embrace the new service model, particularly those living in congregated settings for many years.

One of the *VFMPR* documents published by the Department of Health, the *Final Report on Consultation: Value for Money and Policy Review*, found that choice and managing budgets were strong themes. Almost three-quarters of those who responded to the consultation wanted to choose different elements of service from different providers and half would prefer people with disabilities to get to choose and manage their own services (Department of Health and Children, 2010).

The NDA conducted focus groups with people with disabilities, their families, advocates and frontline service providers. Some of the main obstacles to independent living that participants reported included poor co-ordination of disability services, together with low levels of long-term planning and institutionalised mindsets and practices in service provision, which sustain ingrained ways of doing things and inhibit more creative initiatives (NDA, 2010c).

## 4.3     Issues Raised by Stakeholders

In this section, further aspects of disability services and the sector as a whole are discussed to highlight themes and respond to the questions set out in Chapter 1.

What emerges from this discussion are the wide-ranging views, experiences, concerns and aspirations of the disability sector in terms of regulation and quality

improvement of services (see Table 4.1). Six main themes are presented here, which give a flavour of the discussion at the workshops and interviews.

**Table 4.1    Key Emerging Issues for Quality, Standards and Regulation in Disability Services**

| |
|---|
| 1. Joining up the 'Independent Republics': Aligning Policy Vision, Services And Resources |
| 2. Standards that Focus on Continuous Improvement |
| 3. Person-Centred Services and Changing Cultures |
| 4. The Value of Measuring Outcomes and Processes |
| 5. Capturing and Sharing the Learning |
| 6. Service User Involvement |

### 4.3.1    Joining up the 'Independent Republics'

This issue, already touched on in earlier chapters but raised by many stakeholders, reflects a broad concern with better governance, quality of services and a greater link between policy and practice.

A key issue raised by stakeholders was the importance of streamlining policy, funding and service delivery so that the sector as a whole was less fragmented. One service provider described the situation to date, that each organisation forms its own identity, with no model as to what to do. In his view, they are all operating as 'independent republics' (SP 42).

The same service provider explained how some service providers in the disability sector found it challenging to fully embrace the challenge ahead:

> Even now, organisations have huge ambivalence. While they may have individual/personalised practices in one part, another part will still be the old model. They can't possibly articulate a different vision, as they are too immersed in the old one (SP42).

One view was that services that are delivered are not policy-bound, in that innovative practice is funded alongside very poor service and there is no standardised approach. One stakeholder commented that 'the State shouldn't be paying for practice at right angles with policy' (ST12).

For some in the disability sector, the funding system for services needs to be overhauled. For one stakeholder, the scale of expenditure was considered to be remarkable and that it was important for increased scrutiny 'to follow the money' (ST16). A service provider echoed this point by reflecting that 'things around funding are very muddled. So far the status quo is rewarded' (SP42).

There was a general view that current policy visions have not been linked sufficiently to governance, service planning, expenditure and delivery and that as the main funder, the HSE needed to play a stronger role in relation to quality. A view shared by a number of stakeholders was that Service Level Agreements (SLAs), (used by the HSE to contract service providers) were a key place to drive quality, where the focus should be on continuous quality improvement.

Some of the issues raised in relation to SLAs were that they varied locally, and that some of them referred to only one or two standards rather than a full set. In addition, some focused on a particular quality assurance system, without a clear rationale for their choice. One service provider interviewed for this report said that:

> With the SLA there is very much a local element. HSE personnel in some regions take a much different view to others and some of them will add in items to check if you are complying with some obscure piece of legislation (SP29).

### 4.3.2    Standards that Focus on Continuous Improvement

A second related issue raised by stakeholders concerned the use of standards for disability services. While there were different views as to the 'how' of greater regulation in the sector and, in particular, what standards should be in place, there was little dissent on their potential value. Standards were viewed as largely welcome, if they not only ensured minimum requirements but also had a role in strengthening continuous improvement, and placed emphasis on the outcomes of service delivery. Nevertheless, there was some anxiety about what the introduction of the HIQA standards for residential services would mean for the sector. The experience in the eldercare sector, however, is that once embedded, mandatory standards provide only the starting point for continuing conversations and quests for continuous improvements, and might suggest the disability sector should 'get beyond' standards and continue on the quality journey.

#### *Urgency*

The importance of making the HIQA standards mandatory as a matter of urgency was a point made by many of the stakeholders. One stakeholder emphasised: 'I really feel that we need to bring our strength as a group to support the introduction of the standards that we agreed in 2009 that were signed off by HIQA' (ST1). Other stakeholders agreed with this urgency, with one pointing out that 4,000 people are in congregated settings with no external oversight. These represent the most vulnerable people in our society, most of whom are out of contact with their families.

The dominant view was that the standards should be put on a statutory footing as soon as possible, with service providers registered and inspected. Some argued that at the very least minimum standards for all service providers should be in place to help prevent poor service provision. One stakeholder commented that in 'my view having read the [Ryan] report when it came out, that if we had a few tick boxes in place 20 years ago, life would have been a lot better for people' (U22).

Another stakeholder thought that standards would have done more to improve the lives of people with disabilities than high-level policy strategies:

> It seems to be that a lot of the funding of the Celtic Tiger was wasted in search of excellence when a small number of improvements would have been the order of the day (ST20).

While there was uncertainty about what standards would mean for the sector, this is not surprising given the long delay between their development and their implementation. However, those working in the sector felt it was important to focus on carrying on delivering a quality service while waiting for the HIQA standards to be implemented:

> The main ethos is to deliver a good service. We are constantly trying to improve the services but now we have this stick hanging over us and I just wish the stick would come down (ST4).

### *More than Minimum Standards*

However, most stakeholders viewed standards as necessary but not sufficient. They would not be a 'catch all'. For some, it was about the type of standards used; for others, it was more about having a wider approach to quality. One stakeholder considered that 'the full value of standards would only be felt if there was an alignment between policy and vision, values and metrics' (SP36).

There was some discussion regarding the earlier NDA standards for disability services and why they were not given official status since their development in 2004. Some stakeholders were concerned, at the time, that the standards were not sufficiently focused on performance, continuous improvement and outcomes. Some organisations who were internationally accredited for quality assurance were judged to not fully meet the standards, thus revealing potential tensions between different quality systems. This reportedly contributed to a debate between service providers who had diverging views on what a quality measure should be and how best it should be assessed. However, beyond these views, the reasons for the lack of implementation of the NDA standards are not documented.

Across discussions with stakeholders, there was a general view that quality improvement needs more than minimum standards. One stakeholder argued that

> It's not about health and safety stuff, a fire hose on a wall ... they only go so far. There needs to be something else. The real issue is replicating expensive models that don't address individual needs. How is the

> sector going to be signed up and incentivised to continue to explore, creating the space beyond the standards? (SP36)

A possible difficulty with standards, as expressed by some, was that they emphasised reaching the standards as though they were the end goal, when quality was a journey as opposed to being a destination (SP31).

One view was that there needed to be greater autonomy among service providers to do the quality work on their own, regardless of standards. This might involve service providers gaining recognition for quality assurance systems already in place. One stakeholder argued:

> I would endorse inspection but I think assessment should lie within the organisation and in practice to engage with HIQA on how you evaluate that. This would be very very useful because it would allow for diversity in terms of organisations, aims and structures and practices (SP28).

The approach that HIQA took would also be important, with one stakeholder emphasising how a good inspector does more than seek compliance. The stakeholder argued that:

> I think that we shouldn't be afraid of them [HIQA] because through meeting with the inspectors and talking to people there, it's not all about ticking boxes because it's about talking to people, talking to their families, talking to the staff, also about their physical environment but the physical environment isn't everything (U22).

Having HIQA involved could be helpful to get a momentum on quality improvements. One stakeholder put it like this: 'It is leverage that (for [us] when we go in we can say well HIQA will be coming in here, show me your evidence, show me what you are doing' (SP35).

These views point to the value of mandatory standards and the potential for sanctions for non-compliance, as outlined in a responsive regulation approach, discussed in Chapter 1. But it also highlights the potential of meta-regulation, whereby service providers are encouraged to self-regulate.

Overall, standards, regulations and inspections were welcomed by those we talked to in the sector. Most wish them to be delivered soon so that the details would be known. For some, the key issue was what was to be measured and how, and in what way it would link to work already underway in quality assurance. There would, however, be a need to closely co-ordinate the different demands on quality from key regulatory bodies such as HIQA and the HSE.

### *Competing Service Models*

One stakeholder felt that given the sector was shifting from one type of service model to another, any regulatory system had to be able to cope with a variety of issues in terms of a continuum of service provision from congregated settings to individualised supports (SP36).

The concerns over regulation were, for some, focused on what it might mean for resources and quality in the sector and that efforts could be directed at the regulatory process and not really on outcomes. In addition, some were concerned that funding a regulation system for residential services may act as a barrier to more person-centred support and individualised service delivery.  One stakeholder commented that:

> I think that one of the really big challenges is not to set up a large regulatory system that's predicated on a system that's not going to be there much longer (ST13).

Another stakeholder thought that in this time of transition between old and new models, funding for interim measures should be available to help service providers bridge that gap. For example, in a facility where there is no accessible bathroom, appropriate facilities should be provided but only as a temporary measure, until the facility is closed (SP43).

Another concern was the possibility of over-regulation in the sector where different services have to meet a range of standards. However, there is no evidence yet that this type of regulator system is emerging. On the contrary, there was a broader sense that given HIQA's distinct role in regulating health and social services, it should be possible to avoid over-regulating the disability sector once HIQA is fully operating in its role.

One way to assuage this fear was in greater engagement with stakeholders. Some of the stakeholders interviewed voiced their concern at the need for increased consultation over the introduction of standards.  One service provider expressed it in this way:

> I am just coming back to the point of stakeholder engagement and how critical it is to everybody.  That natural human quality we all have is fear of the unknown (SP30).

Another made the distinction between consultation and working in partnership. In their view, regulation and legislation are key drivers to working in partnership with HIQA as opposed to just consultation (SP30).

Another talked about the importance of reviewing any regulation after a few years, a process that has just been completed for older people's residential centres:

> If we have an assurance and I don't know if there is a mechanism being put in place, whereby we know that perhaps in two three years down the road there would be an opportunity for us and our staff to feed into the review and the continuous improvement from a standards point of view  (SP31).

### Resourcing Quality Assurance

A related issue raised was the cost for a service provider of maintaining a quality system in a time of constrained resources, both in terms of the fee for the quality

assurers and in terms of staff time. Some stakeholders felt that adding mandatory standards to this mix will require resources to be redirected to meeting them at a service level, and supports would need to be in place to help with this. There was some uncertainty expressed by service providers about whether they would be able to meet mandatory standards and continue their quality assurance systems in-house.  Those organisations with, or seeking, accreditation again expressed concern about how they would afford it in future. One stakeholder said, 'We would love to go for EFQM[88] but really there is a very big question whether we could possibly afford to do it' (SP32).

For those service providers who already have well-developed quality systems in place, they wondered how it would fit in with HIQA standards. One service provider speculated that 'maybe being accredited with CQL could be a waiver against inspection' (SP36)?

Some service providers talked about how they were managing to provide increased quality of service with fewer resources. In part, this was due to more flexible working practices, and for others it was adopting person-centred care and individualised supports, moving away from resource-intensive congregated settings.

One stakeholder concluded that 'the lack of money now means that people are looking at much more simple solutions'. For some providers, this means moving away from a medical model of support that characterised many congregated settings. 'People are having access to good care when they need it but people don't necessarily need a nurse to give them medicine' (U22). Another stakeholder commented:

> Because of the cutbacks, what they have had to do is to get a lot of flexibility from their staff in organisational hours, the way they work. Frontline staff who maybe are involved in training taking on a couple of hours in respite care, which would be a carer's job, so there is a lot of flexibility going on (ST20).

Another service provider was concerned about the likely introduction of tendering for services and how this might reduce innovation in the voluntary sector:

> That is the challenge in the tendering environment where the specification comes down and this is the service that the HSE wants from you.  All of the organisations, small and large, evolved from perceived gaps. Funding was allocated to support an organisation generally after it had been innovative all on its own.  In a tendering environment we lose that link in a chain so what happens then? How do we continue to evolve better and better services? The standards themselves won't facilitate us to do that and the tendering environment will limit us to do that (SP28).

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[88]    The European Framework for Quality Management is discussed in Chapter 3.

A different and final point raised about the changing service model and reduced expenditure was in relation to the funding of individuals with individualised budgets in the future, if the current policy proposals were to be adopted, and how they were more vulnerable to cutbacks than large service providers.

> All in individual canoes paddling on their own and a metre-high wave comes along ...'

He went on to add:

> A thousand canoes give you mobility, nimbleness and a kind of freedom but it can turn out to be fragile and short-lived when cutbacks happen (SP36).

### 4.3.3      Person-Centred Services and Changing Cultures

The proposed policy move towards person-centred and tailored services positions the service user at the heart of service provision and in essence empowers the individual to direct services in many cases. One challenge that the associated increased mainstreaming of services will bring, is that the focus in relation to quality has to be directed at the individual and not just at the service provider. Putting the person at the centre of quality assurance poses a number of challenges. It moves the emphasis away from a setting or residential centre and how it functions, towards the priorities of every individual there. With different levels and types of disability and capability, this can make the supports needed essentially custom-made to the individual, rather than group activities. It requires service providers to think differently about how they link the individual into a wider range of mainstream services, community activities and supports.

As one stakeholder described it, parallel universes of activities have been built, one for people with disabilities and one for the rest of society, and that needs to change (ST20). Another stakeholder described some of the current provision as 'an empty service that doesn't support the individual to grow. It is throwing money at a problem but not trying to solve it'  (U25).

No-one doubted this change was needed for the sector. One stakeholder commented on the lack of variety, the lack of diversity and the lack of resources in services, which put severe restrictions on service users' experience (ST21).

However, there were stories of changing service models reported by stakeholders.

One service user was moved from a congregated setting to living in her own place with supports, a story told by a service provider:

> After a while she started saying [to support staff] 'will you not come every day because I have to get the house done'. She didn't need the same level of support. She has a whole new life and she hasn't been in the psychiatric services since. It was very dramatic (ST13).

Other case studies from a service provider give a feel for the process that many providers are working through in relation to moving people out of congregated settings:

> People have been surprising us. This man told us he didn't want to live in a place [group home] 7 years ago. He packed his bags every weekend. That's how he told us …. Eventually we figured out how to work with the staff to do it. It didn't take any more money. The guy now lives in his own place. The first place didn't work out. But instead of going back to a group home, people had the confidence to say what are the problems that are here and how would we address them there. This man has a significant hearing impairment, he has Downs Syndrome, and he is in his fifties. He didn't present enormous complexities of supports but we would previously have seen him as someone who didn't do this kind of thing. Now he goes to meet people who he doesn't know for dinner (SP36).

> In another case, staff closed a group home. All of the individuals went to live in different arrangements for fewer resources … So having individuals with very challenging behaviour supported individually in their own arrangements costs less money than a slot in a group home where they hate it. These are the good stories (SP36).

These show that staff took a problem-solving approach to supporting their clients, through trial and error. It was an effective combination of a bottom-up approach and a willingness to find solutions. One stakeholder outlined how person-centred approaches require a bottom-up process and a change of culture to empower people (U33).

For someone being supported to live independently in the community, a quality service might mean giving support to strengthen resources by, for example, working to strengthen their support circle and giving them the financial resources to make choices. This approach recognises that enabling people with disabilities to achieve the outcomes they want in their daily lives is the ultimate goal of disability services. It is no longer only about specialised services and their quality, but about the supports built in around mainstream services as part of a wider service model.

### Barriers to Changing Service Models

Changing the service model was the key. For one service provider, trying to help an individual who was unhappy in the congregated setting, they:

> poured resources in, the traditional behaviour supports, psychology, training, and staff. We kept trying to make that thing work. Leadership training, staff training. Once they realised that [it meant] moving the person to a *different* model of individualised supports, it began to change (SP36).

However, others talked about the challenges they faced in terms of funding and contracts when they tried to offer a new service, while still paying for the old one:

> Our other frustration is we are trying to close down services and move people into the community ... But the costs of the service don't decrease because one person has moved out.  That is our biggest challenge (SP35).

This view reflected the complexity of the disability service sector with large service providers continuing to operate congregated settings while at the same time, offering supported services for people to live independently. Transitional funding and supports will be required to make this change effectively.

### *Cultural Change*

The transition to more person-centred services will not be an easy one to make. However, service providers provided examples where change had been successful, albeit very difficult to achieve. One service provider for children with disabilities found that helping the parents to get more involved was initially one of the challenges in taking the service from a nurse-led residential centre to a respite one, where children lived at home. Before this change, children in the centre did not own coats or shoes as they never went outside. Now the centre receives no referrals for residential care, and most parents expect to care for their child at home, but with support such as respite care (SP39).

One implication of this change in approach towards greater independence for people with disabilities will be a different approach to risk management. With increased numbers of people living in the community with supports, there will be increased tension between providing a safe service and one that allows for a certain amount of risk. One stakeholder suggested that parents have different expectations with regard to the levels of risk in the services provided for their children. Younger parents want their service providers to take risks for their children, to 'push the boat out' in what they can be encouraged to do (SP33).

The issue of risk is not a new one for disability services. Robert Perske argued in 1972 that 'to deny any [disabled] person his fair share of risk experiences is to further cripple him for healthy living' (Perske, 1972). It is also an issue raised in the the *Disability Policy Review Report* (Expert Reference Group on Disability Policy, 2011: 144) which argues that

> the effective management of risk, which includes the identification, analysis and mitigation of negative outcomes, is an important element of ensuring the quality of supports and services for people with disabilities.

Risk emerged as an issue, too, in the way that the new model of service provision might be regulated:

> People with disabilities are being connected to a much greater extent to communities and this is what policy is saying and has been saying. But you hear that this person has to be Garda vetted. Normal human interactions are suddenly not allowed. So we have to really start

thinking more creatively and about risk and safety again in a more progressive and mature way (ST13).

Another barrier experienced was in terms of the language used in different models of service. For example, under the new model of support for people with disabilities, the need for medicalised care will gradually reduce. However, one service provider explained how the medical model was still prevalent in relation to quality and health care standards:

We are shifting language from clinical to community but standards use clinical language ... Services are all structured around moving away from the notion of the treatment focus service as opposed to a quality of life support service, it is very challenging when you get into the language of HIQA where they talk about clinical audit and how do you translate that?... How do we translate that back into our own language and produce it (SP28)?

There were some ideas expressed about how to incentivise change. These included, for example, awards for good practice along the lines of the O2 Ability Awards for Best Practice in the inclusion of people with disabilities as business customers and employees; and a small percentage of the annual budget of a service could be used to fund innovative practice along the lines of the new policy directions, with increasing proportions the year after.

One stakeholder suggested:

If you incentivise about 10 per cent of the annual budget to be used now this way, next year use 20 per cent and the next year use 30 per cent. This will get things moved on (ST13).

Another stakeholder thought that:

Best practice models of service at average cost or below should be rewarded for providing such a [quality] service. There should be a national approach to profiling, supporting and disseminating best practice and innovation [like the English National Development Team (mentioned in Chapter 1]. How can partnership be advanced and promoted in new models of service delivery? (U33)

Other stakeholders commented on benchmarking and being creative to encourage innovation. One example given was when an airline was looking at reducing the turnaround time of the aeroplanes; they went to a Formula 1 race track and learned how to improve time efficiency. Another example was a children's hospital in the UK, where a child was moved from one ward to another without a clear logic. They brought in a dance choreographer to reflect on better ways of moving patients around (ST15).

Stakeholders commented on the value of innovation in the delivery of services:

> Innovation as well, you don't want such a rigid system that it inhibits any kind of creativity and innovation within organisations because ... you have to be responsive all of the time because clients, needs evolve so much over a period of time *(SP28).*

### *Quality as an Organisational Journey*

For voluntary disability organisations on a quality journey, and working towards continuous improvement, there has been an absence of regulatory guidance or support. Some organisations spoke of the work they had to do in quality assurance on their own. One service provider needed to start from scratch and it took six months from a blank page to get things started (SP37).

Many organisations had to work hard to change the way they did things:

> That didn't happen sitting around the table, that took a lot of blood, sweat and a good few rows but we are now at the stage where we have redesigned ourselves, our principal services in the last five to six years, with a view to establishing a way to record the experience of a service user (SP28).

They explained it further as

> reinventing the wheel because it is very difficult to get a quality assurance tool objectively accredited which fits all of your needs ... these tools or systems that are there are process orientated a lot of the time, so if you have good practices, you will get good outcomes. The experience for the individual who was in that service, there isn't an easy or simple way of measuring that. So you end up coming up with your own mechanism to measure the outcomes on top of the process that you put in place and the measurement around that (SP28).

One organisation talked about the accreditation process undertaken by the Council on Quality and Leadership (CQL) every three years. For them, it has provided independent validation and international recognition. They had to consider the cost carefully but they felt 'it is embedded in the organisation now. We want to do the best we can for people who use this service. We wanted a model to push us. When we screw up, we mess up people's lives' (SP43).

Another service provider found that CQL 'turns an organisation inside out. POMs are personally focused and make staffing and rostering, for example, secondary to personal needs' (U33).

For another service provider, CQL was like 'futuristic car-design, it raised the bar for everything else. It tapped into bowling alone stuff' (SP36). 'Bowling alone' refers to Robert Puttnam's work on social capital, which highlighted the value of community life and making wider social networks.

### 4.3.4       The Value of Measuring Outcomes and Processes

Some service providers felt their purpose was to deliver positive outcomes for people. In their view, clearly stated outcomes for all services would link the service user, their quality-of-life outcomes and the service provider more directly. Service providers talked about the challenge of measuring outcomes that are defined in terms of the needs of the service user and not the service provider. For them the hardest part was to articulate what an outcome was and how it was different from what the service provides. One stakeholder commented that 'people confuse process and outcome' (SP36).

As outlined earlier, some service providers are working with service users to identify the individual outcomes for each person served, which, they have found, is challenging:

> You try and do the easy things first. People choose where and who they want to live with and then it gets harder. It turns organisations inside out. Not about fitting in someone but about them making the decision. There are still people living in group homes who don't want to and we have to change the model. It takes acts of extreme ingenuity to make it happen (SP36).

However, some stakeholders talked of their experience of setting out outcomes and not achieving them, and the importance of looking at processes in the organisation as well. One service provider said:

> What we were finding from outcomes was we were measuring and measuring them and nothing was getting any better. If we don't look at the start of the processes to say what are we putting in to get these outcomes, then we are all setting ourselves up to saying we weren't really closing the loop (SP28).

It is not always easy to decide what the outcome should be and how it should be measured. One service provider commented that the 'benchmark is a good life, not a good residential home' (SP34).

Taking a quality-of-life outcome as a starting point for service provision provides a very different context for quality assurance than just looking at the delivery of care, support or health services.

### *The Quality of Human Interaction*

For one service provider, the key focus was to get staff to see the person they were caring for and not just the care tasks. For that service, 'quality is about knowing each individual and their needs and how to meet them' (SP34).

Another service provider felt:

> That is the challenge for us.  We are really good at the care stuff, the clinical, the tasks, the getting people up and washed but all the other

unpaid social values and social roles, we are really bad at developing those for people (SP35).

The role of relationships in supporting greater quality of life was raised by service providers and those caring for relatives. As one stakeholder put it: 'Michael doesn't care about things or technology, it is people who make or break his day' (ST20).

Another stakeholder commented:

> Evaluating the quality of human interaction moves the focus away from providing a service, to the impact of the service on the quality of life. There are self-reflection tools for staff to look at values, dignity etc. and that feeds back. How do I know if I have given that in my care (SP34)?

This is part of the social valorisation approach, developed by Kendrick and referred to in Chapter 3, which focuses on these interactions as the key to quality service provision. In one stakeholder's view, the key issue is to recognise that quality is about relationships. Trying to get that piece right will impact on all others (SP36).

There is a wide range of views as to what quality is among service providers, how it should be measured and evaluated, and what the outcomes should be for service users. However, most of the service providers consulted were aiming for improving the quality of life of their clients, not just providing a quality service.

### 4.3.5    Capturing and Sharing the Learning

One service provider commented on the overall lack of focus on quality for services:

> There is an overall deficit in Ireland in relation to looking at the quality of things generally. We have put systems in place and things don't necessarily change. This is one of the big challenges that no matter what happens there has got to be some capacity there to build on the learning from it, rather than just generating report after report that sits there (U27).

One approach is to develop a system of continuous quality improvement and good performance leading to ongoing incremental improvements and connecting with the 'adjacent possible' (NESC, 2011b: 74, Johnson, 2010).  Johnson suggests that 'the trick to having good ideas is not to sit around in glorious isolation and try to think big thoughts.  The trick is to get more parts on the table'. This points to the value of staying close to the experience on the ground, rather than waiting for 'big thoughts' (*ibid*: 42). Innovative practices and advancements in quality approaches may emerge through service providers working together on challenging problems and sharing the learning.

As well as increased regulation, sharing of good practice and increased learning for partners within a framework, there is a need, expressed by some, to ensure that the capacity-building and support mechanisms are there as well to enable people to work together (SP31).

Seddon, as outlined in the earlier report, *Overview of Concepts and Practice* (NESC, 2011: 29), emphasises increasing purpose and performance rather than compliance in public services in the UK by providing a platform for innovation. This includes 'learning about what works' (Seddon, 2008: 193). Understanding what works and what does not and exploring ways of doing things better is a key part of effective quality improvement. While absent on a system-wide level in the disability field, there are examples of this on the ground and also in organisations like Genio.

The value of diagnostic monitoring in improving quality was outlined in the earlier NESC report (NESC, 2011b). Applying a problem-solving approach to challenging problems can benefit the service provider in learning from the challenges, and can, if the learning is shared, contribute to system-wide reflection and change. Some stakeholders pointed out the potential role for HIQA inspectors in sharing good practice across the sector; they would in time have a unique overview of services.

Another potential contribution to developing a learning culture was to use peer review of services as a way of sharing the learning. Organisations could visit each other, co-ordinated by the HSE nationally. All agencies would be expected to take part (SP43).

Another service provider said:

> I think the challenge for us would be to pull together and pool our resources. We are not talking about doing everything the same but already we have similar systems and we should look at the systems (SP31).

One example of a successful network was given by a service provider:

> The POBAL Delivering Outcomes to People Project involved individuals in networks and was useful. Lots of stories of good practice and a rights-based approach. Any opportunity to benchmark we grab it because it is quite difficult *(*SP29).

There was acknowledgement that the focus on quality needed to be the concern of all staff, and not just a designated person as it was around cultural change. One stakeholder commented that 'It's not more work, it's not somebody's job to look after quality, it is everybody's responsibility and it is the only way we do things around here' (ST15).

The value of a comprehensive and co-ordinated monitoring of outcomes is integral to an effective regulatory system. Without understanding what, why and how the service is delivering a quality service, as part of routine diagnostic monitoring, and examining what impact this has on an individual's personal outcome, it is difficult to examine how well a sector is doing in meeting the needs of its service users. While some quality assurance systems such as CQL/POMs place a strong emphasis on data monitoring, the data gathered by this approach, and all others, would need to be held against some robust interrogation by 'the centre' to be able to assess what outcomes are being delivered and in what way.

**4.3.6     Service User Involvement**

Service providers were asked in the workshops to reflect on how they involved service users. It was a challenge for some providers as to the best way to do this. Some of the accreditation systems, such as those run by CQL, involve service users and families:

> It is challenging trying to get people involved. Service users are worried about their particular service and their agenda, thinking about the quality in the whole organisation. They really don't care as long as their service suits them and they are happy (SP28).

Another service provider felt:

> There is an element of tokenism, putting someone with a disability on a group and they really don't support them to contribute and develop (SP35).

Another view was that getting feedback on a service was manageable, but getting input to strategic planning and organisational goals was more difficult: 'It is simpler to deal with the individual service user's experience of the service' (SP28).

Another said:

> We have tried different things over the years and at the end of the day we said if we could get a good picture of what the person's experience was or the service they got from us, we are doing well.  They come in and do their programme and they don't care what a strategic plan is as long as they get what they want (SP29).

The presence of quality in services can sometimes be hard to assess and service users may not find it easy to comment on poor-quality care. Involving parents and carers would seem to be important, with advocacy supports, if needed.  One parent described her experience as one where she could tell poor-quality respite care for her severely disabled child by the presence of nappy rash, of being slumped in the seat the wrong way, stained clothing and unwashed wheelchairs. For her, quality was evidenced by her child being in the same state as in her care and she learned that it was important to feed back to services on the level of care. Adopting transparent quality assurance systems would be valuable in this context as it would outline what is expected in providing quality of care.

In terms of consulting and supporting families, this parent also found that with her current service provider, there was a quick response to any criticism with action taken, a marked improvement on her previous experience. When her child was younger, the onus was on her to fight for quality and even for services:

> It was all find the information yourself, no booklet was handed to you with all the services that were available, or even to let you know where you could go if you wanted to get a hoist, a bathing aid, etc. Nobody told you any of that, so you started asking, what am I actually entitled to?  I felt being more articulate was on my side. The impression I got

was that if you didn't shout loudest, you were left by the wayside (ST21).

## 4.4    Conclusions

Despite the lack of regulation in the disability sector as a whole, some standards are being adopted on a voluntary basis and a growing number of providers are aiming for high levels of quality assurance. However, it is not clear yet the extent to which all organisations will learn from this standard-setting and embrace continuous improvement. The examples provided suggest that there are service providers already striving for excellence.

A key issue raised in discussions with stakeholders in the sector is a concern that a lack of standards and external oversight is putting vulnerable adults and children with disabilities at risk. There is evidence that this is the case.  Final Report of the Commission to Inquire into Child Abuse: *The Ryan Report* (2009) documented significant abuse that took place against children with disabilities living in residential institutions.[89] Chapter 5 of the report, which details abuse against children with intellectual disabilities in the Lota centre, draws attention to 'an enclosed and inward-looking institution ... where children with a near-total dependence on others to care made them very vulnerable' (The Commission to Inquire into Child Abuse, 2009).[90] It concluded that objective standards should be introduced to institutional settings and that independent inspection is essential (7.12, vol. 4).[91]  Without such oversight, there is no mechanism to prevent serious harm or abuse and with many vulnerable people in residential centres, most stakeholders were of the view that standards, regulations and inspections were needed as a matter of urgency.

An Enquiry Report, from the Irish Human Rights Commission on the John Paul Centre for adults with severe to profound intellectual disabilities, run by the Brothers of Charity Services in Galway, found that there were serious gaps in the provision of services to residents or people using the facilities of the Centre in 2008/9. The inadequate services stem from systemic problems with the legislative, strategic and policy frameworks set at the national level (NESC, 2012b).

The Enquiry found that:

> The inadequacy of the centre's services appears to reflect 'inattention by the State authorities to the individual's needs'. It noted that the Government had planned to provide for the needs of people with disabilities for a number of years in the form of the Health Strategies

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[89]    The period covered was between 1914 and 2000, being the earliest date of admission and the latest date of discharge of those applicants who applied to give evidence of abuse.

[90]    Information supplied by the NDA in correspondence with NESC.

[91]    Cited in communication from the NDA.

(1994 and 2001), the Disability Strategy (2004), the Health Acts 1947 to 2007, the Disability Act 2005, the EPSEN Act 2004 and the Citizens Information Acts 2000–2007.  However, the enquiry emphasised that the net impact of these initiatives for the individuals in the centre has been limited.

One view expressed in the sector was that a focus on standards can bring you to a place where you are ticking all the boxes, where people can have safe lives, but are not enjoying everyday life, and not meeting the important criteria. However, as Henry Ford argued, and as already quoted in the first report from the project (NESC, 2011b), 'if you think "standardization" is the best you know today, but which is to be improved tomorrow—you may get somewhere.  But if you think of standards as confining, then progress stops'  (Ford & Crowther, 1926).

There is widespread recognition in the disability sector that the current model of provision for people with disabilities has to change. The recent policy proposals made as part of the *VFMPR* and new policies from the HSE point to change in line with international good practice towards individualised/person-centred supports rather than specialist disability services. The transformation has been estimated, by the Expert Reference Group on Disability Policy and the Working Group on Congregated Settings, to take approximately seven years in the move from congregated settings to person-centred, tailored provision.  This will bring a set of challenges for regulators in terms of ensuring quality and raising standards, and for service providers, some of which have also been experienced by the eldercare services sector.

One key point is that not all stakeholders in the disability sector have the same view as to what a quality service outcome is, with some service providers seeking a better quality of life as an outcome and some seeking a better quality of service (which may, or may not, lead to a better quality of life). Ultimately, the meaning of quality is undergoing change from a focus on service provision to a focus on outcomes based on a way of living for people with disabilities. There is anxiety expressed by some in the sector that quality as defined today will not be appropriate tomorrow, and a new regulatory system for residential settings will hold things in suspended animation. But the risk of not regulating the current services is considered by many to be far greater.

This chapter has identified a number of key issues for the disability sector, many of which have regulatory implications. There are areas of consensus, good practice and innovations as well as some unresolved issues, tensions and challenges. As the disability sector is in transition, the views expressed understandably include a sense of anxiety and frustration at times about what is to come and how it will unfold. No doubt in a year's time, many of these will have dissipated and be replaced by another set of issues on the ground. The main message from this discussion is that quality is taken very seriously by many service providers, and their experience and willingness to engage on developing regulation and quality in the sector is a strength of considerable value going forward.

# Chapter 5
# A Fine Balance:  Regulation and Quality in Disability Services

## 5.1     Introduction

This chapter reviews the regulation and quality system for disability services and argues that while some of the foundations are weak, such as the lack of formal regulation and external oversight, other key elements have flourished, such as international recognition in quality assurance practices among some service providers. What is required, in our view, is a rebalancing of the regulatory system so that it includes regulations and inspections, on the one hand but also endorses and capitalises on the continuous search for excellence that exists, on the other. In this way, the disability sector could have a responsive and smart regulatory system to protect the vulnerable, be cost-effective and develop the strengths of the sector that are already working to achieve quality. How this can be explored, the risks and gains that lie therein, will be now be examined.

The NESC project on quality, standards and accountability has identified key principles and approaches from international and national literature that have been applied to a range of service sectors. The report, *Overview of Concepts and Practice* (NESC, 2011b), as outlined in Chapter 1, brought together a number of key themes: responsive regulation, involvement of service users, devolution with accountability, monitoring and learning and cost-effectiveness, which are examined below as they apply to the disability sector.

The remainder of this chapter seeks to answer the questions set out in Chapter 1 regarding the effectiveness of this regulatory system and what needs to change (see Boxes 1.1 and 1.2). The chapter concludes by outlining the potential of a quality forum for the disability sector as well as charting some of the challenges that remain.

## 5.2     How Effective is the Current Regulatory System?

The concept of responsive regulation avoids simplistic command and control or just 'bottom-up' approaches but includes a combination of positive engagement  and sanctions of a central authority in a responsive way with frontline providers. It refers to a working relationship between the regulator and regulatee and the wider institutional environment in which this relationship is embedded (NESC, 2012a). For such a system to be effective, the central authority (e.g. a regulator such as HIQA) needs to use a broad set of tools that include formal, legal sanctions and regulations as well as supports and engagement around best practice. It is evident that, in the

disability sector, this set of tools has been underdeveloped and, in particular, the absence of formal regulation has been a significant weakness.

### 5.2.1    Lack of Formal Regulation

There has been no central authority acting in a regulator capacity for the disability sector. While standards have been developed by HIQA, they remain voluntary and have not been yet applied to regulations, and HIQA has not been given the authority to monitor or inspect.  Thus, there has been a lack of formal regulation, mandatory standards, external oversight and inspection of services from the State. Unlike residential centres for older people, disability services remain largely unregulated and many service providers have *no* quality systems in place (HSE, 2012a). As outlined in Chapter 4, this lack of oversight is a concern as it leaves vulnerable people at risk of abuse or neglect at worst, and at the least, allowing poor quality and uneven services to develop. In broad terms, the search for quality has not been driven by the State, but primarily by individual service providers seeking to deliver a better service, with international benchmarks as their guide.

There has been slow progress in the formal regulation of the disability sector over the last decade. This may be both due to financial and political reasons, including the cost of introducing regulation and inspection and the reform needed to improve services across the sector. Registration, regulation and inspection of disability services will reveal weak service areas, which, following the path set out in relation to the care of older people and nursing home provision, will lead to the closure of some services with the need to find alternative services. There are difficult decisions surrounding potential closure of services or reduced funding to local providers, charities and religious organisations. Other factors include the ongoing HSE transformation process and some service provider resistance to standards. However, there is a growing momentum for change and recent policy movements towards more person-centred disability services. Providing services in line with person-centred approaches as planned will require a radical reallocation of existing resources over a phased period, with likely additional interim funds needed to carry all services over the quality threshold. This will not be an easy transition to make for services or for people with disabilities, some of whom may still feel at home in congregated settings, despite their outdated institutionalised approach.[92]

### 5.2.2    Other Key Elements of Responsive Regulation

While a range of quality responses exist from some service providers seeking to provide an excellent service, at the same time there is a lack of information about what other services are providing in terms of quality. There is a lack of guidance, support and encouragement to achieve best practice and this, in combination with

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[92] Research and experience in other countries show that the process of resettling people after a long time in an institutional setting can be challenging and for some people adapting to this change will need considerable time and support to be successful.

the lack of formal regulation, would seem to have increased the gulf between the weakest and the best service provision. Without a central authority to be a key player in responsive regulation, an effective regulatory system has not developed. However, private (and non-profit) quality assurers have played a critical role in supporting and guiding service providers on their quality journeys.

As for most service sectors, the 'regulatory system' for disability services in Ireland is a composite of State, private, voluntary and community bodies, rather than one single regulator driving standards and improvements. While this is where many other jurisdictions are ending up, this is Ireland's starting position and a potential advantage (NESC, 2011b: 76). The disability sector is a good example of this complex mesh of actors. It illustrates our earlier assertion that standards and quality are affected by a range of different organisations operating in a variety of different ways (NESC, 2011b). However, such a mix of actors is only one potential element of an effective regulatory system and it requires official recognition for such regulatory roles.

This element of responsive regulation is known as 'smart' regulation. This is the idea that other key actors in the system perform and achieve regulatory goals, i.e. they act as as 'quasi-regulators'. This can include a variety of regulatory tasks, including standard setting or providing supports to implement standards. At first glance, this could be said to apply to the disability sector. The National Disability Authority (NDA) has played a role in the development of standards, alongside HIQA; the Health Research Board (HRB) provides an information role in the maintenance of the two disability databases; the HSE uses the Service Level Agreements (SLAs) to increasingly consider quality issues; and independent quality assurance organisations and systems such as Centre on Quality Leadership (CQL), European Framework for Quality Management (EFQM) and Practical Quality Assurance System for Small Organisations (PQASSO) have played key roles in building up service providers' capacity for self-monitoring and quality evaluation. There is also vibrancy in the work of national umbrella organisations such as the Disability Federation of Ireland, the National Federation of Voluntary Bodies (NFVB) and, more broadly, the Wheel, in encouraging and developing quality assurance and better governance capacity, as well as the work of organisations operating at local level.

However, the relationship between these actors is not officialised or systemised to any great extent. There is no overall regulatory 'map' of key players and their functions to achieve effective regulation of the sector and, therefore, nothing is in place to capitalise on this potential strength for the disability sector as a whole.

Voluntary disability organisations are using a variety of quality strategies, from the voluntary application of HIQA standards, to quality assurance systems such as POMs/CQL or EFQM. This multiplicity can be seen as strength in regulatory terms demonstrating that there is no single system but *multiple routes* to quality. Many organisations have shown considerable innovation in developing new models of service provision and applying quality assurance systems. It is not clear, however, what impact these quality assurance systems are having on service provision nationally. Anecdotally, and in discussion with service providers, they seem to be

central in raising the bar for many service providers in the absence of any State requirement for quality assurance. Conferences, seminars and networking opportunities are held to promote and share good practice; but with reduced resources, service providers are finding it more challenging to fund and continue to invest in this quality development work. However, this sharing of good practice is essential in the development of quality services. With the service received dependent on where the person lives, this raises equity and fairness issues for the disability sector.

A related element of responsive regulation considered here is 'meta' regulation, in which organisations put in place systems of self-regulation and regulators seek to assure themselves that these systems are adequate and being followed, i.e. it is the regulation of self-regulation. It is the case that many service providers have been left to act as 'independent republics' in terms of their own quality initiatives and practices, leading to excellence in some service provision, but not in others. This is a distinguishing feature of the disability sector in terms of its regulatory system. However, this quality 'work' is not monitored by an official centre or regulator so there is little learning captured from their activities and no official recognition of its value and place in the regulatory system. While this is changing with the new SLAs in place, it is not yet clear how this will be monitored.

Thus, this is a sector characterised by forward-looking and ambitious policy goals, on the one hand, and a lack of regulation of services, on the other.  While having a vision for the direction of policy and practice is essential, it would seem that these have to be embedded or they will remain aspirational. This gap between the top and bottom levels of action, from the State to service providers, has created a complex sectoral landscape in terms of the quality of care provided and the different service models in use.

With different service providers providing varied services in terms of quality and focus, there is a critical role for outcomes that are at the core of the best practice evidence, cited in this report and in the V*FMPR*. There has been a lack of focus on outcomes across the disability sector, with the exception of some service providers, and little accountability in terms of the quality of service delivered. International and national good practice point to the value of identifying and measuring outcomes in disability services. There would be great value in developing a coherent and integrated set of outcome measures. However, it is not yet clear how outcomes could be best defined, measured and monitored effectively across the disability sector. Section 5.2.5 will examine this further.

Other key elements of responsive regulation are discussed in the following sections.

### 5.2.3    A Focus on, and Involvement of, Service Users

Service user involvement has increasingly been evidenced as key to successful regulatory systems at all levels of service design, delivery, regulation and monitoring of outcomes and processes. It is a fundamental part of developing a quality system as a closer relationship with service users, their families and advocates can keep services 'real' as needs and wants change over time. This ongoing interaction is

central to the closer alignment between quality services and the needs of service users.

Understanding what service users want and how they evaluate services is critical to the delivery of a quality service. Currently, the disability sector is open to criticism for not providing the quality, range and quantity of services required. As outlined in Chapter 3, a lack of communication between service providers and service users has been raised as an issue in recent consultations on the *VFMPR* at the Department of Health.

At a policy level, people with disabilities have been consulted regularly as part of ongoing policy developments and reviews and several structures are in place that include service users, such as the National Consultative Fora and the National Disability Strategy Implementation Group. Such representation has also been a feature of the standards development process of both the NDA and HIQA.

However, while the value of such engagement is clear, some service providers place great emphasis on engaging with service users, while others report that it can be challenging (see Chapter 4). However, with the expected introduction of direct payments and individualised budgeting, it is intended that service users will increasingly be at the helm of their service options, rather than having to take the only available service on offer, assuming that the service is available in their locality. This change will in turn place additional importance on the provision of appropriate advocacy and supports as well as on effective service user involvement in achieving greater quality and regulation of services. Without such supports and a responsive regulatory system, service users will not be able to make informed and diverse choices about the services they require.

### 5.2.4    Devolution with Accountability

As outlined in the *Overview of Concepts and Practice* report, the evidence suggests that an emerging approach to regulation is to set a small number of guiding principles 'at the centre' and then devolve their application to the local context. The centre would have an oversight role to ensure compliance but local providers would have the opportunity, and, in some cases, the incentive, to improve quality and performance.  The overriding priority is on achieving and improving outcomes for the service users (NESC, 2011b).

Devolving responsibility to key actors, such as service providers, can be effective as part of a regulatory system, but only with clear accountability mechanisms, as already described in Chapter 1.  In the absence of formal regulation, the disability sector has mushroomed in terms of quality assurance systems and approaches, with service providers taking responsibility for this practice. The driver for many service providers to develop governance and quality assurance systems seems to be grounded in quests for excellence and innovation and by a genuine desire to improve the lives of the people with disabilities who use their services. While some service providers have taken responsibility for quality, there is no clear accountability if quality services are not achieved. Some State funded services have no quality assurance practices in place. Ultimately, the HSE can withdraw funding

from poor services but such extreme action is rare. The HSE is in the process of developing clearer quality guidelines and it is expected that this will tighten up the requirements for quality assurance systems to be in place. However, it is not yet clear to what extent this will be monitored in practice.

Alongside the Department of Health, the HSE and HIQA, other key actors in the disability sector have important roles, including the NDA, the HRB, representative voluntary agencies such as DFI and the NFVB. However, as in other service sectors, the relationships are *ad hoc* and there are areas both of duplication and potential for oversight in terms of what services are provided and the quality checks that are in place. What would seem to be absent is a more strategic and comprehensive strategy for service quality for the disability sector, which would bring in all the relevant bodies to work in partnership.

Underpinning such an approach would be greater co-ordination between policy, service planning and delivery in pursuit of common aims to achieve and improve outcomes for service users. In addition, a stronger emphasis on good governance and accountability across all levels of service planning and delivery would support the achievement of outcomes.

### 5.2.5     Monitoring and Learning

The literature reviewed in the *Overview of Concepts and Practice* report (NESC, 2011b: 41) outlined the value of learning as part of a regulatory system and that developing diagnostic monitoring, problem solving and reflecting on this learning can be effective at all levels. As part of this learning, the systematic gathering and monitoring of information is critical to a responsive regulation approach (NESC, 2011b). Data us gathered across the disability sector, to inform the HRB databases and to provide service level information for the HSE. Further data is recorded by the HSE from SLAs but it is not clear how this is used for monitoring or learning purposes. There are skills and experience in quality assurance systems, and in service providers who have, in some cases, built up quality systems from scratch involving detailed analysis of individual and organisational outcomes. But the capacity to monitor, reflect, problem-solve and share the learning has not been developed extensively across the disability sector and therefore the ability for service providers to become learning organisations is at best uneven, i.e. good in some areas but absent in others.

There is a need to strengthen capacity within the disability sector and 'in the centre' in the kind of diagnostic monitoring and Quality Service Review (QSR) presented in Chapter 1.  Harnessing this experience for the benefit of the wider sector could be part of a wider monitoring and learning element of a new regulatory system. Incentivising the sharing of good practice is of great potential value, through regular meetings, peer review and other mechanisms, as well as considering national and international benchmarks. There are examples of interesting practice to draw from, for example, in relation to web-based learning, such as the HSE's learning hub and the English National Development Team, (NTDI) mentioned in Appendix A, for sharing of good practice. Furthermore, the capacity of State-funded organisations

such as the NDA and the HRB to provide research, review and find evidence-based practice solutions could be further utilised.

At a time of change and with reduced resources, the disability sector will need support to develop this learning capacity. If this does not happen, learning will remain piecemeal and partial, and the potential for building quality from the bottom up will not be realised. Work by Genio, with funding from the Department of Health and the HSE, provides a valuable way forward in their model of funding innovative projects and in seeing how to scale up to mainstream levels without losing the innovation. The sharing of such learning throughout the disability sector would provide a good example of 'triple-loop learning', outlined in Chapter 1.


### 5.2.6      Cost-Effectiveness

Achieving reform is central to implementing the recommendations of the *VFMPR* and:

> the Department of Health is committed to using this VFM and Policy Review of Disability Services as a mechanism for implementing reforms to the system of financing and delivering disability services and enhancing the cost-effectiveness of those services.

However, it acknowledges that the relationship between quality and costs is a complex one;  they are inextricably linked and 'it is futile to measure the efficiency of a process if it is not delivering the required result to the required quality' (Department of Health, 2012a: 87).

The provision of quality services and supports are therefore integral to the new model. The *VFMPR* emphasises the key role that good governance and accountability will play to ensure quality of services and supports in future, as well as HIQA's role as regulator.  As with residential centres for older people, it is likely that formal regulation and inspection will require additional costs, but that this will safeguard vulnerable groups and bring wider and social benefits for people with disabilities and their families (NESC, 2012c: xv).

The additional drivers of quality outlined in this report will not necessarily require new resources. Their emphasis on quality assurance practices, monitoring and learning, and service user involvement, require a change of focus and work practices at a service provider level, as well as at national planning and delivery level, in particular the move from institutional to person-centred services. If implemented and regularly reviewed, these measures are likely to reduce waste and poor practice.

## 5.3    What Needs to Change? Embedding Responsive Regulation

There is no perfect regulatory system. Our work to date across different service sectors, and our review of literature and practice, show that there is no one 'size fits all' and all regulatory systems need regular revision.

We suggest that three key areas of change are required to move towards a more effective regulatory system for disability services:

1.  Establishment of **formal regulation**, such as mandatory standards (flexible and performance-oriented) and external oversight of residential services (and, in time, other services where this form of regulation is appropriate), as part of a balanced, harmonised set of regulatory tools;

2.  Effective quality assurance processes, a focus on **continuous improvement** and the achievement of outcomes for all service providers (e.g. through SLAs); and

3.  Connect the key actors to develop a **forum** for performance dialogue on responsive regulation practices, problem-solving strategies and review (e.g. Quality Services Forum, see below).

### 5.3.1    Establishment of Formal Regulation

It is important that the State has some external oversight and can regulate, to some extent, the quality of services being provided on its behalf. Standards for residential services for adults and children with disabilities, currently under review by HIQA, are expected to be made mandatory by 2013, along with the registration of service providers and inspections. This will finally bring in the mandatory standards and formal regulation that is required to safeguard the most vulnerable service users in residential settings.

According to the NDA, standards should sit among a range of tools like the best systems elsewhere in the United States, New Zealand and Victoria in Australia (NDA, 2010b). However, standards alone do not make an effective regulatory system. Other developments that are likely to increase the extent of formal regulation include the increased focus on quality in the HSE's SLAs. As yet, there is no clear overall picture of what a regulatory system could be for this sector and how these different elements will be connected. It is, as clearly voiced by some stakeholders in the previous chapter, a complex sector in which to build an effective regulatory system, given the breadth and depth of variety of practice and the ongoing transformation.

While formal regulation is important, a responsive regulatory system has to use a balance of tools, including rewards and sanctions, and involve key stakeholders in the delivery of quality services. Such approaches include smart and meta-regulation,

outlined in Chapter 1 and above, and as the disability sector continues on its regulatory journey, these should also be considered.

However, in relation to this transition, an important question that emerged from the discussion with stakeholders (outlined in Chapter 4) is how does a focus on fine-grained, gradual improvement of existing services (through the use of standards) relate to  radical change in service models, for example, in the move away from congregated settings? Some stakeholders are concerned that establishing a formal regulatory structure for residential services (through mandatory standards, registration and inspection) might suspend the sector and act as a deterrent to the application of new models, such as person-centred supports and individualised budgets. This view is shaped, understandably, by the considerable time delay experienced by the disability sector from the first development of standards to their expected commencement. It is likely that future standards could be developed and implemented within a much shorter period of time. Furthermore, the experience of the eldercare sector is that the process of introducing mandatory standards increased discussion concerning continuous improvement and reforming practices, rather than being a deterrent.

A further point is that while the intention is that some people with disabilities will live more independently with supports, others argue that there will still be a need for some residential services, which will require regulation. Here, as in the health area, for example, it is suggested that the best way forward is to have a general framework of standards and that service providers can implement them according to their own particular context, for example, residential standards for older people. Quality assurance systems, especially those already in existence, could have an important role to play. This relationship between changing models of provision and quality and regulation is of wider scope and will be explored further in the report, *Achieving Quality in Ireland's Human Services* (NESC, 2012a).

Safeguards will be required to be put in place during the transition from one provision model to the other, in particular, to ensure that regulations and standards are in place for the care of vulnerable adults and children. This transition will also need to include regulatory participation to review the development of service models and share innovative quality assurance processes. The proposed quality forum could provide an important nexus to which key stakeholders could belong while the sector moved forward.

As shown in the report on residential services for older people (NESC, 2012c). HIQA has demonstrated the value of mandatory standards and inspection as a way to improve quality in services. However, as a regulator, HIQA *alone* cannot ensure quality service delivery. Service providers in the disability sector have been using quality assurance systems and these could continue to have a role.

The value of this emerging regulatory system is that it will be, for the first time, closely managed and driven by a regulator, but it will require all stakeholders to have a role. Regulatory interventions are more likely to succeed if they are responsive to the culture, context and conduct of the regulated organisations (Ayres & Braithwaite, 1992). However, responsive regulation must at the same time be progressive, where a regulator works with organisations to improve and develop

the quality and services. This is a particular challenge where organisations are, for various reasons, resistant to change.

As this report shows, service providers are being asked to think differently about their future role, seeing the value in personal (family and friends) supports and community connections outside of what they offer in a specific service. Supporting people with disabilities in this context will involve building networks out into the community while at the same time deconstructing a system of dependency inside congregated settings. There is an emerging view that active citizenship, or participation in normal life activities, is the quality benchmark that services need to aim for, not just the quality of the service provided.

### 5.3.2    Effective Quality Assurance, Continuous Improvement and a Focus on Outcomes

One emerging conclusion of this report is the value of building on existing good practice in the disability sector in relation to quality assurance, continuous improvement and outcomes. However, it is as yet unclear how current practices in these areas will be impacted by the introduction of mandatory standards for residential services.

In other jurisdictions, such as the UK, service providers are treated as self-regulators and once they are accredited with a recognised quality assurance system, they are not subject to the same level of scrutiny as those without such systems. The benefits of such self-regulation (meta-regulation) are (i) cost-savings due to a reduction in inspections; (ii) greater autonomy for service providers; and (iii) a diversity of quality provision.

However, the risks include (i) a lack of general oversight of these services; and (ii) inequity, as some are inspected while others are not; and (iii) a lack of shared learning. While there are no current plans by HIQA to adopt this meta-regulatory approach, it is one worth considering as part of a broader regulatory system and would increase partnership in regulation, where different players in the regulatory system share some of the regulatory work (smart regulation). This involves a model whereby the centre governs (and regulates) through promoting collaborative, critical and honest self-evaluation and self-improvement (Leadbetter, 2006). The UK's Healthcare Inspection Concordat (Agreement), mentioned in Appendix A, shows how such a working partnership can be valuable.  This involved twenty organisations working together to audit their work against ten objectives that were designed to promote closer working between the signatories.

Most people with disability use mainstream services so it is not only specialised services that should meet standards. As well as the fundamentals of effective regulation such as safety, accountability and good governance for those services, quality for service users will be experienced as being able to access the appropriate mainstream service, with adequate community supports. Tailoring of services to the needs of people with disabilities is important in this context. Appropriate assessments of need, advocacy supports and defining goals and outcomes are

therefore critically important elements of quality in service provision for people with disabilities.

NESC's report on the Development Welfare State (NESC, 2005b) argues for the importance of defining goals and outcomes for service users, service providers and system-wide outcomes.

The *VFMPR* recommends that:

> The achievement of measurable outcomes and quality for service users at the most economically viable cost should be an ongoing process and be subject to regular review and audit (Department of Health, 2012a: 127).

This approach, it is argued, will streamline policy goals with outcomes directly and is also very much in line with the recommendations of the OECD review of the Irish Public Service and the subsequent ongoing transformation programme (OECD, 2008).

It seems opportune that the work on measuring personal outcomes will take seed here and help reinforce quality into the heart of the new service model.  Given the person-centred focus of new service models, how can these be most effectively compared and monitored to achieve greater learning? What is the benchmark for the evaluation of these outcomes across the disability sector, and not just for each individual?

Furthermore, who decides on the outcomes selected and for what service users? There are many people with disabilities who are already living in the community, but without sufficient supports. DFI argues that their outcomes need to be progressed in any new model of service provision (DFI, 2011a; DFI, 2011b). Further dialogue, required to establish how outcomes, measured on an individual level (as well as at service and sector level) can be effectively quantified, compared and used as a performance indicator. Services could be monitored through continuous improvement and some external oversight but with the individual's needs, quality of life and personal outcomes as the central driver.

### 5.3.3    Quality Services Forum

From our work, it would seem to be the case that for continuous improvement and innovation we need a *combination* of (a) standards and inspection; (b) a range of other drivers, such as quality assurance systems and service user involvement that are (c) connected to each other in an appropriate way. Given that actions towards both (a) and (b) are currently progressing in the disability sector, we now turn to (c), the connection between these elements.

One possibility is that this could be achieved through the establishment of a Quality Services Forum for performance dialogue, monitoring and analysis against agreed outcomes for the disability sector[93] with a defined (and complementary) role for all participating stakeholders; and a supporting set of responsive regulation principles/framework, which could be developed through discussion as part of such a forum. However, this must be underpinned by an active regulator working with the disability sector, equipped with a wide range of regulatory tools, including standards, regulation and inspection.

Such a forum would bring together the different regulatory stakeholders to 'weave the web' through discussion of quality outcomes, encompassing service users, service providers, representative bodies, statutory agencies and regulators, among others. The weaving of the regulatory web provides the potential for inter-connection and dialogue that may already be there on an *ad hoc* basis but without the working centre. Using the 'weaving the web' metaphor, the centre or 'spider' is there to manage the 'web' and make sure it is in good working order. It would enhance the prospects for an appropriate responsive system of regulation that includes all stakeholders, and they would not be easily isolated from their wider social interactions (Hulme, 2009), a sum greater than its parts. It could bring the elements of disability policy and regulation together, giving the sector greater cohesion. However, there are a variety of ways this could be formalised or developed to suit the disability sector and could work with existing structures, such as the National Consultative Fora, for example, with a focus on improving quality. In addition, the National Disability Strategy (NDS), as in other jurisdictions, could play a stronger role in the regulatory system for the delivery of quality services. The *interactive element* of such a forum in the current disability sector would be important, given the years it will take to shift provision from the old to new models, as set out by the *VFMPR*. Discussion with stakeholders on an ongoing basis is valuable.

Appendix B illustrates the different participants in the disability sector who could be part of a Quality Forum. This would include HIQA as the regulator, the NDA in advising on standards, and on monitoring codes of practice under the NDS, and in providing evidence-based research and information for the disability sector on best practice in quality provision and measuring outcomes. The Department of Health has a key role developing policy-aligned provision, with the HSE also having a key role in planning, funding and delivering services, as well as now in relation to quality and patient safety; both have important quality dimensions. HSE managers could, for example, have discretionary powers to reward excellence in quality assurance. Other key roles include monitoring data/evidence indicators, and the HRB has played a supporting role in maintaining the national disability databases. This tool could be developed further in the context of quality assurance and measuring outcomes.

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[93]  While particularly valuable for the disability sector at this time, such a forum could be useful for other social service sectors.

A forum of this kind could help identify and tease out some of the existing tensions surrounding the regulating of services, some of which are identified below. There would be capacity to derive benchmarks of good practice across all disability service areas, drawing from existing best practice among service providers.

Underpinning the forum would be a set of principles or quality framework for the disability sector. This would bring a common focus to regulation for all stakeholders that is not there at present. In addition, it would help avoid over-regulation and duplication through close collaboration, for example, in relation to standards for day services, currently being developed by the HSE (as part of *New Directions*) or support services in the home for which a regulatory plan has yet to be established.

Drawing from all the documentation and research material used in this project, the elements of a potential forum are set out in Table 5.1. This is not a static model, but rather provides some of the elements to be considered. These would need to be developed further to see how they would be most effective within the disability sector.

**Table 5.1          Suggested Elements of a Quality Services Forum**

|  |  |
| --- | --- |
| **Collaboration and Dialogue** | **Close working relationship between a wide network of actors including the regulator, service providers, service users and policy makers with regular meetings to review and discuss the regulatory system (weaving the web).** |
| **Service User Involvement** | **Involvement at all stages of regulatory development and standard setting, as well as in the design of monitoring and evaluation for services.** |
| **Learning culture** | **Support guidelines for self-regulation, use of peer review and sharing of good practice among service providers through the forum.** <br><br> **Discussion of outcomes/evidence indicators at individual, service and sector levels and other service data that could be shared and be part of a learning/reflective process (diagnostic monitoring). Setting out benchmarks that include quality of life and quality of service.** <br><br> **Rewards: recognition for innovation in quality services.** |

## 5.4     Regulatory Challenges for the Disability Sector

The regulatory future for disability services is emerging. Both HIQA and the HSE are likely to play increasing roles in safeguarding the quality of services in the next year. As outlined in Chapter 3, the *VFMPR* also includes recommendations regarding quality and regulation for the disability sector. The main regulatory recommendations raised by the *VFMPR* include:

- A quality framework for disability services, including quality assurance practices and increased formal regulation of residential services;

- Transparency, greater accountability and good governance, including allocating funding on the basis of measurable service user outcomes; and

- Identification and dissemination of good practice as well as research, development and implementation of innovative interventions.

The implementation of these recommendations would strengthen the regulation of the disability sector. However, given the increasing regulatory roles of both HIQA and the HSE, there is no clear mechanism for cross-agency discussion on the sector, or for service user and service provider involvement. The value of such discussion is that it would allow stakeholders take a step beyond the immediate challenge at hand, to broader quality and regulatory issues, and if tied in with systematic monitoring and reflection, would help develop a learning culture. Given the service models are in transition, it places increasing importance on 'learning by doing' and share good practice and outcome data. Such learning is available already with innovative service providers if the appropriate mechanisms are put in place to capture and share this across the disability sector.

A further challenge is how to best regulate home-care and personal assistance services. This is not included in the *VFMPR* and yet such services are central to successful delivery of the new person-centred model.

A Quality Services Forum could consider what constitutes an effective regulatory system and, as outlined at the start of this chapter, what a quality service entails. An effective regulatory system is not always in harmony as friction and different ways of seeing things are integral and should be used as a basis for reflective practice. Allowing for difference in approaches, given the innovative practice that exists, is likely to lead to a more vibrant service sector. However, to be effective, such a system needs 'the centre' to play a clear and driving role by setting out mandatory standards, enforcing regulations where necessary and providing the 'gorilla in the closet' (Gunningham, 2010b) that underpins the broader regulatory framework. However, the centre or State is also singularly placed to play the softer role of bringing the stakeholders and quality drivers together – joining up policy and driving the development of quality.

There are key issues that the Quality Forum could usefully explore:

i.      There are tensions in regulating two co-existing models of provision in times of profound change and transition; moving from a model of paternalism to a rights-based approach.

ii.     Creating a dynamic and responsive regulatory system in a sector that has not traditionally worked together is a challenge. Fostering a collaborative focus to regulation will help, rather than service providers potentially viewing it as a further arena for competition for resources. This could become a bigger issue with increased tendering for services.

iii.    There is a need to take seriously the concern that some service users have over regulation. Some think that increased standardisation is at odds with increased individualisation of services and will restrict choice and autonomy. It is the case that all services will, in the near future, need to provide quality services on a par with other services, following criteria and standards set out and enforced. However, this is unlikely to deter the new model of provision striving for person-centred, tailored services at home and in the community. It does, however, present a challenge for the development of appropriate standards and measurement of outcomes and, in particular, the importance of an appropriate assessment of need process.

iv.     There is value in supporting people with disabilities to be the judges of quality, be centrally involved in regulation and have increased expectation of reaching their personal outcomes.

v.      Within the disability sector, there are different views as to what a quality service should be and variation between quality assurance systems, regulations and standards. What will be the key quality indicators? There is a challenge to be met in identifying, agreeing and monitoring appropriate outcomes over time in a consistent robust way that will inform service planning and delivery. This applies to all service areas and is aligned with the ongoing public-sector reform agenda. POMs/CQL provide a useful model here and the *VFMPR* also outlines suggested outcomes for the sector for individuals, services and the sector as a whole. It is worth reflecting again on the words of one of the stakeholders from Cheshire Homes,. consulted as part of the project: 'It's about holding quality in hearts and minds. Standards you can meet, but you are not going to meet quality of life with them alone.'

vi.     How can the learning from existing good practice among some service providers be best utilised by the disability sector, and, in doing so, help move towards the new model of service delivery?

vii.    Other questions include, how should innovation and good practice be rewarded so that the system is not solely focused on compliance with mandatory standards? How can a diversity of quality approaches be supported to foster innovation and excellence, while still safeguarding the most vulnerable?

viii.     There are lessons for this sector from the care of older people: with residential centres now regulated, there is on ongoing challenge to regulate home care services and supports. Much can be gained in a cross-sectoral discussion of these and other significant issues emerging from regulating human services.

## 5.5     Next Steps

This report is one of a series of reports on quality and standards in human services, the others examining eldercare, end-of-life care, the school system and policing. The first report, *Overview of Concepts and Practice,* and the final synthesis report, *Achieving Quality in Ireland's Human Services*, bring together the literature and findings from this project, identify areas of common practices and differences and raise questions regarding the future of social regulation in Ireland. It is hoped this work, in its totality, will help foster greater dialogue on the role of regulation and quality assurance in the delivery of our services, show, for the first time, the diversity and strength of many service providers striving for excellence.

# Appendix A
# International Quality and
# Regulatory Systems

In other developed countries, there has been change in terms of models of disability services and supports, moving away from high levels of institutional provision and block-funding of services with limited systems of oversight towards more tailored and flexible, quality services. As the National Disability Authority (NDA) argue:

> the challenges Ireland now faces to reorient its services are not unique, and we can learn from the experiences of other countries which have undertaken a similar journey, and from innovative service developments here in Ireland (NDA, 2010a: 18).

The NDA concludes that in order to be fully effective, standards and regulations need to be developed and implemented as part of an overall quality framework, underpinned by robust, ongoing surveillance activities at national level, based on agreed indicators. The UK and Victoria (Australia) provide good examples of this approach (NDA, 2010b).

One issue emerging relates to finding ways to reduce the burden of assessment through harmonising standards and measurement criteria. The NDA argues that

> increasingly service systems are seeking to introduce interoperable (harmonised) quality assurance systems as a means of reducing the burden of assessing quality and achieving improved efficiencies in quality assurance, monitoring and evaluation (NDA, 2010b: 83).

This points to the value of using a single audit tool or set of standards that have have a broad applicability across various forms of service provision (e.g. residential and day services), which would reduced the burden of audit or review.

The NDA cites the UK's Healthcare Inspection Concordat (Agreement) as an example that involved twenty organisations working together to audit their work against ten objectives that are designed to promote closer working between the signatories. These included objectives aimed at delivering more consistent and coherent programmes of inspection; improving services for patients, clients and their carers; and reducing unnecessary burdens of inspection on staff providing healthcare. Each objective is underpinned by a number of practices that focus developments on areas that will help to secure effective implementation (Commission for Healthcare Audit and Inspection, 2006).[94] This approach is an example of bringing in some local

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[94] This was superseded by the Care Quality Commission established in 2009 as a single body to regulate and inspect health and social services in England.

autonomy and continuous learning while still retaining some overall accountability in the delivery of services.

The *World Report on Disability* (WRD) also emphasises the value of a quality framework in which different roles are ascribed to stakeholders:

> Governments should develop, implement, and monitor policies, regulatory mechanisms, and standards for health care provision to ensure that they include people with disabilities. Service providers should provide the highest quality of health services. Service users, disabled people's organizations, and professional organizations should increase awareness, participate in policy development, and monitor implementation of policies and services. Through international cooperation, good and promising practices can be shared and technical assistance provided to countries to strengthen existing policies, systems, and services (WHO & Bank, 2011: 82).

With regard to community settings, many of the jurisdictions were concerned with how to guarantee quality while facilitating innovation in community-based and self-directed supports. One positive example is local area co-ordination in which a local area co-ordinator works with families to find and build different kinds of supports within their community. Related to this is the rise of advocacy services that help people access mainstream and other services and assistance technologies, using ICT to enable independence for people with disabilities and older people (NDA, 2010b). A further trend is towards personalised services. This involves not just personalised services but replacing a model in which the centre controls, initiates, plans and instructs, with one where the centre governs through promoting collaborative, critical and honest self-evaluation and self-improvement (Leadbetter, 2006).

Victoria State in Australia has developed a quality service framework with integrated accreditation, standards and monitoring of outcomes and evidence indicators across service areas (Department of Human Services, 2011).

> The Quality Framework is a system to ensure that services and services for people with a disability are regularly reviewed to meet agreed standards and are constantly being improved. It underpins the effective measurement, monitoring and improvement of service quality.[95]

This is achieved by using a range of quality management tools, whereby disability service providers measure the quality of their practice by gathering data against evidence indicators that describe areas of life that are important to people, and areas of good practice that are important to organisations. The quality framework defines six organisational practice areas which are: organisational culture and governance; policies and practice; support options; working with the individual;

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[95]  http://www.dhs.vic.gov.au/for-service-providers/disability/service-quality-and-improvement/quality-framework-for-disability-services/implementing-the-quality-framework/about-the-quality-framework

working with personal networks and working collaboratively. (See Appendix C for a model of these.)

The WRD gives an example of personalised services in the United States:

> The Illinois Home Based Support Services Program, a direct payment scheme, supports people with disabilities and their families to decide which services to buy, including respite care, personal assistance, home modifications, recreational and employment services, therapies, and transportation. Families that used this service were less likely to place family members in institutional care. Efficiencies resulted because families tended to not spend all the available funds, and home-based care costs were lower than those of institutionalization (WHO & Bank, 2011: 152).

The WHO/World Bank report goes on to explain that:

> In practice, and depending on needs and preferences, people with disabilities may opt for varying levels of choice and control. In the United Kingdom, despite the growth of personal assistance schemes, the majority of people with disabilities still do not opt for direct payments. So a range of models is needed, and further research should determine which models of personal assistance are most effective and efficient (WHO & Bank, 2011: 153).

A further service trend outlined in the world disability report is towards community-based rehabilitation programmes (CBR) which focus on facilitating disabled people's participation in the community (WHO & Bank, 2011:154).

These new models all present regulatory challenges. The NDA recommends that a set of service area-specific outcome indicators should be written into service specifications, attached to Service Level Agreements (SLAs).[96] However, it is not clear what would then happen, should a service provider fail to achieve acceptable levels.

Finally, in terms of international trends and developments, the European Coalition for Community Living, a European NGO, is part of a movement towards independent living for people with disabilities with all related services being re-engineered accordingly. The Coalition has been working on interpreting the UN Convention in relation to what it requires for independent living and services. This will have relevance for services here once the Convention is ratified and in light of the shifting policy direction towards person-centred services.

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[96] This is a view similar to that expressed in an earlier report (Comptroller and Auditor General, 2005).

***Using Outcomes***

According to the NDA, the thrust of policy in recent years internationally, and in Ireland, has been towards support for independent living, expansion of provision of personal assistance, and providing new residential care places within the mainstream community (NDA, 2010b).  In this way, mainstreaming services for people with disabilities, as opposed to specialist provision, is increasingly part of current policy but the supports needed to access and utilise mainstream services have been slower to develop. For instance, one evaluation study argues that policy changes have occurred at a European macro level of law and policy (and in Ireland too) without having a significant impact on the lives of people with disabilities, with poor co-ordination of services and unsatisfactory experiences reported on the ground (Lundstrum *et al.*, 2000).

The NDA conducted a *Review of International Outcome Measures in Disability Service Provision* (NDA, 2010c: 2) with a particular focus on independent living. In assessing outcomes, the NDA refers to data or research findings on the long term changes that have occurred in the lives of people with disabilities as a result of policies, services and programmes. Of the six areas covered, Norway has some of the most comprehensive data sets of outcomes on a societal level for people with disabilities but not exclusively for those using services.

In England, local authorities are required to report annually on social care performance outcomes for people with disabilities using services. These include improved quality of life, increased choice and control, and economic well-being. These are graded from performing poorly to performing excellently. The English government has worked towards social care outcome measurement as part of a project called the Quality Measurement Framework 2006–2010, which includes a toolkit for local authorities to assess and monitor performance, including social care. At a specific service level, individual home care services are also inspected by the Quality Care Commission and reports published online up to 2010. England is currently developing a new system of standards that recognise excellence. Scotland, too, has a set of national outcomes that local authorities have to work towards.

Finally, the United States has a voluntary performance measurement and evaluation system related to disability services called the National Core Indicators (NCI), in which twenty-five States are participating. This is a multi-State collaboration of State disability agencies interested in measuring how well public developmental disabilities services support people (Bradley, 2011). Its premise is that improving performance starts with measuring performance over time and against multi-State benchmarks. It has resulted in a thirteen year-old database on over 12,000 individuals.

Across the jurisdictions examined by the NDA, of which only four are cited here, there is a move towards outcome-oriented standards. For example, England's Care Quality Commission has replaced the National Minimum Standards with Compliance Guidelines, and, while still mandatory, assess, the care received rather than the systems providing the care. Outcome-oriented standards are essentially statements of required outcomes for the user of a service or support.  Also, Scotland's National Care Standards for care in the home have outcome and performance dimensions.

While the NDA notes that there is a lack of data-led outcome monitoring across the EU, it also argues that this is changing. One initiative is the EU-funded network ANED [97], a dynamic source of research-based information with regard to disability policy and services, including those related to independent living and their impact on the lives of people with disabilities across the EU Member States.

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[97]   Academic Network of European Disability Experts.

# Appendix B
# Stakeholders/Roles in a
# Disability Quality Service Forum

## Stakeholders/Roles in a Disability Quality Service Forum

| | | |
|---|---|---|
| HIQA (standards, regulations, inspection) | Quality-Assurance Systems and Organisations | Service users, family and circles of support |
| NDA (quality advice, research, networking, shared learning); other research institutions | Service providers (State , private and community, and voluntary) | Dept. Health (policy and direction)<br>Linked to UN Convention<br>National Disability Strategy |
| HSE (SLAs), Disability Unit, Quality and Patient Safety Directorate | Monitoring Data, e.g. HRB and CSO measuring personal and health outcomes/quality-of-life indicators | Umbrella organisations, professional bodies,  other stakeholders (sharing the learning) |

# Appendix C
# Victoria State Quality Framework: Organisational Practice Areas and Outcomes for Service Users

## Victoria State Quality Framework: Organisational Practice Areas and Outcomes for Service Users

The Victoria Quality Framework includes organisational practice areas and outcomes for service users. This illustrates how these might work together. The diagram depicts how the areas of life important to people and the organisational practice areas work together to support outcomes for people with a disability.



**Source** Department of Human Services, Victoria State, Australia

# Appendix D
# Additional Disability Sector
# Standards, Guidelines and Frameworks

## Additional Disability Sector Standards, Guidelines and Frameworks

| | | |
|---|---|---|
| **Framework for the Delivery of Early Intervention Disability Services, Children 0–6 (HSE, 2010)**[98] | **Used by the HSE to develop early intervention services. It sets out standards for the development of co-ordinating teams for children's services in a local area. These were developed by the HSE in consultation with those working in early intervention and parents.** | **Voluntary.** |
| **Guidelines on the Individual Education Plan Process (National Council for Special Education, 2006)** | **Guide to good practice in relation to the preparation, implementation and review of Individual Education Plans (IEPs) for children with special educational needs.** | **Voluntary.** |
| **Guidelines on Person-Centred Planning in the Provision of Services for People with Disabilities in Ireland (NDA, 2006a)**[99] | **Recommendations on how to go about drawing up a person-centred plan and creating a context that will support its realisation.** | **Voluntary.** |
| **Guidelines for local implementation groups on developing a governance structure and policies for children's disability service (HSE, 2011a)** | **Sets out working practices and systems for developing governance of disability services in local areas. These were developed by a sub-group of the National Co-ordinating Group of the Progressing Disability Services for Children and Young People programme.** | **Voluntary.** |
| **Guidelines for Accessible Maritime Passenger Transport (Department of Transport and NDA, 2010**) | **Produced as part of the Department of Transport's Sectoral Plan drawn up under the Disability Act 2005, which outlines that obligations to do with accessibility provision will apply to all operators of public transport services, both public and private** **.** | **Voluntary.** |

[98]   Following on from the Report of the National Reference Group on Multi-Disciplinary Services for Children 5–18 (2009).

[99]   Person-centredness is defined in the draft National Standards for Disability Services as 'seeking to put the person first' (NDA & Department of Health and Children, 2004).

| | | |
|---|---|---|
| Quality and Risk Management Standard (HSE, 2007) | This presents a framework to manage risk using an integrated quality and risk management system. | Compliance to the standard is assessed by the HSE through approved documentation. |
| Children First: National Guidance for the Protection and Welfare of Children (DCYA, 2011) | Guidance for all services working with children. | Voluntary. |
| Draft National Standards for Disability Services (NSDS) (NDA and Department of Health and Children, 2004) | Pre-HIQA standards for all health-funded disability services. These refer to disability services more generally. They are presented as an integrated quality framework and are divided into five sections with criteria for each section. | Voluntary. |
| Draft National Code of Practice for Sheltered Occupational Services Dept Health (Department of Health and Children, 2003) | This Code provided for standards for the operation of sheltered occupational services, including rights and entitlements, the provision of allowances, personal development activities, complaints procedures, and diversity and equality. These have not been adopted formally. | Not mandatory and not in use. The HSE review of day services has recommended that HSE-funded service providers should no longer provide sheltered employment or supported employment. |

# Appendix E
# Personal Outcome Data
# Analysis Example

# Outcomes Analysis



**Outcomes Present, Support Present, Priorities**

Legend: ■ Outcome  ■ Support  ■ Priority

Y-axis: Percentage (0–100)

Categories (X-axis):
- Are Connected To Support Networks
- Are Respected
- Are Safe
- Choose Personal Goals
- Choose Services
- Choose Where They Live
- Choose Where They Work
- Choose With Daily Routine
- Decide When To Share Info
- Exercise Rights
- Experience Continuity And Security
- Free From Abuse And Neglect
- Have Friends
- Have Intimate Relationships
- Have The Best Possible Health
- Have Time, Space and Privacy
- Interact With Community Members
- Live In Integrated Environments
- Participate In Community Life
- Perform Different Social Roles
- Realise Personal Goals
- Satisfied With Personal Life
- Satisfied With Services
- Treated Fairly
- Use Their Environments

# Appendix F
# Stakeholder Research

The NESC Secretariat is grateful to all those who participated in this project. For confidentiality reasons, individuals are not named but include representatives from statutory agencies, government departments, voluntary organisations, umbrella organisations, carers and service users. Some of the consultations were workshops and interviews, while others were phone calls. A few individuals took part in their roles as carers and service users. Those consulted included:

The National Disability Authority

HSE National Disability Unit

The Health and Information Quality Authority

The Department of Health

Inclusion Ireland

The Wheel

Irish Wheelchair Association

National Learning Network

Central Remedial Clinic

Not for Profit Business Association

Enable Ireland

National Council for the Blind in Ireland

The Disability Federation of Ireland

National Federation of Voluntary Bodies

Cheshire Homes

Western Care

Prosper Fingal

Excellence Ireland Quality Association

Genio

Sunbeam House Services

The Children's Sunshine Home

National Institute for Intellectual Disability, TCD

Centre for Disability Law and Policy, NUIG

Dara Residential Services

KARE

For coding purposes in the text, those consulted have been given a number and a prefix when quoted. Those working with service providers are prefixed with SP, umbrella organisations with U and other stakeholders with ST. When referring to individuals as service providers, it should be noted that those consulted were often quality co-ordinators or managers and were not necessarily talking only about their service but quality issues in general. Wherever possible, anonymity has been protected.

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