Quality and Standards in Human Services in Ireland: Disability Services

Non-Technical Summary
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This report focuses on quality and standards in disability services. It is one of eight reports from a NESC project that looks at how quality processes, standards and regulations contribute to continuous improvement in delivery of 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 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. 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) 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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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 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.

3 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 shared across the wider disability sector. Combined with regulation, inspection and standards, the disability sector could set the benchmark for good regulatory practice.
QUALITY AND STANDARDS IN END-OF-LIFE CARE IN HOSPITALS – NON-TECHNICAL SUMMARY