



An Chomhairle Náisiúnta Eacnamaíoch agus Shóisialta
National Economic & Social Council

Quality and Standards in Human Services in Ireland: Disability Services

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 NESC¹ 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.² 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 side exists, which shows the excellence and internationally recognised quality provision by some voluntary providers who have brought in their own quality

¹ 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.

² HSE figures for 2009.

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.³ 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 importance. There would be great value in developing a

³ 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).

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.

