

FROM CONGREGATED TO COMMUNITY LIVING

MOVING AHEAD



Mapping the National Disability Policy Landscape



TRINITY
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Health Research Board

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This report was undertaken as part of the Moving Ahead project, a research study that aimed to examine the role of factors that contribute to the successful transfer of residents with intellectual disabilities from congregated to community-based living arrangements in two regional areas in Ireland. The study was undertaken by a team of researchers from Ireland and the UK, led by Trinity College Dublin. The research was awarded funding from the Health Research Board's *Health Research Awards 2012-2014*.

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Further details of the study can be found at <http://socialwork-socialpolicy.tcd.ie/moving-ahead/> or by contacting Dr Christine Linehan, Principal Investigator at the School of Social Work and Social Policy, Trinity College Dublin and School of Psychology, University College Dublin.

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1. The Development of Irish Disability Services

- 1.1 The historical development of services for people with disabilities in Ireland can be traced to an edict by the Westminster Parliament in the early 19th century not to provide ‘outdoor relief’ to those in need. Assistance would be provided only to those who entered workhouses, thereby excluding those who remained in the family home. The quantum of workhouses expanded to meet demand and by the mid 19th century over 150 workhouses existed throughout Ireland.
- 1.2 Men, women, and children who had fallen on misfortune were housed in separate areas of workhouses, distinct from ‘lunatic cells’ which were generally relegated to the rear of the workhouse. The Dickensian conditions in these workhouses, combined with the development of disability specific facilities internationally, were instrumental in the establishment in 1896 of Ireland’s first specialised institution for people with disabilities, the Stewart Institution for Idiotic and Imbecile Children¹.
- 1.3 After political autonomy in 1922, the Irish state assumed responsibility for providing supports for those in need: for example, those with intellectual disabilities, epilepsy, or mental health difficulties, as well as unmarried mothers and their children. The fledgling state, however, had few resources. In addition, it had a strong Catholic identity and an enmeshed relationship with the Catholic Church. The Irish Constitution (1937) recognised the special position of the Catholic Church as the church of the majority of the population. Governments of the new state were almost exclusively Catholic and were influenced by individual members of the Church Hierarchy as well as by Catholic social teaching². Ruth Barrington’s seminal review of the role of the Church in Irish health policy noted that Catholic moral precepts were applied quite simplistically to health and social needs, Catholic social teaching promulgated the principle of ‘subsidiarity’, drawn from the papal encyclical, *Quadragesimo Anno*, 1931, which held that the state should refrain from involvement in local activities as long as groups in the community were reasonably effective. These precepts also coincided with Irish preference for a minimalist role for the state in matters affecting the individual and the family³. Thus the Church came to dominate health and social care service provision in 20th century Ireland, including provision for those with intellectual disability.⁴
- 1.4 In this context, the Irish state adopted a hands-off approach, delegating many aspects of health, social care and education, to religious orders⁵. Department of Health memoranda in the 1950s record the government’s explicit preference for religious orders to deliver intellectual disability services, resolving to ask heads of religious orders personally to expand services and, if necessary, to ‘induce’ further orders to enter the field⁶. This attitude to service development should be viewed in light of a number of factors in addition to the lack of the state’s financial resources. Religious orders were held in ‘reverence’ in the overwhelmingly Catholic country,

¹ McCormack, B. (2004). *Trends in the development of Irish disability services*. In P.N. Walsh and H. Gash (Eds) *Lives and Times: Practice, policy and people with disabilities*. Wicklow, Rathdown Press.

² Barrington R. 1987. *Health, medicine and politics in Ireland 1900–1970*. Dublin: Institute of Public Administration.

³ *ibid*

⁴ Sweeney J. (2010). *Attitudes of Catholic religious orders towards children and adults with an intellectual disability in post-colonial Ireland*. *Nursing Inquiry*, 17 (2) 95-110.

⁵ *Ibid*

Comptroller and Auditor General Report on Value for Money Examination (2005). Health Service Executive: Provision of Disability Services by Non-Profit Organisations. Dublin; Government of Ireland.

⁶ Ryan, A., 1999. *Walls of Silence: Ireland’s Policy Towards People with a Mental Disability*. Red Lion Press, Kilkenny.p.46.

the lives of orders' sainted founders were 'part of the common consciousness of the nation'⁷. In addition, in a social climate where intellectual disability was often stigmatised, religious orders were entrusted with providing services that could be relied upon to be confidential⁸.

- 1.5 The Irish state practiced little oversight of health, education and social services in the mid-20th century. Although the government financed intellectual disability services through capital and land grants, it had little control over them; terms and conditions for services provided, if they existed, were not made public⁹. Accountability for quality of care for people with intellectual disabilities was governed by the rule of the religious orders, and by their responsibility to their head and the local bishop¹⁰. Provision for people with intellectual disabilities thus developed into a 'hit or miss' service¹¹. In 1957, the Assistant Inspector of Mental Hospitals noted there was 'no way of achieving co-ordination or organisation' in accommodation for people with intellectual disabilities¹². Since that time, concerns regarding a lack of co-ordination, organisation and oversight of voluntary services in Ireland have been a consistent theme, and this report returns to this issue in Section 6.
- 1.6 Among many religious orders establishing specialised facilities in the early years of the Irish state were the Daughters of Charity (1922), the Sisters of Charity of St. Vincent de Paul (1926), the St. John of God Order (1931) and the Brothers of Charity (1939). Specialist residential schools expanded rapidly during the 1930s and both children and adults with intellectual disabilities, who had previously received generic supports, were transferred in large numbers to receive more specialist care in these facilities
- 1.7 By the 1950s the pace of expansion of intellectual disability specific services outstripped available religious staff. Others, typically nurses, were employed to supplement the workforce and a nursing specialisation in intellectual disability was established¹³. Concurrently, professional specialisation in intellectual disability was introduced in several disciplines including psychology, education, occupational therapy and speech therapy.
- 1.8 In addition to the extensive involvement of religious orders in intellectual disability services, another strand of voluntary services developed, 'parents and friends associations'. These lay organisations met the needs of families who did not wish to avail of existing institutional care. They grew rapidly in the 1960s, creating considerable local interest and awareness in disability matters. This increase in disability services, combined with rising expenditure for residential accommodation, was a significant factor in the production of a Government White Paper, *The Problem of the Mentally Handicapped* (Department of Health, 1960)¹⁴. The paper noted that in order to adequately meet the demands of ever increasing numbers of people with intellectual disability seeking residential supports in particular, the number of residential places needed to be doubled from the 3,200 then available, to approximately 7,000 places.

⁷ *Ibid p.120*

⁸ *Ibid p.116*

⁹ Sweeney J. (2010). *Attitudes of Catholic religious orders towards children and adults with an intellectual disability in post-colonial Ireland. Nursing Inquiry*, 17 (2) 95-110.

¹⁰ *Ibid*

¹¹ Ryan, A., 1999. *Walls of Silence: Ireland's Policy Towards People with a Mental Disability*. Red Lion Press, Kilkenny. p.116.

¹² *Ibid p.49.*

¹³ Sweeney J. (2010). *Attitudes of Catholic religious orders towards children and adults with an intellectual disability in post-colonial Ireland. Nursing Inquiry*, 17 (2) 95-110.

¹⁴ Department of Health (1960). *Report: The Problem of the Mentally Handicapped*. In Commission of Inquiry on Mental Handicap. Dublin, Government Publications.

- 1.9 The subsequent *Commission of Inquiry into Mental Handicap* (Department of Health, 1965) marked a fundamental paradigm shift in disability supports nationwide by acknowledging that superior quality outcomes were afforded to those availing of community care when compared with those in institutional settings. The Commission noted that as community services were not feasible for all individuals, a range of facilities was required. It concluded that, as before, services should be provided through voluntary bodies, whose development health authorities should encourage. The Commission also required of the state that it should ‘accept responsibility for co-ordinating the activities of the various organisations involved’.
- 1.10 By the early 1970s, the number of voluntary providers registered with the National Association of Mental Handicapped of Ireland, an umbrella lay organisation founded in 1961, had increased to almost 100. By international standards, relatively few residential centres nationwide were large in scale: only three centres provided for more than 300 residents, and a further 12 centres provided for 100-200 residents¹⁵. Larger settings were coming under increasing pressure internationally, most notably in the UK, where a series of scandals highlighted the sub-standard provision of these institutional settings¹⁶.
- 1.11 The publication of the Green Paper *Towards a Full Life* (1984)¹⁷ set out Government policy in the 1980s for people with disabilities. The paper identified that the ‘*main thrust in the development of services has come from voluntary bodies, including religious orders and parents and friends associations*’ which at that time comprised over 140 organisations nationwide. The report identified over 5,000 individuals with ‘mental handicap’ availing of places within residential centres and noted that while demand for such centres was unlikely to decline, residents were more likely to have severe to profound levels of disability, reflecting growing trends towards community living for those with milder levels of disability.
- 1.12 In 1990, the Irish state’s first, and only, intellectual disability specific policy paper was published. *Needs and Abilities* acknowledged that ‘*greater numbers of children and adults for whom hitherto admission to a residential centre would have been envisaged can, in fact, live to their full potential within the community*’¹⁸. The report recommended that ‘*large numbers of highly dependent intellectually disabled persons should not be placed in one location. New residential provision should be in small clusters of 3 to 4 houses at a number of locations*’.
- 1.13 The almost exclusive role of nonprofit organisations in providing intellectual disability services in Ireland has continued from the foundation of the state to the present day¹⁹; in 2004 they provided approximately 90% of services²⁰. The state, however, provides most of the funding

¹⁵ Moloney, H., (1971). *Provincial Superior Brothers of Charity, Dublin. Paper read at World Federation of Mental Health and National Society for Mentally Handicapped Children. Action for the Retarded Conference, Spring, Belfield, Dublin.*

¹⁶ Department of Health and Social Security. (1969). *Report of the Committee of Inquiry into Allegations of Ill-treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff (Cmnd 3975).* London: Her Majesty’s Stationery Office. Morris, P. (1969). *Put Away.* London: Routledge and Kegan Paul

¹⁷ Department of Health (1984). *Towards a Full Life: Green paper on services for Disabled People.* Dublin, Government Publications.

¹⁸ Government of Ireland (1990). *Needs and Abilities: Report of the Review Group on Mental Handicap Services (1990).* Dublin, Government Publications.

¹⁹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland.* Dublin, Department of Health.

²⁰ Comptroller and Auditor General Report on Value for Money Examination (2005). *Health Service Executive: Provision of Disability Services by Non-Profit Organisations.* Dublin; Government of Ireland.

for these services; in 2009, non-exchequer funding accounted for just 5-7% of disability services in Ireland²¹.

- 1.14 Disability policy in Ireland has advanced markedly in recent years since the publication of *Needs and Abilities*, culminating in a *Value for Money and Policy Review of Disability Services in Ireland* published in 2012. Before outlining recent policy developments, a brief review is presented profiling the population of people with intellectual disabilities in Ireland, and the disability-specific services that are available to support their needs.

2. The Profile of Intellectual Disability in Ireland

- 2.1 The National Intellectual Disability Database (NIDD)²² provides an extensive profile of the demographics and service use of people with intellectual disabilities across the Irish state who are registered with, or are identified as being in need of, specialist disability services. In 2012, the number of individuals with intellectual disability registered on the database was 27,622, a prevalence rate of 6.02 per 1,000 population²³.
- 2.2 Prevalence rates from the database vary by severity of disability and by geographical region. The prevalence for those with a mild level of intellectual disability is currently 1.99 per 1,000, rising to 2.41 per 1,000 for those with moderate intellectual disability, and declining to 0.89 and 0.21 respectively for those with severe or profound levels of intellectual disability. The prevalence for those with mild intellectual disability is likely to be an underestimate given that the database excludes those who are not in receipt of, or in need of, disability specific services. Consequently, the database over-represents those with higher support needs who have a mild level of intellectual disability. Geographically, Sligo reports the highest prevalence of intellectual disability at 10.6 persons per 1,000 population, while Clare and Meath report the lowest prevalence estimate, both citing a prevalence estimate of 4.7 per 1,000 population.
- 2.3 The true nationwide prevalence of intellectual disability should not be determined from the NIDD given its exclusion of those who are not currently using or needing services. Some indication of the true prevalence rate may, however, be gleaned from the National Disability Survey which identified 50,400 persons nationwide self-reporting a diagnosis of intellectual disability²⁴. Caution is needed, however, in interpreting the variation in these figures. First, the definition of intellectual disability differs between the NIDD and the National Disability Survey, with NIDD using the World Health Organisation's International Classification of Diseases Tenth Edition (ICD-10), while the National Disability Survey uses the World Health Organisation's International Classification of Functioning (ICF). Second, further analysis of those who reported an intellectual disability on the National Disability Survey revealed that a proportion reported their main disability to be dyslexia, other forms of specific learning disability, attention

²¹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health.

²² The National Intellectual Disability Database is one of two disability databases, the other being the National Physical and Sensory Database, which are managed by the Health Research Board on behalf of the Department of Health. The databases aim to provide a comprehensive and accurate information base for decision making in relation to the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities. More information can be found at <http://www.hrb.ie/health-information-evidence/disability/>

²³ Kelly, F., Kelly, C., & O'Donohoe, A., (2012). *Annual Report of the National Intellectual Disability Database Committee 2012*. Dublin, Health Research Board.

²⁴ Central Statistics Office (2008). *National Disability Survey 2006*. Dublin; Stationery Office. Persons with specific intellectual and learning difficulties: level of difficulty by type of disability: Table F.6 (p.64)

deficit disorder or brain injury. These individuals would not be registered with NIDD unless they report an ICD-10 diagnosis of intellectual disability. Finally, as stated above, the NIDD registers only those individuals with an intellectual disability for whom specialised services are provided or requested. As such, they comprise a smaller group than all those who defined themselves as having an intellectual disability on the National Disability Survey, irrespective of whether they avail of services. Another source of prevalence data emanates from the 2011 Census which identified 57,709 individuals self-reporting 'intellectual disability' as a long-lasting condition²⁵. Again, it is possible that this figure is over-inclusive, including those who may not have a diagnosed intellectual disability.

- 2.4 For those persons with a diagnosed intellectual disability who are in contact with disability-specific services, comprehensive demographic and service use data are available from the NIDD. In 2012, a total of 27,622 individuals were registered on the database. There were more male (58%) than female (42%) persons registered on the database, with the highest proportion of both male (39%) and female (41%) persons diagnosed as having a moderate level of disability. Age profiles reveal that over one-third of those on the database are under 19 years of age (37%), with approximately one-quarter in each of the age brackets from 20-34 years and 35-54 years. Just 13% are 55 years or older. Changes in age trends reveal that increases in registration are largely confined to the two older age groups, a likely reflection of improved care standards and increased longevity. Just over 40% of those persons registered on the database were identified as having a co-morbid physical and/or sensory disability.
- 2.5 The majority of individuals registered on the database (n=18,330; 66%) live at home with their parents, other relatives or foster families. Those who do avail of full-time residential supports (n=9,255) are supported in a variety of residential living arrangements, the most common of which is the community group-home (n=4,226), followed by those in residential centres (n=2,561) and 'other' placements (n=1,311) which include psychiatric hospitals, intensive placements, nursing homes, and mental health community residences. An additional 1,157 persons live in independent settings.
- 2.6 A breakdown of those registered on the database by main residential circumstances is presented in Table 1 below.

²⁵ Central Statistics Office (2012). *Our Bill of Health*. Dublin, Stationery Office.

Table 1: Main residential circumstances of individuals registered on the National Intellectual Disability Database by degree of intellectual disability 2011

	Not verified	Mild	Moderate, severe, profound	All
Home	2,304	6,806	9,220	18,330
Community group	19	933	3,274	4,226
Residential Centre	2	232	2,327	2,561
Other full-time	13	246	1,052	1,311
Independent	52	894	211	1,157
Insufficient	3	5	16	24
No fixed abode	0	10	3	13
Total	2,393	9,126	16,103	27,622

- 2.7 A notable age trend is apparent: the proportion of persons who live in home settings decreases with age, while the proportion of individuals who live in full-time residential services increases with age. Given the increased longevity of people with intellectual disabilities, and the ageing profile of caregivers, it is likely that the demand for residential supports, most especially for those in older age groups, will increase in the coming years.
- 2.8 A level of ability trend is also apparent: individuals with greater levels of disability are more likely to avail of full-time residential supports. Almost half, 41%, of those with a moderate, severe or profound level of ability live in full-time residential services, in comparison with 16% of those with a mild intellectual disability. In addition, there is an association between a person's level of ability and their type of residential setting. Of those with a moderate, severe or profound disability who avail of residential services, 49% avail of community group home accommodation while 37% are supported in residential centres. This contrasts with 66% of those with a mild level of ability who reside in community group homes while just 17% live in residential centres.
- 2.9 Since the establishment of the database in 1996, residential trends reveal a significant increase (77%) in the number of people supported in full-time community group homes; a significant decline (78%) in the numbers of people supported in psychiatric hospitals; and a substantial increase in planned or emergency centre-based respite (457%) which has aimed to support individuals to continue living with their families in their local communities.
- 2.10 The database also provides information on the number new full-time residential places required to meet known demand. This demand has increased slightly from 2,248 places in 2011 to 2,271 places in 2012. Seven out of ten of those requiring a new residential place (1,623 individuals, 72%) have a moderate, severe or profound intellectual disability.

3. The Configuration and Funding of Disability Services

- 3.1 The Health Service Executive (HSE) has primary responsibility for the provision of specialist disability services to all eligible persons with disabilities in Ireland. Where HSE are unable to provide these services at regional level, primary responsibility is transferred from HSE to locally-based voluntary, non-statutory organisations.
- 3.2 Specialist disability services funded under the Health Vote (40) include, in order of expenditure: residential services; adult day care services; disability allowances; multidisciplinary teams; personal assistant services; respite services; rehabilitation; aids & appliances; placements requiring revision and early intervention teams^{26 27}.
- 3.3 The budget allocation for these specialist disability services in 2013 was €1.535 billion, a reduced allocation of 1.2%²⁸. Unlike other international jurisdictions, much of this funding is allocated to non-health related services, such as housing, day services and respite supports. In Ireland, three quarters of all disability funding is allocated to the provision of residential and adult day care services; residential services alone accounting for 48% of the entire budget²⁹. Expenditure on residential services for people with intellectual disabilities in 2009 totaled €371 million. The majority of this funding was allocated to those in receipt of seven day residential services, and was divided equally between larger institutional facilities and community-based settings³⁰.
- 3.4 In total, there are 217 specialist disability service providers nationwide³¹. These provider organisations may be classified as follows:
 - Statutory services delivered directly via the HSE (1 organisation providing multiple services nationwide)
 - Non-statutory organisations funded under Section 38 of the Health Act 2004 (17 organisations)
 - Non-statutory organisations funded under Section 39 of the Health Act 2004 (199 organisations, however, it should be noted that the number varies annually)
- 3.5 The non-statutory providers are essentially commissioned by HSE to provide disability specific services on behalf of the HSE (Section 38) or to provide a similar service, or ancillary to, a service that the HSE may provide (Section 39). While theoretically the distinguishing factor between the two types of organisations is whether they provide 'on behalf of' or provide 'ancillary to' the HSE, the difference between them may be largely historical and no longer apparent.

²⁶ National Disability Authority (2010). *Advice paper to Value for Money and Policy Review of Disability Services*. Dublin, National Disability Authority

²⁷ Non health related services, such as education, maybe funded via other Government Departments.

²⁸ Health Service Executive (2012) *National Service Plan 2013*.

²⁹ National Disability Authority (2010). *Advice paper to Value for Money and Policy Review of Disability Services*. Dublin, National Disability Authority

³⁰ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health. P.4

³¹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health. P.4

- 3.6 Funding allocated to non-statutory providers varies considerably with just over one-third of all providers (34%) receiving less than €250,000 per annum. In total, these providers receive less than one half a percent (0.4%) of the disability budget allocated by HSE to non-statutory providers. This contrasts with the top one-fifth of providers (17%) who receive between €10 and €150 million each per annum. In total, these providers receive over 86% of the HSE disability budget. As such, a relatively small number of providers account for a considerable proportion of the Irish state's specialist disability service³².
- 3.7 Unlike other international jurisdictions non-statutory providers, who comprise the majority of all specialist providers, do not engage in a competitive tendering process when commissioned by HSE to provide services. Rather the historical development of the non-statutory sector in Ireland has resulted in a sector which has evolved over time to have a 'negotiated' rather than 'contested' procurement relationship with the state³³.
- 3.8 Typically, an incremental determination process is employed whereby annual funding is allocated in a block grant to non-statutory providers using the funding provided in previous years as an estimate of the budget required to provide the same service in the coming year. While the term 'incremental' may suggest that budgets are automatically increased in successive years, it is possible that budgets may decrease from one year to another³⁴.
- 3.9 Budgetary negotiations between providers and the HSE are formalised under contractual agreements termed Service Level Agreements (SLAs; where allocations exceed €250,000 per year) or Grant Aid Agreements (GAA; where allocations are less than €250,000 per year). Funding is typically distributed from regional HSE Local Health Offices nationwide, or in the case of some of the larger providers directly from HSE³⁵.
- 3.10 Concerns have been expressed regarding the transparency of the incremental determination process. These concerns include the uncontested nature of the funding and the fact that the rationale for the initial allocation of funding may no longer be apparent, most especially for more established services who have received incremental funding over many years³⁶.
- 3.11 In addition, there are concerns that funding is determined on the basis of places (e.g. one residential place; one day service place) rather than individual need (e.g. greater funding for those with higher support needs)³⁷. This has resulted in per capita funding variations across regions and service providers, meaning that individuals with similar needs receive widely differing funding depending on the region they live in and the provider they receive services from³⁸.

³² Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health. P.37

³³ Comptroller and Auditor General Report on Value for Money Examination (2005). *Health Service Executive: Provision of Disability Services by Nonprofit Organisations*. Dublin, Government of Ireland. P.13

³⁴ National Disability Authority (2011). *The introduction of individual budgets as a resource allocation system for disability services in Ireland*. Dublin, National Disability Authority. P.22

³⁵ Further details of the distribution of disability funding is outlined in Vega, A., O'Shea, S, Murrin, C., & Staines, A., (2010). *Towards the development of a Resource Allocation Model of Primary, Continuing and Community Care in the Health Services*. Dublin, Dublin City University.

³⁶ Report of the Comptroller and Auditor General Volume 2 (2010). *Accounts of the Public Services 2009 Vote Management*. Dublin, Government of Ireland.p.589

³⁷ Comptroller and Auditor General (2005). *Report on Value for Money Examination: Provision of Disability Services by Nonprofit Organisations*. Dublin, Government of Ireland. P.9

³⁸ National Disability Authority (2010). *Advice paper to Value for Money and Policy Review of Disability Services*. Dublin, National Disability Authority.

- 3.12 The state has acknowledged that service delivery is conducted without standardised methods for assessing individual need or resource usage; for linking individual need to target outcomes; or for determining costs of individual resources³⁹. Preliminary research piloting a standardised resource allocation model for national use is currently being undertaken by the National Disability Authority⁴⁰.
- 3.13 While HSE does not have data on total pay costs for disability services, estimates for service providers in the former Eastern Regional Health Authority suggested that pay costs account for between 70%-84% of the disability budget. In 2009, the estimated pay bill was approximately €1.2 billion, which included a substantive increase of 35% in the pay budget from 2005–2009 for HSE and some Section 38 providers⁴¹.
- 3.14 The largest staff grouping within the sector is support staff (n=11,280; 47%): drivers, catering staff, attendants, personal assistants, and home helps. Another large staff grouping is that of nursing, social care and therapists who comprise 43% (n=10,211) of the workforce, indicating that the Irish disability sector is professionalised to a significant extent. Therefore, changes in staff mix are estimated to return significant savings. A 10% change in case mix from nursing to social care staff, for example, is estimated to reduce the cost for care by €3.5 million.
- 3.15 The Health Information and Quality Authority (HIQA) has statutory responsibility for setting and monitoring standards on the quality of healthcare services in the public sector. HIQA's regulatory role is best known in relation to its Social Service Inspectorate which has responsibility for the registration and inspection of designated centres, defined as residential homes for children, older people and people with disabilities⁴². As of 1st November 2013, organisations providing residential supports to people with disabilities must comply with the Health Act 2007 (amended) and National Standards for Residential Services for Children and Adults with Disabilities, which collectively comprise the regulatory framework for quality inspections. This framework opens all residential and campus centres to inspection by HIQA who check for compliance against the National Standards.
- 3.16 Recent research in this area suggests that quality standards vary nationwide, with some organisations operating in the absence of formal quality standards while others have gained international awards for excellence⁴³. This variety may be perceived as advantageous by endorsing 'multiple routes to quality'. It may also, however, reflect a lack of consensus on defining quality within the disability sector.

³⁹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health

⁴⁰ See National Disability Authority website
<http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/8A76108C3F4680E88025795A003BAE74?OpenDocument>

⁴¹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health. P.55

⁴² The Health Act 2007 requires that all "designated centres" are registered and inspected. A designated centre is defined in Part 1, Section 2 of the Act, as an institution at which residential services are provided by the Health Service Executive (HSE) or other service providers. It includes, therefore, those run by private companies and voluntary organisations. The registration and inspection of designated centres is the responsibility of the Social Services Inspectorate (SSI) within the Authority. The term "residential service" is used to refer to designated centres in the standards.

⁴³ National Economic and Social Council (2012). *Quality and Standards in Human Services in Ireland: Disability Services*. Dublin, National Economic and Social Council.

4. Recent Developments in National Disability Policy

- 4.1 Since the publication of *Needs and Abilities* in 1990, a raft of policies have been developed aiming to transform disability services from a traditional, and congregated model of care, towards a model whereby people with disabilities are supported to live a life of their choosing within their own local communities. This proposed new model of disability service provision is underpinned by values of person-centredness, inclusion, community integration, participation, independence and choice⁴⁴.
- 4.2 Key policy documents since 1990 recommending changes to disability support services are listed in Table 2. A brief review of some of the more salient policies impacting on supports for people with intellectual disabilities follows.

Table 2: Key disability policy documents since 1990⁴⁵

1994	Services to People with Autism.
1996	Towards an Independent Future: Report on the Working Group on Health and Personal Social Services for People with Physical and Sensory Disabilities.
1996	A Strategy for Equality: Report of the Commission on the Status of People with Disabilities.
1997	Employment Challenges for the Millennium: Report of the National Advisory Committee on Training and Employment.
1997	Enhancing the Partnership: Report of the Working Group on the Implementation of the Health Strategy in Relation to Persons with a Mental Handicap.
2001	Quality and Fairness: A Health System for You.
2004	National Disability Strategy.
2006	A Vision for Change: Report of the Expert Group on Mental Health Policy.
2006	Towards 2016: Ten Year Framework Social Partnership Agreement 2006-2015.
2009	Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18.
2011	National Housing Strategy for People with a Disability 2011-2016.
2011	Time to Move on from Congregated Settings: A Strategy for Community Inclusion.
2011	Report of Disability Policy Review.
2012	New Directions: Review of HSE Day Services and Implementation Plan 2012-2016.
2012	National Review of Autism Services.
2012	Value for Money and Policy Review of Disability Services.

⁴⁴ National Disability Authority (2010). *Advice paper to Value for Money and Policy Review of Disability Services*. Dublin, National Disability Authority.

⁴⁵ Includes material taken from Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Department of Health. P16 and National Economic and Social Council (2012). *Quality and Standards in Human Services in Ireland: Disability Services*. Dublin, National Economic and Social Council p.27

STRATEGY FOR EQUALITY: REPORT OF THE COMMISSION ON THE STATUS OF PEOPLE WITH DISABILITIES

- 4.3 A *Strategy for Equality; the Report of the Commission on the Status of People with Disabilities* (1996)⁴⁶, was instrumental in proposing a rights-based approach to disability in Ireland. The Commission was strongly influenced by international trends promoting the rights of people with disabilities including the enactment of the *American with Disabilities Act 1990*, and the development of the *United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*, adopted in 1993. Following a comprehensive, and pioneering consultation with people with disabilities and their caregivers, the Commission recommended wide ranging changes to the manner in which people with disabilities were supported across many life domains including education, health, housing, research, transport and work.
- 4.4 Key recommendations from the Commission included the enactment of a Disability Act, the establishment of the National Disability Authority, and the right to an individual assessment of need with allied statement of need. The Commission also recommended that the Department of the Environment, Community and Local Government should develop a comprehensive policy on housing for people with disabilities with a view to affirming '*the right of people with disabilities to live as independently as possible, if they so chose*'⁴⁷.
- 4.5 The rights-based position taken by the Commission was not followed through in subsequent legislation resulting in the withdrawal of the Disability Bill presented to the Oireachtas in 2002. Through a renewed process of consultation, the Disability Act was passed in 2005 following publication of the National Disability Strategy (NDS) in 2004.

NATIONAL DISABILITY STRATEGY⁴⁸ & TOWARDS 2016: TEN YEAR FRAMEWORK SOCIAL PARTNERSHIP AGREEMENT 2006-2015⁴⁹

- 4.6 The National Disability Strategy (NDS), launched in 2004, aimed to create a comprehensive strategy to underpin the participation of people with disabilities in Irish society. The NDS comprises the following elements:
- Disability Act 2005.
 - Education for Persons with Special Education Needs (EPSEN) Act 2004.
 - Sectoral Plans devised by six Government Departments.
 - Citizens Information Act 2007.
 - Multi-annual investment programme of €900 million targeted at high-priority disability support services from 2006 to 2009.
- 4.7 *Towards 2016, Ten Year Framework Social Partnership Agreement 2006-2015* outlines the vision, mission and strategic objectives of the NDS. Among many long-term goals aiming to

⁴⁶ *Commission of the Status of People with Disabilities (1996). A Strategy for Equality: Report of the Commission of the Status of People with Disabilities. Dublin, Stationery Office.*

⁴⁷ *Report of the Commission on the Status of People with Disabilities (1996). A Strategy for Equality. Summary available at http://www.fedvol.ie/_fileupload/Next%20Steps/strategy_for_equality.pdf*

⁴⁸ *National Disability Strategy (2004)* Available at <http://www.justice.ie/en/JELR/NDS.pdf/files/NDS.pdf>

⁴⁹ *Department of the Taoiseach (2006). Towards 2016, Ten Year Framework Social Partnership Agreement 2006-2015. Dublin, Government Publications Office. P.66*

improve the quality of life of people with disabilities, *Towards 2016* notes that '*every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximize their potential*'. Priority areas for development identified in *Towards 2016* included:

- assessment for, and access to, appropriate health and education services including residential care
 - the development of a comprehensive employment strategy for people with disabilities
 - the introduction of national standards
 - the enhancement and integration of supports in line with social welfare commitments
 - the development of a housing strategy for people with disabilities
 - the development of information and advisory services for people with disabilities
 - the continued introduction of accessible public vehicles.
- 4.8 Implementation of the NDS is monitored since late 2011 by a high level group chaired by the Minister of State at the Department of Justice and Equality. The National Disability Strategy Implementation Group (NDSIG) is committed to 're-energising' the National Disability Strategy via '*a realistic implementation plan including sectoral plans with achievable time scales and targets within available resources, while ensuring whole of government involvement and monitoring of the Strategy in partnership with the disability sector*'⁵⁰. A National Implementation Plan 2013-2015 identifies four high level goals of: equal citizenship, independence & choice, participation, and maximizing potential. The goals are detailed into an action list identifying the organisations responsible for implementation, the key performance indicators and the timeline within which the action should be completed. The Implementation Group is scheduled to meet four times a year to monitor progress.
- 4.9 Most recently, a total of six high-level policy documents have been published which propose radical reform of the disability sector (see Table 2; 2011-2012). This raft of policy is complimented by other publications emanating from semi-state bodies such as the National Economic and Social Council⁵¹ and the Economic and Social Research Institute⁵². The sheer quantum of policy reflects a prioritisation of reform within the disability sector by Government. The following section presents a review of some of the more influential policies currently framing the proposed reform of this sector.

⁵⁰ Department of Justice and Equality (2012). *Policy: National Disability Strategy*. Available at <http://www.justice.ie/en/JELR/NDA%20-%20POLICY%20-%202.pdf>

⁵¹ National Economic and Social Council (2012). *Quality and Standards in Human Services in Ireland: Disability Services*. Dublin, National Economic and Social Council

⁵² Watson, D., & Nolan, B., (2011). *A Social Portrait of People with Disabilities in Ireland*. Dublin, Economic and Social Research Institute.

A VISION FOR CHANGE: REPORT OF THE EXPERT GROUP ON MENTAL HEALTH POLICY⁵³

- 4.10 The Expert Group on Mental Health Policy outlined '*A Vision for Change*' in the national configuration of mental health services. Specific recommendations were made for the development of services for people with intellectual disability who have co-existing mental health difficulties. The report noted the dearth of specialist services for this population, and the considerable barriers faced by people with intellectual disability accessing mainstream mental health services. In addition, epidemiological data was deemed poor resulting in widely varying prevalence estimates of those with intellectual disability and mental health conditions.
- 4.11 *A Vision for Change* advocated that a spectrum of mental health services be provided for people with intellectual disability. These services should include health promotion, early detection, crisis management and specialised mental health services. Intellectual disability services should provide support in the areas of health promotion, early detection and crisis management. The establishment of specialist 'mental health in intellectual disability' teams (MHID) was recommended to provide specialised mental health services. These teams should take referrals from general practitioners and be established on a catchment area basis, with three teams proposed per 300,000 population. The MHID teams should be distinct and separate from, but closely linked to, pre-existing multidisciplinary teams located within intellectual disability services.
- 4.12 In addition to the proposed new configuration of services, *A Vision for Change* called for the establishment of a national forensic unit, greater awareness of and support to older persons with intellectual disability who are at risk of dementia, and the enactment of mental capacity legislation to address those involuntarily detained in intellectual disability settings. It is now anticipated that this legislation, term the Assisted Decision Making Capacity Bill, published in 2013 with an expected enactment in 2014, will provide for the statutory assumption of capacity, define assessment of capacity as time- and issue-specific, and will introduce a system of public guardianship.

REPORT OF THE NATIONAL REFERENCE GROUP ON MULTIDISCIPLINARY DISABILITY SERVICES
FOR CHILDREN AGED 5-18 YEARS⁵⁴

- 4.13 *The Report of the National Reference Group on Multidisciplinary Disability Services for Children Aged 5-18 Years*, published in 2009, aimed to address the wide variation in services for children with a disability throughout Ireland. Currently services are provided by both statutory and non-statutory agencies, some of which provide generic supports to children with disabilities and others which are disability specific. Of these, some generic teams are employed solely by HSE, others by non-statutory agencies, with some having employees from both sectors working in integrated partnerships.
- 4.14 *Progressing Disability Services for Children and Young People* is a national programme aimed at reconfiguring children's services based on the recommendations of the National Reference Group report. The programme aims to achieve a unified approach to delivering disability health services ensuring that there is a clear pathway to services irrespective of where individuals live, or of the nature of their disability.

⁵³ Government Publications (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin, Government Publications.

⁵⁴ Health Service Executive (2009). *Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18*. Dublin, Health Service Executive.

- 4.15 The programme proposes that children should receive services as close to their home as possible. Primary Care Teams which provide mainstream services within the community are the first level of support. It is envisaged that typically all children who have one area of need would receive services from primary care. Children with more complex needs may be referred to early intervention or school aged teams, termed Network Disability Teams. Referral forums should be established in each region to coordinate referrals for children with complex needs. All teams should have access to Specialist Disability Services where a high level of expertise is required. The aspiration is that no child be left without a service.
- 4.16 The programme is led by HSE in cooperation with the non-statutory provider organisations, the Department of Health and the Department of Education & Skills. A National Coordinating Group (NCG) monitors the programmes progress while implementation is the remit of the four Regional and Local Leads in each of the four Health Service Executive Regions. Local Implementation Groups are supported throughout the duration of this programme through the development and dissemination of guidelines and discussion papers.
- 4.17 While the team composition of those working in children's services will, by definition, change during this restructuring, HSE note that staff in nearly all circumstances are expected to be employed by their current employer, whether statutory or non-statutory. This restructuring of children's services aims to introduce a greater level of engagement and cooperation among disability and generic health services. With greater coordination of services, it is hoped that children with disabilities will no longer be denied a service on the basis of their geographical location or the severity of their disability.

THE NATIONAL HOUSING STRATEGY FOR PEOPLE WITH A DISABILITY 2011-2016⁵⁵

- 4.18 *The National Housing Strategy for People with a Disability 2011-2016* outlines a framework for the delivery of housing for people with disabilities through a policy of mainstreaming. Nine strategic aims are identified including: equality for people with disabilities to access the full range of housing options; the development of national protocols to coordinate effective interagency cooperation involving all relevant agents in the provision of housing for people with disabilities; consideration of the specific housing needs of people with disabilities moving from institutional to community-based settings; and improvement of the collection and use of information regarding the nature and extent of the housing needs of people with a disability.
- 4.19 The housing strategy identified an array of mainstream housing supports which, to date, are rarely availed of by people with disabilities, including social housing support and the use of the private rental sector to meet social housing need. In particular, the potential of private rental schemes were examined including the Rental Accommodation Scheme (RAS) which provides accommodation within the rental sector to recipients of rent supplement under the Social Welfare Scheme, and the Social Housing Leasing Initiative (SHLI) which leases properties from private owners for use by those on local authority waiting lists. Voluntary and Cooperative Housing was also noted, in particular, the Capital Assistance Scheme (CAS) which permits housing bodies to provide accommodation to meet certain specific categories of housing need,

⁵⁵ Department of the Environment, Community and Local Government (2011). *National Housing Strategy for People with a Disability 2011-2016*. Dublin, Department of the Environment, Community and Local Government. Much of the preliminary work for the National Housing Strategy for People with a Disability was undertaken in a report prepared by Michael Browne 'Citizens Information Board/Disability Federation of Ireland Social Policy Report' (2007). *The Right Living Space: Housing and Accommodation Needs of People with Disabilities*. Dublin, Citizens Information Board/Disability Federation of Ireland. This report recommended that a 'continuum of housing provision' be made available to people with disabilities.

including people with disabilities. These, and other schemes, were considered as potential new delivery mechanisms to address the provision of housing for people with disabilities.

- 4.20 The Strategy notes that housing associations availing of schemes such as those outlined above, and providing care and health related supports for tenants with disabilities, can apply for funding from HSE for the health related elements of this service. To ensure effective coordination between all of the relevant agents involved in the provision of housing and related supports, including the Department of the Environment, Community & Local Government, the Department of Health, local authorities, the HSE and the Irish Council for Social Housing, national protocols were developed to formalise these working relationships. In addition, local authority-led Housing and Disability Steering Groups will be established to coordinate the implementation of the strategy at local level.
- 4.21 Noting that people with intellectual disabilities traditionally do not apply for housing supports, the Strategy proposes that where individuals express a wish to live independently or with supports in the community, they undergo an assessment of housing need to determine what housing supports may be required, from which they receive a statement of housing need. This individual assessment of housing need is proposed to align with Part 2 of the Disability Act 2005, and will gather information on the individual's disability, the level of supports required and currently provided, and the type of accommodation deemed most appropriate to best meet the individual's disability-related needs. The assessment will be used by local housing authorities to determine the type of housing supports deemed most appropriate to meet the individual's need.
- 4.22 Assessments will determine not only the adequacy of an individual's current residential situation, but will also consider the likelihood of a housing need arising in the future. That is, assessments will be inclusive of individuals who are not currently experiencing acute need, but who may do so in future, for example, in the event of an ageing parent dying or no longer being able to provide care.
- 4.23 The Strategy made specific reference to people with disabilities currently residing in institutional settings, noting that research over three decades consistently indicates people with disabilities experience better quality of life in community settings than in institutional care. The report also noted more recent research comparing evidence on quality outcomes for residents in dispersed and clustered community housing, which found that dispersed housing was superior to clustered housing on the majority of quality indicators studied⁵⁶. In light of this evidence-base, the Strategy endorsed recommendations from the HSE Congregated Settings Working Group (see below) that congregated settings close over a seven year period, and that residents be moved to a range of community-based living options including individual tenancies.
- 4.24 Implementation of the National Housing Strategy is detailed in the 'National Housing Strategy for People with a Disability 2011-2016 National Implementation Framework'⁵⁷. The implementation plan identifies a newly established Housing Sub-Group led by the Housing Agency as the key agent providing guidance to local authorities on the provision of housing for people with a disability. This sub-group coordinates with related stakeholders including the National Consultative Forum on Disabilities and the HSE Congregated Settings National Implementation Group. The report notes that '*significant financial implications arise for the local government sector in respect of Government proposals regarding the deinstitutionalisation of people with*

⁵⁶ Mansell, J. and Beadle-Brown, J., (2008). *Dispersed or Clustered Housing for Disabled Adults: a Systematic Review*. Canterbury: Tizard Centre.

⁵⁷ Department of Environment, Community and Local Government & Department of Health (2012). *National Housing Strategy for People with a Disability 2011-2016 National Implementation Framework*.

disabilities' (p.5). The report further notes that the proposed seven year timeframe of deinstitutionalisation, as outlined in the HSE's Time to Move on from Congregated Settings detailed below, is unlikely to be realised. The challenge is to find expenditure to meet the estimated required budget of €1.9 million per annum, rising incrementally €1.9 million per year throughout the seven year timeframe to a total annual expenditure of €13.3 million thereafter. As an interim step, the Department of Health provided a ring-fenced €1 million fund in 2013 to meet social housing costs within that year to finance an expected 150 units.

TIME TO MOVE ON FROM CONGREGATED SETTINGS: A STRATEGY FOR COMMUNITY INCLUSION⁵⁸

- 4.25 Established by the Primary and Community Care Directorate of the HSE, the Working Group on Congregated Settings was charged with developing proposals to deliver community-based, person-centred options for people with disabilities who currently reside in congregated settings. Specifically, the Working Group were charged with: identifying the number of congregated settings nationwide and the number of residents supported within those settings; identifying the cost of the current provision; and determining a costed implementation plan for the transition of identified residents from congregated to community-based settings.
- 4.26 All statutory and non-statutory organisations that support residents with intellectual, physical or sensory disabilities who were registered with the national disability databases⁵⁹ were surveyed to identify residential settings where ten or more residents shared a single living unit, or where the living arrangement was defined as campus based⁶⁰.
- 4.27 Nationwide 72 congregated settings were identified located in 20 counties, ranging in size from settings with one unit, to the largest setting which comprised 34 units. Twenty-nine of the settings were single unit settings, supporting between 8-52 residents in each unit. The largest setting comprised 34 units, providing 340 places. On average, 18 residents were supported in each unit.
- 4.28 Transfers and admissions to these settings were retrospectively examined for a ten year period, from 1999 to 2008. Throughout this time period, over half of all settings (64%) had made arrangements for service users to transfer to the community; however, a significant proportion had not (36%). In total, 619 people were identified as having transferred out of congregated settings over this time period. The numbers of those being admitted to congregated settings during the same time period, however, was 692, indicating that admissions exceeded transfers over the decade of review.
- 4.29 A total of 4,099 residents, of whom 3,802 had intellectual disabilities, were identified living in the 72 congregated settings in 2008. These residents comprised just under half of all residents with intellectual disabilities registered on the NIDD as availing of full-time residential supports nationwide in that year. The profile of residents in congregated settings revealed that the majority had a moderate (34%) or severe (44%) level of intellectual disability, over 80% had an additional disability, almost half were aged 40-60 years, and almost three-quarters had been

⁵⁸ Health Service Executive (2011). *Time to Move on from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*. Dublin, Health Service Executive.

⁵⁹ National Intellectual Disability Database and National Physical and Sensory Disability Database managed by the Health Research Board on behalf of the Department of Health.

⁶⁰ The survey excluded organisations supporting individuals on the autistic spectrum and organisations defined as intentional communities. Individuals supported in de-designated units located on the grounds of psychiatric hospitals but designated to intellectual disability supports were included.

living in their current setting for over 15 years. An assessment of the dependency level of residents revealed that 37% could speak in sentences, 54% engaged in behaviours that challenge and 57% took psychotropic medication. While the data report a high degree of support needs among these residents in relation to everyday activity, the Project Manager's reports following site visits to many of these settings indicated that these support needs were no different from those of many people with intellectual disability currently being supported in the community.

- 4.30 The condition of some of these settings is best described by an extract from the Project Manager's observations following a site visit:

"A unit for 15 severely disabled people, two have significant medical problems which result in their being peg fed. All others need high levels of support in all the essential activities of daily living. The number of staff on duty at any given time is three. There are significant periods in the day where only two people are on duty to cover the basics i.e. getting people up, dressed, washed and fed. Service users either do not have a day programme or, if they do, it is a very limited session, maybe once or twice per week. Some people get no day provision at all".

- 4.31 The lack of appropriate day service activities was consistently evident. Over one quarter of all residents in these settings had no, or a limited, day programme delivered in their ward. Less than one in five was involved in off-campus activities. The report notes '*routines typically appear to be characterised by early-bed-times with the median times for the first people in a unit going to bed at 9pm, and the last at 10.30pm*' (p.56).
- 4.32 Staffing levels within these settings were a cause for concern. A total of 5,368 staff personnel were employed across all centres where data was available, a ratio of 1.65 staff per resident. These levels were deemed by the Project Manager to be insufficient '*to respond to the needs of these clients, to respect their rights and to treat them with the dignity they deserve*'. The Project Manager noted that '*staff are aware that thinking has moved on and there is a lot of discussion about person centredness, rights, quality of life etc. Many people expressed their frustration at wanting to be able to respond to their clients in this way but not having the staff to do so*' (p.58).
- 4.33 Data gathered on costs of the congregated settings revealed a total cost of €417 million, with an average per capita cost for each resident of €106,000, of which 83% was pay costs. There was, however, significant variation in per capita costs, which ranged from €37,394 to €231,575⁶¹. One quarter of all centres had a per capita cost under €77,000; half had per capita costs between €78,000 and €130,000, and the remaining quarter of centres had per capita costs of over €130,000.
- 4.34 A national policy and support framework was proposed by the Working Group for the transitioning to community-based settings of all residents identified in the report. Within the framework of the National Disability Strategy, the Department of Health was recommended to adopt a clear policy on the closure of the congregated settings. The policy should apply to all residents, irrespective of the severity of disability, and should state that no new congregated settings should be developed, no new admissions should be sanctioned and that the target

⁶¹ An overriding issue commented on by service providers in Wales, following a site visit, was the disparity in salaries between UK and Irish support staff. Gross annual salaries in the UK were cited as £13,319 for Support Workers, £21,835 for Service Managers and £31,077 for Area Managers. These figures can be contrasted with annual gross salaries in Ireland of €34,357-€45,939 for Social Care Workers and €55,598-€63,885 for Social Care Managers. The Working Group noted that notwithstanding currency differences, Irish support staff report higher salaries than their UK counterparts. In addition, UK providers were free to determine salary scales unlike Irish providers who were typically tied to salary scales set by the Department of Health

timeframe should specify completion within a seven year period. This policy should be reflected in the National Housing Strategy for People with a Disability ensuring the eligibility of people with disabilities to publically funded housing supports. A National Implementation Group, established within the framework of the National Disability Strategy, should oversee the implementation of the Working Group's recommendations.

- 4.35 The Working Group detailed the new model of support which they recommend should comprise a broader plan than mere accommodation; arrangements for housing must form part of a wider person-centred support plan of community inclusion. The new model proposes that those currently resident in congregated settings would have access to dispersed housing⁶² in local communities with individualised supports ('supported living'⁶³) designed to meet individual need. While some individuals may choose to live on their own, others may choose to share with other people. Where home-sharing with other people with a disability is the preferred option, the Working Group recommends that no more than four co-residents share one dwelling.
- 4.36 The Working Group recommended that housing authorities and the HSE should have distinct responsibility for the needs of people with disabilities living in the community. HSE should provide for the health and personal needs of residents while housing authorities should provide for housing need. In addition, the governance, management and delivery of residential supports should be separate from the provision of inclusion supports⁶⁴, thereby ensuring that the person with a disability has maximum choice of support providers.
- 4.37 Regarding the proposed funding stream for the reconfiguration of residential supports to those in congregated settings, the Working Group stated that the current level of resources being invested in congregated settings would be sufficient to implement the recommended changes. The report noted that bridging funds may be required for a period while both the newer community residences and the older congregated settings are operating simultaneously.
- 4.38 The accommodation needs of those transferring from congregated settings should be met through a combination of new builds, local authority housing, voluntary housing, leasing, private rental, and purchasing or leasing from voluntary housing associations. Irrespective of an individual's preferred option, all those transferring from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Schemes.
- 4.39 Local implementation teams within each Integrated Service Area (ISA) are recommended to take local responsibility for ensuring that local planning and delivery systems are present to implement this policy. These local teams should be monitored by a National Implementation Group to ensure national oversight. Accelerated Learning Sites, providing robust examples of evidence-based transitions to community living are recommended to showcase good practice, and to provide learning experiences through a comprehensive evaluation. The implementation of these actions is ongoing from the establishment of the National Implementation Group in October 2011.

⁶² Dispersed housing is defined as apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population.

⁶³ Supported living is defined as providing the range and type of individualised supports to enable each person to live in the home of their choice and be included in their community. Forms of individualised supports include in-home support (e.g. paid staff, smart technology), inclusion support (e.g. facilitating links with the local community), community-based primary care and specialist supports (e.g. public health nurse, home help), work/further education, person-centred planning and advocacy.

⁶⁴ Inclusion supports are defined as the main means of meeting the individual's support and lifestyle requirements and include the person's immediate network of supporters, which may include paid staff, as well as friends, community contacts and volunteers.

- 4.40 Established by the Primary Community and Continuing Care Directorate of the HSE in 2007, the National Review of HSE Funded Adult Day Services sought to examine day services for people with physical, sensory and intellectual disabilities and people with mental health difficulties, and to make proposals for a ‘modern service that can respond to these unique and diverse individual needs’ (p. 13).
- 4.41 The National Working Group undertook four key tasks:
- a national census of day provision
 - a consultation with stakeholders
 - a programme of international and Irish research
 - a demonstration phase of innovative models being piloted by provider organisations.
- 4.42 The census undertaken by New Directions revealed considerable diversity in the types of day services currently being offered to people with physical, sensory and intellectual disabilities, and to those with mental health difficulties. This diversity reflected the lack of any clear definition of what comprises a day service⁶⁶. To address this challenge a typology of 13 day services was developed (see box). These categories provide a first step in clarifying the types of activities that may be deemed to comprise a ‘day service’ for people with disabilities in Ireland.
- 4.43 A total of 81 organisations, over 90% of which are non-statutory organisations, were identified as providing day services to over 25,000 individuals with disabilities in 817 locations nationwide. The large number of locations is thought to reflect a move away from congregated day services towards smaller, community-based services. In total, 65% of these locations provide services for people who have a primary diagnosis of intellectual disability, a group who comprise over 13,000 individuals, that is, over half of all recipients of day services.
- 4.44 The HSE budgetary allocation for day services was determined for 2007 and totaled €307 million. An additional €21.5 million was sourced within the same year by providers to deliver services. With regards to staffing, over 5,600 staff members were identified as working to deliver day service provision, most of whom were employed in the capacity of Supervisor/Instructor or Care/Support personnel.

⁶⁵ Health Service Executive (2012). *New Directions: Review of HSE Day Services and Implementation Plan 2012-2016*. Dublin, Health Service Executive.

⁶⁶ There are no nationally agreed definitions of any day services with the exception of ‘rehabilitative training’

Day services as defined in the context of New Directions

Day Care Programmes Services for those with higher support needs focusing on health care.

Day Activation/Activity Typically enhancing skills such as independent living, recreational activities, etc.

Active Community Participation/Inclusion Programmes to facilitate community inclusion.

Sheltered Work/Therapeutic Work activity in a location with no third party involvement, no contract work, not open to the public.

Sheltered Work Commercial Work activity which includes contract work and contact with public - money is exchanged for goods or services.

Sheltered Work –Like Work Work with discretionary ‘top up’ for individuals who work in HSE or provider organisations in ‘like work’ positions e.g. kitchens.

External Work – Like Work Work with discretionary ‘top up’ for individuals who work in open employment e.g. supermarket work.

Open Employment – no supports Work in the open labour market with no supports / support may have been available but is now withdrawn.

Supported Employment Paid employment in open labour market with employee status.

Sheltered Employment Work in an enterprise specifically set up to employ people with disabilities.

Rehabilitative Training Training programmes to equip people with social and work-related skills.

Education Programmes Programmes funded by Department of Education.

Voluntary Work

- 4.45 The consultation with stakeholders, including people with disabilities, family members, carers and people working within the disability field, provided a mixed response to the quality of day services available. While many commented on the wide choice of activities available under different programmes including computers and art classes etc., those who worked in intellectual disability services were critical of the ‘over-nursing’ of people using the services, noting that while many services still provide laundry and meals, ‘we would prefer to see service users provided with the skills necessary to carry out such activities independently’ (p.50).
- 4.46 Among many suggestions gleaned from the consultation process, stakeholders called for day services that would support individuals undertake worthwhile activities; to do ‘*ordinary things in ordinary places*’ that would be tailored to individual need. Independence was considered a key outcome yet was, according to stakeholders, restricted by finance. Independence was also restricted by staffing levels with service provider organisations commenting that low staffing ratios resulted in health and safety concerns. People with disabilities also commented on the low staffing ratios, stating that insufficient staff numbers resulted in a lack of one-to-one support and people feeling they were being ‘*controlled*’ rather than being facilitated.
- 4.47 The National Working Group developed a new approach to day service provision based on the principles of person-centredness, community inclusion & active citizenship and high quality services. The approach is entitled New Directions: Personal Support Services for Adults with Disabilities and is operationalised by a suite of 12 personal supports. Service providers are encouraged to deliver all 12 supports to people availing of their services, and to work with each individual to tailor a programme of support that meets individual need.

- 4.48 The 12 supports include support for (1) making choices and plans (including person centred planning); (2) making transitions and progression; (3) inclusion in one's local community⁶⁷; (4) accessing education and formal learning; (5) maximising independence; (6) personal and social development; (7) health and well-being; (8) accessing bridging programmes to vocational training; (9) accessing vocational training and work opportunities; (10) personal expression and creativity; (11) having meaningful and social roles; and (12) influencing service policy and practice.
- 4.49 In reconfiguring day service provision, the National Working Group identified a number of areas of concern in current practice. Consideration is required for 'vulnerable' groups identified in the census of day service recipients, specifically those under 18 years and those over 65 years for whom current provision may not best meet need. Another area of concern is the status of some individuals with disabilities who are currently engaged in 'work like activities'. In particular, there is a concern that those engaged in 'sheltered employment' and those engaged in 'external work-like work' may be eligible for legal status as 'employee', a status that would afford them certain employment related privileges. Finally, for those who are engaged in employment activities, the National Working Group propose that HSE should not be the responsible authority delivering these services, but rather that consideration should be given to the transfer of this responsibility to the Department of Jobs, Enterprise and Innovation.
- 4.50 The implementation of New Directions will require each service provider to develop its' own implementation plan for the delivery of the 12 personal supports based on the principles of person centred planning. Guidance will be provided in the format of a Quality Assurance System setting out the criteria that service providers must follow to deliver these supports, and a self-assessment tool will be available to assist service providers benchmark their existing provision against each of the new supports and make the necessary changes to align their service delivery to the new system⁶⁸. In implementing these changes, the National Working Group calls for a national change management process to be led by HSE which would support the roll out of demonstration projects, three year plans to be developed by all service provider organisations and for the development of local coordination between specialist and mainstream providers to build a joint approach to community inclusion.

VALUE FOR MONEY AND POLICY REVIEW OF DISABILITY SERVICES⁶⁹

- 4.51 The Value for Money and Policy Review of Disability Services was an extensive evaluation of the effectiveness and efficiency of disability services in Ireland, both statutory and non-statutory, funded under the Health Vote (see Section 3.2). It was conducted under the auspices of the Government's programme of Value for Money Reviews from 2009-2011, supported by an Expert Reference Group on disability policy who were charged with assessing the extent to

⁶⁷ Being part of one's own community is defined as 'knowing people in the community who are not involved in the provision of services; living and working in ordinary places; being able to access publicly funded community services such as libraries, public offices and adult education programmes; using local services and facilities, such as shops, cinemas and pubs; being able to contribute to and be part of specialist community associations for people with disabilities; being able to contribute to and be part of mainstream community associations such as residents associations, sports clubs and voluntary bodies; volunteering; being able to vote and to influence local planning'.

⁶⁸ The Priority Issues of Concern (PIOC) element of New Directions comprised a project team established in 2009 which addressed a number of key priority issues requiring immediate action. These priority areas included clarifying the role of HSE in employment, training and work; strengthening the HSE system for planning, monitoring and quality assurance; and strengthening the capacity for person-centredness.

⁶⁹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health.

which objectives of the state's Disability Services Programme were met, and if not, to propose policy amendments.

- 4.52 The Expert Reference Group (ERG)⁷⁰, reporting in 2011 prior to the publication of the Value for Money and Policy Review of Disability Services, noted the disparity between current policy, as articulated in *Towards 2016* (see section 4.7), and the perception and expectation of people with disabilities regarding their current support services. While '*full and independent lives*' are endorsed by policy, the ERG concluded that the reality for many people with disabilities is that services are congregated, overly professionalised, and have segregated people with disabilities from their local communities.
- 4.53 Endorsing a submission to the Value for Money and Policy Review by the National Disability Authority, the ERG argued that current services were resource-intensive, based on a medical model of disability, and largely delivered in segregated settings with high staff/service user ratios. The ERG commented that this model 'must also be considered in light of the current environment with regard to the economic climate, changing demographics and changing expectations' (p.11). The ERG concluded that despite considerable investment, including a multi-annual investment programme of €900 million targeted at high-priority disability support services from 2006 to 2009 (see section 4.6), the current model of service delivery had not met its objectives. In addition, the ERG concluded that no evidence existed that a more cost-effective version of the same policy would be any more effective. To achieve the policy objectives articulated in both *Towards 2016* and the public consultation conducted for the review, the Value for Money and Policy Review supported the ERG in concluding that the approach used to achieve these policy objectives must change (p.160).
- 4.54 The ERG (with modifications proposed by the Value for Money and Policy Review in italics which specifically relate to funding from the Health Vote) proposed a policy framework that aims to '*realise (contribute to the realisation of)* a society where people with disabilities are supported, (*as far as possible*), to participate (*to their full potential*) fully 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 wellbeing' (p.12 ERG). The amended statement is endorsed by the Value for Money and Policy Review as an expression of '*a revitalized and re-orientated Disability Services Programme*' (p. 164).
- 4.55 This policy proposal has two overarching goals:
- Goal 1: Full inclusion and self-determination for people with disabilities.
 - Goal 2: The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.
- 4.56 The ERG proposed reframing service delivery towards a model of individualised supports delivered, where possible, via mainstream services. The new model is similar to that available in other international jurisdictions where the allocation of state funding is based on a standardised assessment of individual need, as opposed to the current allocation based on an incremental determination process awarded directly to provider organisations (see section 3.8). Individual support plans will be developed based on a standard assessment of need. An individual budget will be determined from which support services are purchased. The individual will therefore be the commissioner of his or her own support services, whether through direct payments (where the budget is managed directly by the individual) or alternative mechanisms

⁷⁰ Department of Health (2011). *Report of Disability Policy Review*. Prepared by Fiona Keogh PhD on behalf of the Expert Reference Group on Disability Policy. Dublin, Department of Health.

including brokerage (where the person identifies supports which are then commissioned and purchased by a third party).

- 4.57 In addition to examining policy and proposals for reframing disability support services, the Value for Money and Policy Review examined the efficiency and effectiveness of disability services nationwide. This comprised a comprehensive review of disability services expenditure for 2005-2009, a public consultation, and a suite of research undertaken by the National Disability Authority examining specialist disability services in six international jurisdictions.
- 4.58 In examining the governance of the Disability Services Programme the Review revealed that although the Disability Unit of the HSE had responsibility for the planning, monitoring and evaluation of the disability programme, resource allocation and operational delivery at the time of publication rested with the HSE Regional Directors of Operations and the Integrated Service Area Managers. The Review proposed that a Director of Disability Services be appointed to lead the implementation of the Value for Money and Policy Review. In addition, a clear line of responsibility was called for from local, to regional, to national level.
- 4.59 The Value for Money and Policy Review proposed the introduction of a competitively tendered process from which services would be commissioned. Successful tenderers would formalise their contract with HSE via Service Level Agreements, where specified outcome and performance indicators would be used to monitor progress. The Review also proposed allocating funding based on individual need, in contrast to the existing incremental determination process. Within the current system, funding is allocated to places, for example, indicative costs for residential and day places are estimated at €80,000 and €14,000 per annum respectively⁷¹. These ‘average’ costs are currently applied across all models of services irrespective of individuals’ specific support needs.
- 4.60 In reviewing the ‘inputs’ to the Disability Services Programme, the Review noted that *‘the HSE does not maintain sufficient information on the sources of funding for voluntary providers because it does not systematically collect data on funding sources and reconcile these to annual accounts’* (p.47). The Review aimed to clarify, for the first time, the financial and staffing components of the Disability Services Programme. Taking 2009 as the year under study, the full disability budget was estimated at €1.859 billion, of which €1.789 billion (net €1.5) was funded by HSE. Non-exchequer funding of services, typically through private donations, was estimated at 5% to 7% of the full budget.
- 4.61 An examination of funding for the Disability Services Programme from 2005-2009 revealed an increase in expenditure of 34% over this time period. The increase is thought to reflect investment from the multi-annual investment programme⁷² (MAIP; see section 4.6), pay awards and increments, an increase in staff numbers and an increase in the overall allocations awarded to providers.
- 4.62 Pay costs were estimated at 84% of total expenditure and, for HSE and Section 38 organisations, were found to have increased 35% from 2005 to 2009. These increases reflect increased staffing levels (up 25% from 2005-2009) and the impact of national pay agreements which saw salaries for social care workers increase 16%-20% during the time period, while salaries for consultants rose 25%. A HR staff census classified staffing within the Disability Services Programme to six categories; ‘medical & dental’, ‘nursing’, ‘health & social care

⁷¹ *The Value for Money and Policy Review notes that neither the HSE nor the Department of Health have provided an explanation as to how these costs were arrived at* (p.54).

⁷² *The Value for Money and Policy Review notes deficiencies in the collection and reporting of performance data for MAIP leading to a lack of clarity regarding ‘how agencies used MAIP money for their clients in terms of new services, existing services, financing core deficits funding and additional staff’* (p54).

professionals', 'management and administration', 'general support' and 'other patient and client care'. The census revealed that the staff case mix remained stable from 2005-2009 with most staff being classified as 'other patient and client care' (38%) or 'nursing' (24%). All staff categories reported increases in staff numbers from 2005-2009 with 'medical & dental' staff reporting the greatest increase at 80%. Average salaries across these staffing categories for 2009 were €120,000 for 'medical & dental', €61,000 for 'management & administration' and 'health and social care professionals', €55,000 for 'nursing' and €38,000 for 'support staff'. Recommendations were made for capping salaries for those at CEO level (average salary €150,000) and senior management to consolidated pay agreement rates.

- 4.63 The professional nature of the workforce was noted: 43% staff were classified within 'nursing', or 'social care/therapy professional' grades. The Review estimated that substantial efficiencies could be accrued to the disability programme by altering the current staff mix, noting that a 10% change to non-professional personnel would reduce the cost of providing care by €3.5 million annually. The Review recommended that the HSE should begin the process of substituting non-professional qualified care staff (care assistants) for professionally qualified care staff to achieve pay savings.
- 4.64 Expenditure to private, for-profit organisations was also reviewed. In total, €21.7 million was paid to 105 private, for-profit organisations in 2009, 1.25% of net disability expenditure. These organisations were funded to provide services including residential, day, respite and home supports. Little detail was available on the persons in receipt of these services, however, the Review notes that as most service providers were described as 'nursing homes' it is likely that they are providing residential supports. As nursing homes, these organisations are subject to statutory inspections by HIQA. The Review recommends that a national protocol be developed to govern the use of private, for-profit organisations and that an individualised resource allocation model within the disability sector should be applied to these providers.
- 4.65 In reviewing the 'outputs' of the Disability Services Programme, the Review noted difficulties in determining the effectiveness of services provided to people with disabilities. A preliminary attempt to gather data revealed that units of output were undefined for many forms of service provision. Some 'complex' outputs (e.g. respite services, early intervention services) were challenging to define and measure. Others (e.g. residential and day services) were considered easier to quantify and cost. Given that these less complex outcomes were responsible for the largest proportion of the disability pay expenditure, a pragmatic decision was made to restrict analysis to the effectiveness of these more tangible outcomes. Effectiveness was assessed by examining the number of places available, the number of places occupied, the staff/client support ratio and the cost per place.
- 4.66 Table 3 below presents data on the average costs for a person with a disability receiving five different services; three day care and two residential. These data reveal the variation in cost for individuals with different support needs, ranging from 'minimum support' to 'intensive or high support'. Of interest is the marked disparity between these costs and the 'flat rate cost' allocated to providers. The Review noted, for example, that the largest cohort of people receiving residential services have high level support needs⁷³, costed in Table 3 at approximately €140,000 per place. The flat rate cost for a residential place awarded to service providers is €70,000, half of the funding required for those with high support needs. This situation has resulted in service providers negotiating with the HSE for funding for two notional places for one individual (p.119).

⁷³ 157 individuals with complex needs in 7 day residential high support setting had a direct pay cost each in excess of €150,000. The total cost for these individuals was 10% of pay expenditure for 7 day high support service users.

Table 3: Summary analysis of data on national resource usage groups

	Average cost per person from minimum support to high/intensive
Day service for children with Intellectual Disability	€8,681-€61,587
Day service for adults with Intellectual Disability (activation and	€8,101-€69,718
Day service for adults with Intellectual Disability (work like)	€17,227-€39,126
5 day residential services for people with Intellectual Disability	€33,624-€62,402
7 day residential services for people with Intellectual Disability	€35,086-€139,739

- 4.67 The Review also examined key drivers of residential costs including the size of service agencies and characteristics of service users. The Review noted marked variation in the costs of services by region and by type of service provider (HSE or non-statutory). No clear reason is apparent for this. Potential differences in staffing costs were examined, specifically between HSE and Section 38 organisations, who must apply consolidated salary pay scales, and Section 39 organisations, who are not obliged to do so. There was no evidence that the pay rate flexibility of Section 39 organisations resulted in lower operational costs. Although smaller agencies were found to have higher costs, the pattern was not consistent through to the larger agencies where there were variations in cost relative to size. The size of residential units, in contrast, were found to relate to costs, with settings supporting five or more residents costing less than those supporting four individuals or fewer.
- 4.68 Costs were also related to disability type, with higher costs observed to support those with autism spectrum disorder, or autism spectrum disorder and intellectual disability, when compared with other disability types. These findings, however, were thought to be confounded by the over-representation of these groups in congregated settings. Those with exceptional need, typically defined as 'extremely' challenging behaviour, most often in combination with autism spectrum disorder and mental health difficulties, reported high costs in excess of €150,000 per annum. In contrast, most service users with challenging behaviour were supported in residential settings with others, but received higher levels of support and/or more staff time. As such, only a small number of service users with challenging behaviour require exceptional resource requirements.
- 4.69 One of the main cost drivers identified by the Review was 'rostering', i.e., '*decisions on the numbers, skill level and skill mix of staff required to be on duty at any given time*' (p.116). An important component of rostering affecting costs is that of rostering staff to work outside core working hours (overnight and at weekends), which attract bonus payments. The Review noted that there are no national guidelines on rostering and that this issue is to be examined as part of the Croke Park Agreement, a public service agreement from 2010 to 2014. The review recommended that all agencies review their rosters within a six month period of the publication of the review.
- 4.70 Recommendations were also made regarding the allocation of funding to service providers in line with those proposed by the National Disability Authority and the Expert Reference Group. The Review noted a lack of transparency in the rationale for current allocations, and proposed that a standardised resource allocation system be introduced.

- 4.71 Mindful that implementing a nationally based resource allocation system of funding will require time to develop and trial, an interim resource allocation model was proposed. This interim model recommended that current flat rates (e.g. €70,000 for a residential place) be replaced by costs outlined in the Value for Money Review until such time as a systematic resource allocation system is implemented nationwide. During this time the HSE are charged with working within individual service providers to assist them in reducing costs to those average costs set out in Table 4 below.

Table 4: Summary analysis of data on national resource usage groups compared with recommended target pay costs per place

	Average pay cost 2009: minimum support to high/intensive	Recommended pay cost: minimum support to high/intensive
Day service for children with Intellectual Disability	€6,245-€29,399	€6,000-€28,000
Day service for adults with Intellectual Disability (activation, day support)	€5,465-€39,143	€5,000-€38,000
Day service for adults with Intellectual Disability (work like)	€10,621-€18,908	€10,000-€18,000
5 day residential services for people with Intellectual Disability	€20,000-€42,000	€20,822-€43,537
7 day residential services for people with Intellectual Disability	€21,000-€88,000	€21,489-€92,077

- 4.72 The Review noted that the available evidence suggests that supporting individuals in smaller settings is more cost effective than in larger institutional settings, noting that cost effectiveness should not, however, be assumed to translate to ‘cheaper’. There is evidence that institutional care may be cheaper, however, this is likely to reflect the poorer staffing ratios in these facilities. When staffing ratios are increased to acceptable levels, as they will be required to do, costs will rise proportionally. The Review concludes that the existing research suggests that it is the nature of the service provided, as measured by the supportive nature of staff and the presence of institutionalised characteristics, which define quality.
- 4.73 In its examination of outcomes in the disability sector, the Review noted the absence of agreed outcomes expected in the sector, and of an agreed set of national indicators. Although disability services aim to enhance the quality of life of those who avail of them, the Expert Reference Group caution that services may, in fact, have isolated people from their local communities. An agreed set of outcome measures are required based on outcomes determined for each individual. Individual outcomes should then feed into a process of continuous assessment of specific types of services, with those that are demonstrated not to be effective, discontinued.
- 4.74 To determine whether outcomes are being achieved within the Disability Services Programme, the Review assessed progress on four main objectives of *Towards 2016*, the social partnership agreement which underpins implementation of the National Disability Strategy (see Section 4.7).

- With regard to '*leading full and independent lives*' the Review examined indicators of independence including access to person-centred planning (PCP), health status, day care provision and residential supports. Findings revealed that some individuals fail to achieve positive outcomes in these areas; some have no access to PCP, no access to accessible materials regarding health care supports, no access to inclusive day activities and no access to independent living options. Efforts to support '*full and independent lives*' may be deemed unsuccessful.
- In examining the objective '*to participate in work and society, and to maximize their potential*', the Review examined educational and employment outcomes for people with disabilities. Educational outcomes, which are under the auspices of the Department of Education, identified most children with disabilities receiving education in specialist settings. This contrasts with Government policy which encourages mainstreaming of education for children with disabilities. Early drop-out rates for those with disabilities were over double those for children who do not have disabilities. Employment outcomes were generally diminished when compared with the general population. Those in specialist disability services had poor access to employment opportunities. Employment rates for those with disabilities in Ireland (32%) were considerably lower than the European average (43%) and the lowest employment rates in the OECD. Observing these outcomes, commitments by *Towards 2016* appear to be unmet.
- '*Access to services, as well as wider environmental accessibility*' was deemed to be beyond the remit of the Review. The Department of the Environment, Community and Local Government was identified as the appropriate authority in this area. In addition, the work of the Centre for Universal Design, National Disability Authority was identified as providing best practice guidelines and policy advice on accessibility in Ireland.
- The final objective was to provide '*support to carers in their caring role*'. Supports provided via the Health Vote include advocacy, advice and support, respite and home support. A consultation undertaken by the Review revealed that just under half of those consulted believed this objective was partially met, and only one in ten believed it was fully met. Once again, the aspirations of *Towards 2016* did not transfer to improved supports for people with disabilities.

- 4.75 Despite these deficits in implementation, the reforms proposed in the Review were a cause of concern for some government Departments given that no costing data were provided by the ERG, nor was evidence provided that experiences in other jurisdictions of cost efficiencies could translate to the Irish context. The Review acknowledged that '*an extensive amount of detailed analysis will be required to develop a migration plan from the current way of delivering disability services to the point where service provision, administrative structures and governance procedures all support the achievement of the proposed vision and goals*' (p.176).
- 4.76 In concluding this brief synopsis of the Value for Money and Policy Review of Disability Services, it is important to bear in mind that the proposed model of reform of the Disability Services Programme occurs within the context of an economic recession. Resource constraints are likely for the foreseeable future, and demographic information reveals that the numbers of people seeking support will increase.
- 4.77 Notwithstanding these financial constraints, findings from this extensive Review leave little doubt that current disability support services are not meeting the objectives set out in *Towards 2016*, nor are they meeting the expectations of people with disabilities, and, according to the financial analysis conducted through the review, they are financially unsustainable. While the

financial viability of the proposed reconfiguration of disability services has yet to be determined, there is now general consensus regarding the proposed direction of policy.

5. From Policy to Practice

- 5.1 The preceding section highlighted some of the major policy developments regarding disability services in Ireland from 1990. Four reports published in 2011- 2012 herald some of the most significant changes ever for the delivery of disability support services in Ireland:
- The National Housing Strategy (2011) aims to mainstream the provision of housing for people with disabilities. A five year implementation plan is scheduled with a direct reporting line to the Cabinet Committee on Social Policy.
 - The Congregated Settings Report (2011) calls for the relocation of over 4,000 individuals with disabilities from congregated to dispersed housing in the community. A seven year implementation plan will report under the auspices of the National Disability Strategy.
 - New Directions (2012) aims to introduce a new framework for the delivery of day services supporting people to '*do ordinary things in ordinary places*'. A National Change Management Plan led by HSE will provide support to provider organisations to develop three year implementation plans.
 - Finally, the Value for Money Review (2012), allied with the policy recommendations from its Expert Reference Group, not only provides further endorsement for the policies outlined above, but recommends a major reconfiguration of the Disability Services Programme. A new National Disability Strategy Implementation Group was established to monitor progress on this reconfiguration, personally chaired by the Minister for State with responsibility for Disability, Equality, Mental Health and Older People⁷⁴.
- 5.2 In February 2013, the National Implementation Framework of the Value for Money Review was published. The framework is defined as an evolving document and phase one of the implementation planning process. This phase included the proposed establishment of implementation structures by Q1 2013, the initiation and evaluation of demonstration projects by Q4 2013, and the undertaking of a policy appraisal of the Value for Money Review by Q1, 2014. Following these activities, phase two commences with the development of a detailed implementation plan for the commencement of migration to the new model of service.
- 5.3 The implementation process is led by a National Steering Group chaired by the Department of Health with representation from HSE, the National Disability Unit and the National Consultative Forum. The Framework notes that '*where possible, existing working groups, for example groups implementing the New Directions Report and the Congregated Settings Report, would be assimilated into the VFM project governance structure*' (p.9). A dedicated project team established by HSE is identified as key personnel implementing this reform. A Director of Disability Services is proposed who would have sufficient authority to ensure recommendations were enacted. This position falls within the remit of the newly configured Social Care Directorate of the HSE.

⁷⁴ House of the Oireachtas: Funding of Disability Services Motion 04 December 2012 available at <http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/takes/dail2012120400047>

- 5.4 Seven core strategic aims are identified, presented in Table 5. Each has actionable outcomes, with named responsible agencies and defined timelines.

Table 5: Strategic aims of Value for Money Implementation Framework

Strategic Aim	Lead Role	Timeline
1. Establishment of administrative and governance framework	HSE	2013-2014
2. Achievement of optimal efficiency	HSE	2013-2014
3. Implementation of commissioning and procurement framework	DOH/HSE	2013-2014
4. Development of resource allocation model	DOH/HSE/NDA	2013-2015
5. Establishment of information infrastructure	DOH/HSE	2013-2014
6. Development of strategic and operational plans	DOH/HSE	2013
7. Migration towards a person-centred support model	HSE	2013-2015

- 5.5 Deliverables to 2013 include the appointment of a Director of Disability Services aimed at creating a national disability function within the new HSE Social Care Directorate, the development of an information strategy, and the development of a resource allocation system.
- 5.6 Deliverables to 2014 include the development of monitoring systems to track the roll-out demonstration projects of individualised living arrangements, the development of guidance on staff mix required to deliver services, and the implementation of a common assessment tool for use in resource allocation.
- 5.7 The recent operational plan for the new HSE Social Care Directorate provides further detail on the short-term advances in implementation scheduled to occur in 2014⁷⁵. The proposed Director of Disability Services position is identified as a ‘Head of Operations and Service Improvement, Disability Services’, one of five key posts reporting directly to the National Director of Social Care. Referring specifically to implementing the Value for Money Review, the plan calls for service provider organisations to work in conjunction with Social Care Directorate personnel to plan their migration to a more individualised model of support between 2015-2019. More specifically, the plan identifies 150 individuals with disabilities who will move from congregated to individualised living arrangements in 2014. Plans for implementing New Directions and Progressing Children’s Disability Services in 2014 are similarly outlined.
- 5.8 The Social Care Operations Plan also highlights the role of ‘demonstration’ projects in managing the transition to a new model of support. These are typically small scale and

⁷⁵ Health Service Executive (2014) Social Care Division: Operational Plan 2014. Health Service Executive, Dublin.

innovative projects, and have been used internationally to disseminate good practice when reforming disability services. A leading organisation in Ireland promoting such demonstration projects is GENIO, a non-profit organisation funded by the State and philanthropic donations. It provides financial support to organisations and individuals wishing to promote more personalised, community-based supports. An evaluation of a number of demonstration projects funded by GENIO was completed in early 2014 evidencing the positive impact of individualised living arrangements⁷⁶.

- 5.9 At the time of publication of this report for the Moving Ahead project, the National Implementation Framework is currently in the process of populating a number of key working groups and sub-groups to support the implementation of reform in the sector. Six working groups are now established⁷⁷:
1. Person Centred Models of Services and Supports – Strategic Planning (with two sub-groups focusing on (1) base-line data and (2) evaluation)
 2. Person Centred Models of Services and Supports – Implementation, Oversight and Support (with three sub-groups focusing on the implementation of the HSE's (1) Time to Move on From Congregated Settings, (2) New Directions and (3) Progressing Disability Services for Children and Young People).
 3. People with Disabilities and Community Involvement.
 4. Quality and Standards.
 5. Management and Information Systems.
 6. Governance, Efficiency and Effectiveness (with five sub-groups focusing on (1) governance and service arrangements (2) implementation of Value for Money tasks (3) Shared Service Platform (4) Procurement (5) Haddington Road).
- 5.10 A Project Manager and Project Lead are now appointed to oversee the implementation of this programme of work. These personnel will report directly to the National Steering Group.
- 5.11 The Next Steps project led by the National Federation of Voluntary Bodies similarly provides supports to provider organisations in the intellectual disability field who are implementing novel and innovative approaches to individualised supports. Twenty-one organisations share their learning from trialing new, more personalised supports. As with GENIO, evaluation data are being gathered to determine the benefits of these approaches and the experiences of participants in transferring to new models of support. The expectation is that these demonstration projects will also provide tangible evidence of how change can be successfully implemented.
- 5.12 To conclude, unprecedented change is anticipated in the disability sector in Ireland. Where policies are implemented, services developed in the next decade will be fundamentally different. Differences should be apparent in several areas: the greater visibility of people with disabilities; their greater access to mainstream provision; and the development of new service arrays such as brokerage and advocacy services, indicating a different and emerging role for

⁷⁶ McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E., & Stevens, R., (2013). *An evaluation of personalised supports to individuals with disabilities and mental health difficulties*. University of Ulster.

⁷⁷ National Federation of Voluntary Bodies Spring Newsletter 2014 available at http://www.fedvol.ie/_fileupload/Newsletters/Final%20-%20Newsletter%20Spring%20April%202014.pdf

provider organisations. The drivers for these changes include national expectations and policies. They also include the awareness that services need to improve if they are to comply with international obligations, such as the United Nation's Convention on the Rights of People with Disabilities⁷⁸, which Ireland has signed but has yet to ratify.

6. The Challenge of Implementation

- 6.1 Services in Ireland are therefore currently in transition to a more personalised model of supports for people with intellectual disabilities. The process to date, however, has been characterised as a '*slow and tentative drift*', with agencies at many different stages of this journey.⁷⁹ In the absence of formal monitoring processes for implementing this transition, it is reasonable to raise concerns about how effective the process will be in meeting national and international obligations and expectations.
- 6.2 Reports and reviews of disability services in Ireland paint a consistent picture of poor or non-existent implementation by voluntary and statutory bodies of changes required by successive reports over several decades. This pattern in three broad areas – funding transparency, service level agreements, and performance (outcome) indicators – is summarised here. This pattern highlights the necessity of monitoring implementation if the '*fundamental*'⁸⁰ changes required in disability services are to be achieved.
- 6.3 In relation to funding transparency, the Comptroller and Auditor General in 2003-2004 reviewed 42 nonprofit organisations in three former health board regions reporting that of these, 12 organisations (which together had received approximately €100m in funding) had submitted no financial statements in 2003. One large organisation had submitted no financial statements for four years to 2004, despite having received €288 million in state funding. The HSE had performed reconciliations between reported income and HSE funding for only six of the 42 organisations. In addition, the Comptroller and Auditor General's financial audits of the former health boards revealed very extensive deficiencies in service and financial accountability and administration of disability services.⁸¹
- 6.4 At that time the Comptroller & Auditor General reported that the nonprofit sector itself recognised the need for better accountability, transparency and governance and viewed correction of this weakness as a matter of priority. However, the 2011 Value for Money Review, as noted in Section 4 above, once again pointed to the absence of a financial data collection and monitoring system in disability services, remarking that it was a significant barrier to the Review's own work. Noting the lack of itemised funding information in disability

⁷⁸ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. p. 173

⁷⁹ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. p. 75

⁸⁰ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. p. 173

⁸¹ These were: the absence of service agreements and provider plans; late receipt and non-receipt of audited accounts; acceptance of unaudited accounts; failure to reconcile grant payments with audited accounts; overpayment of grant amounts; failure to maintain grant registers and grant files; and no register of recipients of aids and appliances maintained. Absence of the following: completed application forms; grant approvals; tax clearance certificates or Revenue Commissioners' confirmation of charitable status; registers recording the receipt of audited accounts; certificates confirming satisfactory service by grantee; written procedures; review of monitoring procedures; formal evaluation of services; receipts of grant payment amounts; and of review of compliance by nonprofit organisations with conditions attaching to funding. C&AG, 2005, Appendix B

organisations and lack of reconciliation to organisational annual accounts, the Review argued that such analyses should be mandatory for the allocation process from 2013. However, in the absence of a formal monitoring mechanism for the Review's recommendations, it is not possible to establish whether this has taken place. Furthermore, the Value for Money review also noted multiple ongoing deficiencies in the state's own capacity to account for its expenditure. The HSE's accounting system does not capture all HSE-funded expenditure on the Disability Services Programme. Different regions have multiple financial systems, and breakdowns on pay or non-pay costs, or on programme-specific costs (e.g. residential, day services, etc.) are not possible with the existing system⁸².

- 6.5 Service Level Agreements (SLAs) are critical to guiding the relationship between the state as commissioner of services and the bodies providing them. Despite the fact that in the 1990s, the Department of Health had planned to introduce SLAs and to link funding to them, in 2005 the Comptroller and Auditor General reported that in 2003-2004, over a third of funding was not covered by SLAs, and that where they did exist, they were high-level frameworks, lacking in specifics, and often not signed until long after funding and service provision had begun. After this, in 2009, the HSE introduced a new governance framework to formally specify disability services, outcomes and performance indicators. Despite this, in 2012 the Value for Money review still found many SLA omissions in disability services, including in systems and protocols; formal documentation of the commissioning process; SLA datasets; regional and national level data aggregation; annual collation and publication of summary SLA data; and in independent validation and auditing of the SLA process. As a result, The Value for Money Review noted, effective performance monitoring in disability services was not possible.
- 6.6 A core element of SLAs is performance (outcome) indicators and, again, the failure to develop these for disability service provision in Ireland has also been noted repeatedly over several decades. The Comptroller and Auditor General in 2005 noted a commitment in *Enhancing the Partnership*, a partnership agreement dated 1996, by nonprofit organisations to develop internal audit and service evaluation functions. These commitments were unmet by 2005 leading the Comptroller and Auditor General to conclude that structures for monitoring, measuring and assessing performance were poorly-developed, albeit acknowledging that the HSE had *commenced a process to compile data which will form the basis of performance indicators relating to the governance and management of disability services*⁸³. In 2009 however the Comptroller and Auditor General again identified many deficiencies in performance indicators and in 2012 the Value for Money Review found that *the position has not changed materially as there had been little progress ... in developing national outcome indicators*⁸⁴.
- 6.7 In the absence of transparency regarding funding, of SLAs and of clear performance goals for disability services, the consistent absence of service monitoring or review is of particular concern. The Comptroller and Auditor General noted in 2005 that there were no formalised procedures for HSE service reviews, and that none of the former health boards reviewed in that report had evaluated all disability services in their catchment area. In 2012, the Value for Money Review reported that the HSE had no information about SLA review meetings held to date – their outcomes, their number, or even whether any had been held at all. This echoes findings of previous studies of the Eastern and Midlands Health Boards which found that staff

⁸² Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. P.47

⁸³ Comptroller and Auditor General Report on Value for Money Examination (2005). *Health Service Executive: Provision of Disability Services by Non-Profit Organisations*. Dublin; Government of Ireland.

⁸⁴ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. P132

had confused expectations and difficulties regarding standards and monitoring⁸⁵.

- 6.8 For many decades, Department of Health strategy and policy documents have repeatedly acknowledged the unique and unparalleled role of non-profit organisations in providing health and personal social services and confirmed the state's commitment to developing its relationship with these organisations^{86 87 , 88}. Given the consistent absence of government oversight of voluntary service providers in Ireland, it has been noted that accountability and representation in voluntary organisations is patchy; some are responsible to their boards, some only to their religious superiors and family and friends groups who may neglect to maintain representative structures. Commentators have noted that some services are driven by organisational missions rather than by the needs of the individuals they serve⁸⁹. In these cases service delivery may be driven by the power of individual personalities who decide policy and direction with little reference to others and resist the need for change⁹⁰. Voluntary agencies, it has been noted, may be reluctant or refuse to co-operate with needs for change; they may also refuse to share information, transfer funding or facilitate moving supported people to another area⁹¹.
- 6.9 It is important to note that legacies of previous service patterns, and concerns about relationships between the state as commissioner and voluntary agencies as service providers, are not specific to Ireland^{92 93}. International trends suggest that when services are provided by voluntary organisations, equity and universal entitlement, features that should be inherent in a public service, may be problematic; and that interdependence between the state and the voluntary sector has led to pervasive blurring of boundaries and problems with accountability of individual voluntary agencies⁹⁴.
- 6.10 As noted by successive reports, therefore, the effective operation of services for people with intellectual disabilities is dependent on clear specification of relationships between statutory and nonprofit organisations and expectations for service provision⁹⁵. The detailed and specific recommendations of the Value for Money Review have the potential to address this situation, but only in the context of fundamental change to a system that has been characterised as

⁸⁵ Donoghue, F., (2002). *Reflecting the Relationships; An Exploration of Relationships between the former Eastern Health Board and Voluntary Organisations in the Eastern Region.* ERHA.

⁸⁶ Department of Health (1994). *Shaping a Healthier Future.* , Dublin: Department of Health

⁸⁷ Department of Health (1996): *Enhancing the Partnership. Report of the Working Group on the Implementation of the Health Strategy in Relation to Persons with a Mental Handicap,* Dublin: Department of Health

⁸⁸ Department of Health and Children (2001). *Quality and Fairness – A Health System for You.* Dublin: Department of Health and Children.

⁸⁹ Power, A., & Kenny, K., (2011). *When care is left to roam: Carers experiences' of grassroots non-profit services in Ireland.* Health & Place, 17, 422-429.

⁹⁰ Ryan, A., 1999. *Walls of Silence: Ireland's Policy Towards People with a Mental Disability.* Red Lion Press, Kilkenny. P.120

⁹¹ Power, A., & Kenny, K., (2011). *When care is left to roam: Carers experiences' of grassroots non-profit services in Ireland.* Health & Place, 17, 422-429.

⁹² Donoghue, F., (2002). *Reflecting the Relationships; An Exploration of Relationships between the former Eastern Health Board and Voluntary Organisations in the Eastern Region.* ERHA.

⁹³ Power, A., & Kenny, K., (2011). *When care is left to roam: Carers experiences' of grassroots non-profit services in Ireland.* Health & Place, 17, 422-429.

⁹⁴ Kramer, R., (1994): 'Voluntary Agencies and the Contract Culture: "Dream or Nightmare?"', *Social Service Review*, March

⁹⁵ Comptroller and Auditor General Report on Value for Money Examination (2005). *Health Service Executive: Provision of Disability Services by Non-Profit Organisations.* Dublin; Government of Ireland.

currently not financially sustainable; nor accountable; nor effective⁹⁶.

- 6.11 The complexity of the disability services system, and the degree of change required mean that change is unlikely to be rapid. According to the Comptroller & Auditor General, effective change management is required, which views the system as an ‘integrated learning process’ engaging in *ongoing policy development, resourcing, capacity development, implementation of services, monitoring and evaluation.*, and including addressing ‘*the capacity of non-profit organisations to meet ... requirements relating to the implementation of the standardisation of services, good governance and greater accountability.*’, which *may require investment in the upskilling of volunteer board members....* The change will require addressing governance, quality assurance, information management, management structures; and operational processes⁹⁷, but *the degree to which the various stakeholders in the disability services delivery system have the required competencies and supportive infrastructure to implement this at the present time is unclear*⁹⁸
- 6.12 To conclude, there is considerable evidence illustrating how successive attempts to introduce greater transparency and accountability within the disability sector have fallen by the wayside. Repeatedly, the Comptroller and Auditor General has highlighted failures in implementing recommendations of successive reports. More recently, the Value for Money and Policy Review has concluded that there is little if any progress on issues of funding transparency, contractual agreements and outcome indicators, issues which have been successively highlighted for improvement. Within this context, achieving the large-scale configuration of the disability service sector as set out in the Review will require considerable adjustments to current practices within and between HSE and nonprofit organisations. In the absence of any formal monitoring process for implementing a reconfiguration of services, it is possible that little more is achieved than the ‘*slow and tentative drift*’ identified by the Value for Money and Policy Review.

⁹⁶ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health. P173

⁹⁷ Department of Health (2012). *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health.

⁹⁸ Comptroller and Auditor General Report on Value for Money Examination (2005). *Health Service Executive: Provision of Disability Services by Non-Profit Organisations*. Dublin; Government of Ireland.