



## **ANED country report on the implementation of policies supporting independent living for disabled people<sup>1</sup>**

**Country:** Ireland

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<sup>1</sup>Glossary of Acronyms at end of report.



*So many lives are only half-lived through lack of opportunity, lack of choice, too many obstacles, too little help, too much of that lazy old thinking which used to say things like – you can't do that because you are a woman, you can't do that because you are in a wheelchair, you can't do that because you are blind, you can't because...What awful arrogance to dare impose restrictions on the life chances of another human being and what a waste of talents and skills it can lead to – for the individual, for his or her family and for all of us as a community...*

*If there has been progress towards a more person centred approach, increased State investment, movement away from institutional settings to community-based services, then the people in this room and those involved in disability lobbying can take a bow.*

Remarks by President McAleese at the opening of the Independent Living Conference, Croke Park, Dublin, Tuesday 5<sup>th</sup> June 2007<sup>2</sup>

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<sup>2</sup>Full text of the speech available from <http://www.dublincil.org/Documents/Remarks%20of%20the%20President.pdf>



## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

While the issue of independent living for people with disabilities has been addressed and highlighted as a desirable goal in a number of policy documents, there has been no definitive statement of a policy imperative to move away from providing support in segregated residential institutions to independent living in the community. The right to 'independent living' in Ireland has no legal status in the Constitution, in statute or in administrative law.

The provision of support to disabled people in Ireland still relies to a relatively significant degree on residential institutions especially with respect to those with intellectual disabilities. Although a small number of people with physical or sensory disabilities remain in these institutions, a far higher number of those with intellectual disabilities are living in segregated residential institutions.<sup>3</sup>

The number of people in such institutions increases with age and, in the case of people with an intellectual disability, with the severity of the disability.

Significant barriers arise in relation to support for people with disabilities who want to live in their own homes but cannot afford to buy a property. While in theory they have the same entitlements to social housing as other members of the community, in practice the limited supply of accessible and adaptable local authority or voluntary sector social housing is a substantial barrier to people with disabilities living independently in their own homes. Furthermore, additional disability related costs mean that the cost of living for people with disabilities is higher than for other members of the community, a fact that may also operate as a barrier to independent living.

The provision of support services to enable people with disabilities to live independently in their own homes, such as Personal Assistant Services and Home Help Schemes is also problematical. Despite the identification of such services as fundamental to facilitating independent living for people with disabilities, they remain underfunded.

Furthermore, access to such services is uneven given waiting lists of differing lengths across the country. This underfunding and uneven access to services may indicate that Ireland is falling short of the standards required by Article 19 (b) of the UN Convention on the Rights of Persons with Disabilities, which requires that persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community.

Other issues of concern include the absence of any formal processes or safeguards to ensure that people do not enter or remain in institutions against their choice, as well as the absence of any mechanism or legally binding standards for measuring the quality of community based assistance and services. Furthermore, as community or voluntary organisations administer funding for Personal Assistance services, people with disabilities in Ireland do not have the opportunity to effectively control their own financial budgets for these supports for independent living.

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<sup>3</sup>As discussed in section 4, while the obligation to provide health services to people with disabilities rests with the State, many of these services are provided by non-profit organisations under arrangements with the Health Service Executive.



## PART 2: LEGAL AND POLICY CONTEXT

There have been major changes in disability law and policy in Ireland over the past number of years. Many of these changes have both directly and indirectly contributed to providing choices for disabled people to live independently. While a number of policy documents have addressed physical obstacles to independent living such as inadequate access to housing for people with disabilities, there has also been some acknowledgement of the need to ensure that support services are in place to facilitate people with disabilities living independently in their own homes.

### **Early Blueprint for Change - Report of the Commission on the Status of People with Disabilities 1996<sup>4</sup>**

The establishment of the Commission on the Status of People with Disabilities in 1993 represented a significant step towards addressing disability issues in Ireland, including the issue of independent living for people with disabilities.

The Commission's terms of reference permitted it to make recommendations 'setting out necessary changes, in legislation, policies, organisation, practices and structures to ensure that the needs of people with disabilities are met in a cohesive, comprehensive and cost effective way'.<sup>5</sup>

On examining community care services for people with disabilities, the Commission acknowledged that the shift from providing services in large institutions to community based services had not been smooth and that community care services had developed in an unplanned and uncoordinated manner.<sup>6</sup> The vital role of the home help scheme and personal assistance services was highlighted<sup>7</sup>, with the Commission recommending that additional revenue funding be provided for these services. The importance of such services in facilitating Independent Living was expressly recognised by the Commission.<sup>8</sup>

The Commission was also of the view that the concept of Independent Living should underpin policy on housing, stating that

If housing is to provide the base from which people with disabilities participate in society, then policies must address not only the question of the physical fabric of buildings and the serviceability of the wider environment but also the services, supports and income required to facilitate independent living.<sup>9</sup>

The Commission also recommended that housing options for people with disabilities should include a mix of different arrangements. Single houses, houses capable of accommodating four or five people, bungalow units clustered together, and groups of town houses with a communal garden should all be included. The Commission stated that they should have the appropriate support staff and be situated close to amenities and retail outlets to ensure maximum independence.<sup>10</sup>

In 1999, the government published *Towards Equal Citizenship*, a progress report on the implementation of the recommendations of the Commission on the Status of People with Disabilities.<sup>11</sup>

<sup>4</sup>Report of the Commission on the Status of People with Disabilities: A Strategy for Equality, 1996.

<sup>5</sup>Ibid at Preface p. iii.

<sup>6</sup>Ibid p. 163.

<sup>7</sup>The operation of these services will be discussed in detail in sections 4 and 4.1.3.

<sup>8</sup>Ibid p.164, 165.

<sup>9</sup>Ibid p. 187.

<sup>10</sup>Ibid p. 192.

<sup>11</sup>Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities: Towards Equal Citizenship, 1999.



In relation to the Commission's recommendations that home help and personal assistance services receive additional funding, the Progress Report noted that the services outlined in this recommendation would be developed on an ongoing basis, as resources permitted, to provide for a flexible range of support services.<sup>12</sup> The Progress Report also noted that

'In recent years, the government's policy has been to integrate people with disabilities into the community rather than placing them in institutions. It is important that appropriate housing be available in community settings to prevent people having to avail of institutional type residential care when they leave the family home because of the absence of appropriate alternatives'.<sup>13</sup>

On this basis the Progress Report noted that the health services would continue to provide accommodation for those with severe disabilities in village type communities, on campus sites and some accommodation in the community. It was accepted however that options must be available for those who can have independent lives, with or without support, but who need specially adapted housing.<sup>14</sup>

### **Law - The Equal Status Act 2000<sup>15</sup>**

This Act prohibits discrimination in a number of areas including the disposal of goods, the provision of services and, significantly, the provision of accommodation. Disability is one of nine grounds on which discrimination is prohibited, with discrimination including a 'refusal or failure by the provider of a service to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities, if without such special treatment or facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service'.

Section 6 of the Act, concerning the disposal of premises and the provision of accommodation, was the basis of a successful complaint in the 2005 case of *Ms. Mariyam Cementwala v Ms. D Colbert, Winters Property Management & Crescent Green* (DEC-S2005-184-186).<sup>16</sup> Ms. Cementwala, who is blind and a long-term cane user, agreed to rent an apartment from Ms. Colbert. The next day however, Ms. Cementwala was told that she could no longer rent the apartment because of safety issues to do with her disability. Ms. Colbert was of the opinion that the stairs leading to the complex would be dangerous for someone who used a cane. The Equality Officer found that there was no failure to provide reasonable accommodation, as none was actually required. However, there was a *prima facie* case of direct discrimination as the tenancy had ceased because of Ms. Cementwala's impaired vision despite the fact that she could use the stairs in question comfortably. This was the first and so far the only) case involving the right to housing for a person with a disability.

### **Standards - Part M Building Regulations 2000<sup>17</sup>**

Part M of the Building Regulations relates to Access for People with Disabilities. Before 2000 the Regulations did not apply to dwellings, but did apply to non-domestic buildings and the common areas of apartment blocks.

The current Regulations now require that new dwellings be 'visitable' by people with disabilities.

<sup>12</sup>Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities: Towards Equal Citizenship, 1999, p. 116-118.

<sup>13</sup>Ibid at p.163.

<sup>14</sup>Ibid.

<sup>15</sup>Equal Status Act 2000 available at <http://www.irishstatutebook.ie/2000/en/act/pub/0008/index.html>

<sup>16</sup>Decision available from the Equality Tribunal website at <http://www.equalitytribunal.ie/index.asp?locID=30&docID=275>

<sup>17</sup>Available at <http://www.environ.ie/en/Legislation/DevelopmentandHousing/BuildingStandards/>



The Technical Guidance Document<sup>18</sup> requires that new dwellings should be designed and constructed so that people with disabilities can safely and conveniently approach and gain access and can access the main habitable rooms at entry level. It also requires that a WC should be provided at entry level.

Where, in the opinion of the Building Control Authority a building contravenes any part of the Building Regulations, enforcement action and prosecution can be taken against the non-compliant party.

Nonetheless, a 2005 National Disability Authority (NDA)-commissioned report on the Effectiveness of Part M of the building regulations revealed a poor level of compliance with the requirements of Part M, particularly in the case of one-off houses.<sup>19</sup> The Report on the Effectiveness of Part M included the results of a survey of forty-eight single one off houses around the country, and revealed a compliance rate of only 24% with the requirements of Part M. Housing schemes fared slightly better with a compliance rate of 64% recorded. It would appear therefore that Part M has not been strictly enforced.

The Department of the Environment, Heritage and Local Government has carried out a review of Part M and in July 2009 a Consultation Document of proposed amendments to Part M was published, along with the related Technical Guidance Document M. The amended Regulations require that new buildings, other than dwellings, should be designed and constructed so that people with a range of disabilities can safely and independently approach and gain access to a building, circulate within it and use the relevant facilities, including sanitary conveniences within it. The final consultation process on proposals for the review of Part M will conclude in October 2009.<sup>20</sup>

### **National Economic and Social Council Report on Housing in Ireland: Performance and Policy 2004<sup>21</sup>**

The National Economic and Social Council was established in 1973. Under its terms of reference the main tasks of the NESC shall be 'to analyse and report (to the Taoiseach) on strategic issues relating to the efficient development of the economy and the achievement of social justice'.

The 2004 NESC Report on Housing in Ireland notes the 'lack of a strategic framework to support the provision of housing and housing supports for people with disabilities' and emphasised the necessity of developing such a strategy.<sup>22</sup>

The location and physical attributes of a disabled person's home were identified as central to that person's ability to participate in society. The Report referred to some key policy issues raised by the 2004 Disability Federation of Ireland publication, 'Housing – The Vital Element'.<sup>23</sup> These issues included the limited range of housing options available to people with disabilities and the continued use of long-stay institutional care due to the absence of suitable alternatives in the community.

<sup>18</sup> Available at <http://www.environ.ie/en/Publications/DevelopmentandHousing/BuildingStandards/FileDownload.1655.en.pdf>

<sup>19</sup> Report available at <http://www.nda.ie/cntmgmtnew.nsf/0/D7B9326DE8BF2CBA802570CF00348A4C?OpenDocument>

<sup>20</sup> Department of the Environment, Heritage and Local Government website, 'Gormley Announces Improvements in Accessibility of Buildings', 08/07/09. Available at <http://www.environ.ie/en/DevelopmentandHousing/BuildingStandards/News/MainBody.20703.en.htm>

<sup>21</sup> Available at <http://www.nesc.ie/dynamic/docs/NESCHousingReport.pdf>

<sup>22</sup> Ibid at p. 157.

<sup>23</sup> Disability Federation of Ireland (2004), Housing: The Vital Element, Dublin, DFI.



### **Current Blueprint for Change - The National Disability Strategy 2004<sup>24</sup>**

The National Disability Strategy was launched in 2004. The government stated that by building on existing policy and legislation, the Strategy would ‘underpin the participation of people with disabilities in society’. The Strategy was composed of a number of key components namely, The Disability Act 2005, The Citizens Information Act 2007, The Education for Persons with Special Needs Act 2004, a multi-annual investment programme for disability support services and sectoral plans prepared by six government departments.

Progress on the implementation of the National Disability Strategy is monitored by the Senior Officials Group on Disability (SOG-D), which reports to the Cabinet Committee on Social Inclusion. This group consists of officials representing the six government departments responsible for implementing the Sectoral plans as well as the Department of the Taoiseach, the Department of Justice, Equality and Law Reform, the Department of Finance and the Department of Education and Science.

A National Disability Strategy Stakeholder Monitoring Group has also been established to monitor progress on the overall implementation of the strategy. This group is comprised on the Senior Officials group on Disability, a number of stakeholder groups, the National Disability Authority as well as the Irish Congress of Trade Unions and Irish Business and Employers Confederation.

### **Centrepiece of the National Disability Strategy - The Disability Act 2005<sup>25</sup>**

This Act is designed to support the provision of disability specific services to people with disabilities and to improve access to mainstream public services for people with disabilities. Some of the key features of the Act include provision for an individual right to an independent assessment of need and a related service statement, provision of a statutory basis for access to public buildings and services and the imposition of a 3% quota on public bodies for the employment of people with disabilities. The Act also provides the outline for sectoral plans for six key Departments in relation to the provision of services to persons with disabilities. Progress reports on the Sectoral plans are to be prepared after 3 years and the Disability Act will be reviewed after 5 years.

S.32 and 36 relating to the sectoral plans for the Department of Health and Children and the Department of the Environment, Heritage and Local Government respectively contain particularly relevant clauses in relation to the issue of independent living. S. 32 (c) requires the plan contain information concerning ‘arrangements for co-operation by the Health Service Executive with housing authorities in relation to the development and co-ordination of the services provided by housing authorities for persons with disabilities’. S.36 (d) requires the plan contain information concerning ‘housing and accommodation for persons with disabilities’.

### **Department of Health and Children Sectoral Plan 2006<sup>26</sup>**

In implementing the provisions of the Disability Act, the sectoral plan of the Department of Health and Children states that ‘to bring a new focus to addressing the housing needs of people with a disability, a National Housing Strategy for People with Disabilities will be developed as recommended in the NESC ‘Housing in Ireland’ Report in order to support the provision of tailored housing and housing supports to people with disabilities. This would have particular regard to adults with significant disabilities and people who experience mental illness’.

In 2007 a National Group was launched to advise on the development and implementation of a national housing strategy for people with a disability and this strategy is to be developed and implemented by the end of 2009.<sup>27</sup>

<sup>24</sup> Available at <http://www.justice.ie/en/JELR/NDS.pdf/files/NDS.pdf>

<sup>25</sup> Available at <http://www.oireachtas.ie/documents/bills28/acts/2005/a1405.pdf>

<sup>26</sup> Available at [http://www.dohc.ie/publications/fulltext/disability\\_sectoral\\_plan/](http://www.dohc.ie/publications/fulltext/disability_sectoral_plan/)



The sectoral plan also provides for a Protocol to be agreed between the HSE and local authorities to govern liaison concerning the housing needs of people with a disability. This Protocol has been developed and will be discussed further below.

#### Department of the Environment, Heritage and Local Government Sectoral Plan 2006<sup>28</sup>

The Department of the Environment, Heritage and Local Government Sectoral Plan recognises that people with a disability frequently have less choice in terms of providing for their housing and accommodation needs. The sectoral plan aims at improving the quality of choice available and at directing resources to areas of greatest priority. The plan reiterates that a National Housing Strategy for People with Disabilities<sup>29</sup> will be developed and states that 'legislation will be introduced that will result in a new means of assessing housing need to ensure that all people can live with maximum independence within their community'. The plan highlights the important role of the voluntary and co-operative housing sector in meeting special housing needs, including those of persons with a disability and reaffirms the Department's commitment through capital funding schemes to supporting this sector.

#### **National Economic and Social Council – Strategy 2006: People, Productivity and Purpose<sup>30</sup>**

Since 1987, the NESC has conducted a three-yearly overview of Irish economic and social developments and challenges. These reports act as the basis for negotiation of Ireland's social partnership programmes. Social partnership is a process by which issues of social policy can be agreed between the Government and the social partners. The social partners include trade unions, employers, farming organisations and the community and voluntary sector.

The 2006 NESC Report acknowledged that the Disability Act 2005 marked 'a major watershed in Irish social policy', and constituted 'recognition, as never before, of the place of persons with disabilities in Irish society and of the State's responsibilities to ensure they participate on an equal basis to other citizens'. The Report noted that when compared with other advanced countries, Ireland fell behind in this area. In relation to the six draft sectoral plans and also their later versions, the report emphasised that they 'should be informed by the constantly advancing frontiers of knowledge as to how health, education, housing and social welfare services and workplace practices can enhance the quality of life of persons with specific disabilities'.

#### Disability as a Core Feature of Social Partnership Process - Towards 2016 Ten-Year Framework Agreement 2006-2015<sup>31</sup>

As noted above, social partnership is a process by which issues of social policy can be agreed between the Government and the social partners. The Government and the social partners engage in negotiations on social policy issues that result in a social partnership agreement. Towards 2016 is a ten year Framework Social Partnership Agreement that runs from 2006-2015 and outlines a number of objectives for economic and social development in Ireland. The framework adopts a new social policy perspective known as the lifecycle approach, which aims at placing the individual at the centre of policy development. The lifecycle phases include children, people of working age, older people and people with disabilities. People with disabilities, in accordance with the policy of mainstreaming will benefit from measures at all stages of the lifecycle.

<sup>27</sup>Department of the Environment, Heritage and Local Government website, 'Minister O'Keefe launches National Group to advise on the development of a National Housing Strategy for People with a Disability', 25/10/07. Available at <http://www.environ.ie/en/DevelopmentandHousing/Housing/SpecialNeeds/PeoplewithaDisability/News/MainBody,15690.en.htm>

<sup>28</sup> Available at <http://www.environ.ie/en/Publications/LocalGovernment/Administration/FileDownload,2011.en.pdf>

<sup>29</sup> Due by the end of 2009.

<sup>30</sup> Available at <http://www.nesc.ie/dynamic/docs/Full%20Strategy%20report.pdf>

<sup>31</sup> Available at [http://www.taoiseach.gov.ie/attached\\_files/Pdf%20files/Towards2016PartnershipAgreement.pdf](http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf)





Section 33 of the agreement deals with people with disabilities and states that ‘the parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community, free from discrimination’. A number of long-term goals are identified with a view to achieving this vision. These goals are that:

- Every person with a disability has access to an income sufficient to sustain an acceptable standard of living.
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services.
- Every person with a disability has access to public space, buildings, transport, information, advocacy and other public services and appropriate housing.
- 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 maximise their potential.
- Carers would be acknowledged and supported in their caring role.

Key issues identified by the Report to be addressed in sectoral plans included assessment for and access to, appropriate health and education services including residential and community based care.

From an independent living perspective, certain commitments outlined in the Agreement are of particular importance. These include a commitment that person-centred supports will continue to be developed for long stay residents in psychiatric hospitals, with a view to their movement back into community living and also a commitment that person centred supports will continue to be provided to adults with significant disabilities having regard to the range of support needs which they require, e.g. nursing, personal assistance, respite, rehabilitation, day activities etc.

A number of progress reports on *Towards 2016* have been published. These progress reports have stated that the Government and the social partners agree that the National Disability Strategy represents a comprehensive strategy for this aspect of the life cycle framework and that the implementation of the Strategy should be the focus of policy over the lifetime of the agreement.<sup>32</sup> The *Towards 2016* Review and Transitional Agreement 2008-2009 confirms the commitment of the Government and the social partners towards the long-term goals set down in *Towards 2016* for each stage of the lifecycle (Children, People of Working Age and People with Disabilities) while recognising that they pose major challenges in terms of availability of resources, building the necessary infrastructure and integrated service delivery.<sup>33</sup>

Department of the Environment, Heritage and Local Government, Delivering Homes, Sustaining Communities: Statement on Housing Policy 2007<sup>34</sup>

The statement on Housing Policy by the Department of the Environment, Heritage and Local Government outlined the Government’s vision for housing policy in Ireland over the next ten years. The key objective outlined in the policy framework is to ‘build sustainable communities and to meet individual accommodation needs in a manner that facilitates and empowers personal choice and autonomy’.

In relation to disability, emphasis was placed on the need for a National Housing Strategy for people with a disability to be developed by 2009.

<sup>32</sup>Progress reports available at

[http://www.taoiseach.gov.ie/eng/Department\\_of\\_the\\_Taoiseach/Policy\\_Sections/Social\\_Partnership/Social\\_Partnership\\_Publications/](http://www.taoiseach.gov.ie/eng/Department_of_the_Taoiseach/Policy_Sections/Social_Partnership/Social_Partnership_Publications/)

<sup>33</sup>Available at [http://www.taoiseach.gov.ie/eng/Publications/Publications\\_2008/Taoiseach\\_Report\\_web.pdf](http://www.taoiseach.gov.ie/eng/Publications/Publications_2008/Taoiseach_Report_web.pdf)

<sup>34</sup>Available at <http://www.environ.ie/en/Publications/DevelopmentandHousing/Housing/FileDownload,2091,en.pdf>



In order to facilitate the continued independent occupancy of their own homes, the Statement also highlighted new grant schemes to be introduced in 2007 for adapting the homes of people with disability and older people. The new schemes were to be more streamlined than the schemes they were to replace with greater targeting to those most in need.

#### Disability in the Programme for Government 2007-2012<sup>35</sup>

Programmes for Government are negotiated between coalition partners before the formation of Government.

Following the 2007 election the three parties in Government (Fianna Fail, Progressive Democrats and the Greens) negotiated the Programme for Government 2007-2012. It addresses disability issues specifically, with the Government outlining its determination to prioritise the interests of people with disabilities during the lifetime of the programme. A further commitment was made that the Government ‘will for each year of the Programme for Government, set out the objectives and outcomes to be reached in the National Disability Strategy having regard to the vision and long term goals for people with disabilities as set out in Towards 2016’.

A number of commitments made in the Programme are particularly relevant to the issue of Independent Living. These include commitments to:

- Reform the Disabled Persons Grant Scheme to improve equity and targeting and to ensure that when work is completed under the scheme the house will be lifelong adapted for the disabled person.
- Plan from the outset for accessibility of public services and local authority facilities.
- Examine ways of assisting those needing to change housing because of care and/or disability needs.
- Enforce building regulations to ensure appropriate accessibility for new buildings and buildings which undergo major refurbishment.
- Ensure that builders are reminded at pre-planning stage of their obligations to make buildings accessible.

#### National Action Plan for Social Inclusion 2007-2016<sup>36</sup>

The National Action Plan again articulated that a national housing strategy for people with disabilities will be developed by 2009, and also announced proposals to amend the Disabled Persons and Essential Repairs Grant Schemes.

#### Draft Legislation on Legal Capacity (2009)

Issues of legal capacity and decision-making are of crucial importance in relation to opportunities for independent living for people with intellectual disabilities. A particularly restrictive system, known as the Wardship system, operates in Ireland in cases where a formal determination of legal capacity is required. The Wardship system does not operate according to the functional model of capacity, under which an assessment of capacity is made in the context of the particular decision which needs to be made. Under the present system, the opportunity for a person with an intellectual disability who has been made a ward of court to decide where and how they wish to live may be severely curtailed. The new Mental Capacity Bill 2008 may however bring some reform to the area.

The Age of Majority Act 1985<sup>37</sup> provides that a person becomes an adult on reaching the age of 18 or once they marry. There is a presumption that once a person reaches this age, he or she will have the legal capacity to make decisions affecting their lives.

<sup>35</sup> Available at [http://193.178.1.117/attached\\_files/Pdf%20files/Eng%20Prog%20for%20Gov.pdf](http://193.178.1.117/attached_files/Pdf%20files/Eng%20Prog%20for%20Gov.pdf)

<sup>36</sup> Available at <http://www.socialinclusion.ie/documents/NAPinclusionReportPDF.pdf>

<sup>37</sup> Available at <http://acts2.oireachtas.ie/zza2y1985.1.html>



A 2003 Inclusion Ireland (formerly Namhi) publication examined the situation in Ireland relating to legal capacity and decision making for people with intellectual disabilities.<sup>38</sup> The Report explains that ‘in practice, decisions are made on behalf of adults with intellectual disabilities by parents or other family members and/or by service providers’.<sup>39</sup>

There is no formal system of assessment of the capacity of a person with an intellectual disability to make decisions, with parents, carers and service providers effectively making an informal assessment and then making the decisions that are needed.

The 2005 Law Reform Commission Consultation Paper on Vulnerable Adults and the Law: Capacity<sup>40</sup> advocated a functional approach to determining matters of legal capacity. Such an approach ‘would allow decision-making capacity to be assessed in relation to a particular decision at the time the decision is to be made’.<sup>41</sup>

Under the current system, where a formal decision on legal capacity is required, this decision will be made by the courts in Ward of Court proceedings as governed by the Lunacy Regulation (Ireland) Act 1871. The Law Reform Commission describes the Wards of Court system as ‘a substitute decision making regime available for adults under Irish law’.<sup>42</sup>

Wardship proceedings arise most frequently in circumstances where a person lacks capacity and decisions in relation to their property or money must be made. To be made a ward, a person must be declared to be ‘of unsound mind and incapable of managing his person or property’.<sup>43</sup> The legal effect of being made a Ward of Court is that the Court is vested with jurisdiction over all matters in relation to their person and estate. A person who is made a Ward of Court loses the right to make any decisions about their person and property. Clearly, this has serious implications for the ability of the person who has been made a ward to exercise choice or control over where and how they live.

The Law Reform Commission disapproved of the current test for wardship which presents capacity as an all or nothing status without taking account of contextual variation in decision-making ability. To illustrate the failure of the present system to acknowledge a middle ground, the Commission provided the example of an adult who can make many decisions independently but is not good at handling money. The Commission proposed replacing wardship with a system of substitute decision-making that would embrace a functional understanding of capacity.<sup>44</sup>

The Scheme for a new Mental Capacity Bill<sup>45</sup> announced in 2008 would see the wardship system abolished and the Lunacy Regulation (Ireland) Act 1871 replaced. The new Bill will operate according to the functional model and lack of capacity will be defined by focusing on the particular time when a decision has to be made and on the particular matter to which a decision relates. This will constitute a significant departure from the current situation whereby a finding of incapacity applies to every decision a person may make. Under the new Bill, capacity will be defined as the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made. The implications of these changes for independent living may be significant in that while a person with an intellectual disability may be found to lack legal capacity in relation to a particular decision, this finding will not apply to all their decisions and they may still be free to make choices in relation to where and how they live.

<sup>38</sup>Namhi, ‘Who Decides and How? People with Intellectual Disabilities – Legal Capacity and Decision Making’, Namhi 2003.

<sup>39</sup>Ibid at p.13.

<sup>40</sup>Available at [http://www.lawreform.ie/files/Consultation%20Paper%20on%20Capacity%20final%20version\\_.pdf](http://www.lawreform.ie/files/Consultation%20Paper%20on%20Capacity%20final%20version_.pdf)

<sup>41</sup>Ibid at p. 55.

<sup>42</sup>Ibid at p. 78.

<sup>43</sup>s. 15 of the 1871 Act.

<sup>44</sup>LRC at pp. 102-103.

<sup>45</sup>Available at [http://www.justice.ie/en/JELR/Pages/Scheme\\_of\\_Mental\\_Capacity\\_Bill\\_2008](http://www.justice.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_Bill_2008)



## Where have new ideas about independent living come from and who has helped to move policy forward?

People with disabilities and their organisations have been instrumental in developing new ideas about independent living and driving policy forward in Ireland.

A relatively recent example of action in this area was the **Independent Living Conference** held in June 2007 and organised by the Centre for Independent Living – an organisation run by and for people with disabilities. The 2-day conference led by experts on Personal Assistant services from Europe, Britain and Ireland was held in Dublin. Formally opened by President Mary McAleese, the conference was regarded as ‘an opportunity for people with disabilities to reassert their right to influence Government around a national policy for PA services in Ireland’.<sup>46</sup> President McAleese in her keynote speech acknowledged that progress towards a more person centred approach, increased State investment in the disability sector and the movement away from institutional settings to community based services was a result of the ‘active, persistent pressure and determination of Ireland’s disabled citizens and their supporters’.<sup>47</sup>

The Conference Report identified a number of key issues that had emerged over the course of the two days. These issues included:

- Access to adequate PA services is a human right and more solid structures need to be in place to support and protect this.
- Personal Assistance budgets and direct payments can work for people with a learning disability.
- The idea of managing ones own service can be quite intimidating and daunting to many and for this reason a number of different options must be available.
- Overwhelming agreement on the need for a national policy on PA services in Ireland because legislation is needed to guarantee a right to Independent Living as currently there is nothing in law to prevent institutionalisation of people with disabilities.
- A general sense that Irish service users are taking a backward step and are losing control and autonomy over service provision.
- A call for clearer and agreed definitions, language and understanding around the Independent Living philosophy.

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<sup>46</sup>Conference Report available from <http://www.dublincil.org/Documents/Conference%20Final%20report.pdf>

<sup>47</sup>Text of President McAleese’s speech available at <http://www.dublincil.org/Documents/Remarks%20of%20the%20President.pdf>



### PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

#### To what extent does the provision of support to disabled people still rely on segregated residential institutions?

Historically, the provision of support to disabled people in Ireland relied to a significant degree on segregated residential institutions. This reliance has diminished in recent years, particularly in relation to those with physical or sensory disabilities. The number of those with intellectual disabilities living in segregated residential institutions however remains a policy challenge, although some progress has been made in providing alternative accommodation to those with an intellectual disability currently accommodated in psychiatric hospitals.

The Commission on the Status of People with Disabilities recommended in its 1996 Report that a review be undertaken of people with disabilities in residential centres to establish accurately their numbers, locations and living conditions.<sup>48</sup> It was also recommended that there should be a review of the people on waiting lists for residential centres to see if these lists could be reduced by the provision of other services. It was envisaged that the information obtained from these reviews would also help the planning of housing and accommodation options for the future.

In 2007 the Health Service Executive established a **National Steering Committee on Congregated Settings**. The Steering Committee includes representatives from the HSE, The National Federation of Voluntary Bodies, The National Disability Authority, Inclusion Ireland, The 'Not For Profit' Business Association and the Department of Health and Children. The Steering Committee is to identify the number of people with intellectual, physical and sensory disabilities currently living in large congregated settings (ten people or more people in one unit) and develop a framework for transferring people to alternative community based settings. The Steering Committee is due to report at the end of September 2009.

Currently, information on the numbers of people with a physical or sensory disability accessing residential services in Ireland is available from the National Physical and Sensory Disability Database (NPSDD). Established in 2002, the NPSDD is a tool created by the Health Research Board to determine the specialised health services currently used or needed by people with a physical or sensory disability. The NPSDD does not however provide information on the circumstances of all those with a physical or sensory disability in Ireland. Only the circumstances of those who have registered with the NPSDD are reflected by the figures.

In December 2008, 29,946 people were registered on the NPSDD. The 2008 NPSDD Committee Annual Report<sup>49</sup> provided statistical analysis for 27,303 of those registered, excluding those people over the age of 66 (2,643 records). Responsibility for the provision of services to those over the age of 66 lies with the Older People's Services within the Department of Health and Children and the Health Service Executive (HSE). The provision of services to those under the age of 66 with a disability lies with the Disability Services section of the Department of Health and the HSE.

The 2008 NPSDD Committee Annual Report revealed that while 23,500 (86.1%) of those registered lived with family members and 2,591 (9.5%) lived alone, a total of 922 (3.4%) of those registered were availing of residential services. The most commonly used residential services were described as nursing home placements (195, 0.7%) followed by dedicated high-support placements with nursing care and therapy services for people with physical or sensory disabilities (169, 0.6%). 74 people were living independently in the community with high or low support, agency support or with house adapted or re-housing. A total of 730 people (2.7%) were identified as not currently availing of residential services but requiring these services in the future.

<sup>48</sup>Report of the Commission on the Status of People with Disabilities p.192

<sup>49</sup> Available at [http://www.hrb.ie/uploads/tx\\_hrbpublications/NPSDDCAnnualReport2008.pdf](http://www.hrb.ie/uploads/tx_hrbpublications/NPSDDCAnnualReport2008.pdf)



The 2007 NPSDD Committee Annual Report<sup>50</sup> provided statistics for the 27,185 people registered on the NPSDD in June 2007 under the age of 66. The Annual Report revealed that 86.7% of those registered lived with family members, 9.1% lived alone and 3.3% of those registered were availing of residential services. The most commonly used residential services were described as dedicated high-support placements with nursing care and therapy services for people with physical or sensory disabilities (0.7%), followed by nursing home placements (0.5%) and placements in an independent unit in a dedicated complex with low support (0.3%). 70 people were living independently in the community with high or low support, agency support or with house adapted or rehousing. 2.8% were identified as not currently availing of residential services but requiring those services in the future.

The percentages from the 2007 and 2008 NPSDD Annual Committee Reports are largely similar to those reported in the first NPSDD Annual Committee Report published in 2004, although the 2004 Report provided information for just 19,677 people.<sup>51</sup> The 2004 Report revealed that 86.2% of those registered were residing with family members, 9.3% were living alone and 3.2% were availing of residential services. 2.3% of those registered were currently not availing of residential services but requiring these services in the future.

The 2008 NPSDD Annual Committee Report also identified that while 7,701 people (28.2%) were in receipt of personal assistance and support services, a further 6,587 people (24.1%) required assessment for personal assistance and support services, while 391 (1.4%) had been assessed and waitlisted for such services. In 2007, the NPSDD Committee Annual Report revealed that 25.9% of those registered were in receipt of personal assistance and support services, while a further 27.8% required assessment for such services. 1.5% of those registered had been assessed and placed on a waiting list for these services.

In 2004, the NPSDD Committee Annual Report revealed that 26.7% of those registered were in receipt of personal assistance and support services. An additional 31.8% however required assessment for such services while 1.8% had been assessed and waitlisted for personal assistance and support services.

The National Intellectual Disability Database (NIDD), also created by the Health Research Board, measures the specialised health services currently used or needed by people with an intellectual disability. The NIDD was established in 1995. As with the NPSDD, the NIDD does not provide information on the circumstances of all those with an intellectual disability in Ireland. Only the circumstances of those who have registered with the NIDD are reflected.

In April 2007 there were 25,613 people registered in the National Intellectual Disability Database. The 2007 Committee Annual Report<sup>52</sup> identified that 8,262 of those registered (32.3%) were living in full-time residential services, mainly in community group homes (3,750 or 14.6%), residential centres (3178 or 12.4%), psychiatric hospitals (329 or 1.3%), and intensive placements. 903 of those registered (3.5%) were living independently or semi-independently, while 16,366 (63.9%) lived in a home setting with parents, relatives or foster parents.

In 2007, there were 387 people with an intellectual disability residing full-time in mental health services, either in psychiatric hospitals (329 individuals) or in mental health community residences (58 individuals).

One of the earliest NIDD Committee Annual Reports dating from 1998/1999 provides information for the 27,149 people registered on the database in April 1999.<sup>53</sup>

<sup>50</sup> Available at <http://www.hrb.ie/health-information-in-house-research/disability/ddu-publications/ddu-publication/publications//375/>

<sup>51</sup> Available at [http://www.hrb.ie/uploads/tx\\_hrbpublications/NPSDD\\_Annual\\_Report\\_2004.pdf](http://www.hrb.ie/uploads/tx_hrbpublications/NPSDD_Annual_Report_2004.pdf)

<sup>52</sup> Available at <http://www.hrb.ie/health-information-in-house-research/disability/ddu-publications/ddu-publication/publications//381/>

<sup>53</sup> Available at [http://www.hrb.ie/uploads/tx\\_hrbpublications/NIDD\\_Annual\\_Report\\_1998-99.pdf](http://www.hrb.ie/uploads/tx_hrbpublications/NIDD_Annual_Report_1998-99.pdf)

This Report revealed that 62.6% of those registered were living in a home setting, 29% were living in full time residential services and 2.5% were living independently or semi-independently. The 1998/1999 report noted that the figure for those living independently or semi-independently was a 28% increase from 1996 figures and represented 'concrete evidence of the philosophy underpinning services which is to enable people to develop to the maximum of their potential through a policy of care in the community'<sup>54</sup>.

The 1998/1999 Report also revealed that 854 people with intellectual disability were at that time accommodated in psychiatric hospitals. The 1998/1999 Report noted that this figure constituted a 12% reduction on the number of people in such accommodation in 1996, and identified the provision of alternative accommodation for people with intellectual disability currently accommodated in psychiatric hospitals as a priority. Clearly, based on the 2007 figures, the number of those registered on the NIDD accommodated in such institutions has been further reduced.

### **How many people from which groups of people are living in institutions compared to those living in the community?**

The proportion of people with disabilities living in residential institutions increases with age and, in the case of those with intellectual disabilities, with the severity of the disability.

The 2008 NPSDD Annual Committee Report identified that only seventeen of those availing of residential services were children. The most common residential services used by those under 18 are dedicated high support with nursing care and therapy service and 'other', with four children availing of each of these services.

The 2007 NIDD Annual Committee Report identified 'notable differences in the age profiles of individuals in the various categories of accommodation'.<sup>55</sup> The proportion of people in the different age categories living in full-time residential services increased with age – 3.2% of those under 19 were in receipt of full-time residential services, compared to 27.1% of 20–34 year olds, 55.1% of 35–54 year olds, and 75.4% of those aged 55 years or over.

The Report notes that there are also 'noticeable variations between level of ability and type of residential situation'.<sup>56</sup> While 76.3% of people with a mild intellectual disability lived in a home setting, only 52.5% of those with a moderate, severe or profound intellectual disability did so. Those with a mild intellectual disability were less likely to be in full-time residential services than those with a moderate, severe or profound disability. Only 15.8% of those in the first category lived in full-time residential services compared to 46% of those in the latter group. Of those in the mild range of intellectual disability who were in full-time residential services, 64.6% lived in community group homes, 18.8% lived in residential centres, and 16.6% were in other full-time residential services. Of those in full-time residential services who had a moderate, severe or profound intellectual disability, 42.2% were in community group homes, 42.1% lived in residential centres, and 15.8% were in other full-time residential services.

### **What processes or safeguards exist to ensure people with disabilities do not enter or remain in institutions against their will?**

There are no formal processes or safeguards in Ireland to ensure that people do not enter or remain in institutions against their choice. There is however a number of organisations providing advocacy services to people with disabilities. A 2004 Comhairle publication on Developing an Advocacy Service for People with Disabilities described advocacy as 'a means of supporting or speaking up for someone, their needs and rights'.<sup>57</sup>

<sup>54</sup>Ibid at p.19

<sup>55</sup>Ibid at p. 43.

<sup>56</sup>Ibid.

<sup>57</sup> Available at [http://citizensinformationboard.ie/publications/advocacy/social\\_speaking\\_up\\_for\\_advocacy.html](http://citizensinformationboard.ie/publications/advocacy/social_speaking_up_for_advocacy.html)



Providing advocacy services to people with disabilities can place them in a better position to ensure that they do not enter or remain in institutions against their will.

The Irish Advocacy Network <sup>58</sup> provides dedicated advocacy services in the area of mental health while the Citizens Information Board <sup>59</sup> provides advocacy services to the general public through the network of Citizens Information Services. Through these services, information providers advocate at different levels in relation to difficulties with access to social welfare, housing, health and employment.

The 2004 Comhairle publication highlights the fact that ‘unlike many other countries, Ireland still has a significant population of people with disability that are resident in institutions. As these people are particularly vulnerable, it is essential that advocacy services are designed to reach out to this group’.<sup>60</sup> The Citizens Information Act 2007<sup>61</sup> provided for the establishment of a personal advocacy service for people with disabilities, which it is envisaged, will deal with more complex cases. As of yet however, the personal advocacy service has not been implemented.

### **Investments in Residential Institutions**

Until recently, generous tax incentives of up to 40% were offered to those who invested in the construction of private hospitals, registered nursing homes, convalescent homes and associated residential units as well as mental health centres. However, the tax breaks, which were introduced in 2001 and 2002, were abolished by the April 2009 budget. The abolition of the tax incentives was not however accompanied by any statement of a commitment towards community or independent living for people with disabilities.

Furthermore, the many facilities built during the lifetime of the tax breaks are still operational. Although the incentives have been abolished, the infrastructure put in place during their existence will continue to be utilised and people will continue to be placed in such facilities until some definitive statement of a commitment to independent or community living is made by the Government.

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<sup>58</sup>Website at <http://www.irishadvocacynetwork.com/>

<sup>59</sup>Website at <http://www.citizensinformationboard.ie/>

<sup>60</sup>Comhairle at p. 64.

<sup>61</sup>Available at <http://www.oireachtas.ie/documents/bills28/acts/2007/a207.pdf>





## PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

### What support is available to disabled people if they want to live in their own homes?

A 2007 Citizens Information Board (CIB) and Disability Federation of Ireland (DFI) joint social policy report on the Housing and Accommodation Needs of People with Disabilities<sup>62</sup> included the results of a survey of community and voluntary organisations involved in the provision of housing and related supports for people with disabilities.

The CIB/DFI Report revealed that there was a general consensus among respondents that most people with disabilities capable of independent living are unable to afford suitable housing in the open market unless they were already homeowners prior to the onset of their disability.<sup>63</sup> People with disabilities may however be able to access social housing either through local authorities or through the voluntary sector.

It has also been acknowledged that the cost of living for people with disabilities is higher than for other members of the community, a fact that may operate as a barrier to independent living. The Commission on the Status of People with Disabilities noted in its 1996 Report, *A Strategy for Equality*, that 'if their earning capacity is seriously reduced and they also have to meet extra costs associated with their condition, people with disabilities are at a serious risk of living in poverty'.<sup>64</sup> *A Strategy for Equality* identified additional costs for people with disabilities such as the cost of equipment, higher medical costs and costs for care and assistance including personal assistance. The Commission on the Status of People with Disabilities on this basis recommended the introduction of a variable Costs of Disability Payment.<sup>65</sup>

A 2004 report commissioned by the National Disability Authority on the Cost of Disability, reiterated these findings and recommendations, stating that there are additional costs of disability that are not fully met by existing funding mechanisms, with the result that the living standards of people with disabilities tend to be lower than those of people without disabilities on similar incomes.<sup>66</sup>

The 1999 Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities, stated that a Costs of Disability Payment would not be introduced. It was stated that such a payment would be very difficult to introduce given the widely varying degrees of disability experienced by individuals. Such a payment would require assessment by a wide range of experts, and the administrative costs could be significant. Furthermore, the Costs of Disability Payment was rejected on the grounds that other groups in society, such as travellers, the homeless and the elderly, may also claim to have special costs related to their medical social condition and may seek equality of treatment.<sup>67</sup>

People with disabilities may however be able to access funding for supports such as personal assistance services or home help. Today, the obligation to provide health services to persons with disabilities rests with the State, with most of these services provided by non-profit organisations under arrangements with the Health Service Executive.

Social service provision in Ireland was heavily influenced by British Government policy during the 19<sup>th</sup> century and relied heavily on intermediaries such as religious orders and charity. The State, as such, did not assume direct responsibility for the development of these services.

<sup>62</sup>'The Right Living Space – Housing and Accommodation Needs of People with Disabilities', available at <http://www.citizensinformationboard.ie/news/news20080115.html>

<sup>63</sup>Ibid p. 29.

<sup>64</sup>Report of the Commission on Status of People with Disabilities, p. 123.

<sup>65</sup>Ibid, p 128 and 129.

<sup>66</sup>Indecon Report on the Cost of Disability, p.163, 9.2.2.

<sup>67</sup>Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities: Towards Equal Citizenship, 1999, p. 60.



The main religious denominations therefore took a predominant role in the evolution of the relevant services. There was no overarching policy framework, and they were loosely regulated (if at all) by the State.

This helps to explain the patchwork quilt of services throughout the country until relatively recently. From a formal point of view this changed from the 1970s onwards with the enactment of the Health Act 1970. Greater control and uniformity began to be possible from that point onwards. In as much as the impact of Church based welfare has had any legacy it rests with the predominance of the voluntary sector in service provision in Ireland. However, in sharp contrast with the past, the delivery of social services through these voluntary intermediaries is now controlled by service-level agreements designed to produce uniformity of provision. The oversight of these service-level agreements remains a challenge. This sector is likely to contract as Government seeks rationalisation in service delivery.

A 2005 Report on Value for Money in the Provision of Disability Services by Non-profit Organisations carried out by the Comptroller and Auditor General recommended that the comparative cost of services provided by non-profit organisations needs to be assessed by reference to the cost of direct provision.<sup>68</sup> The Report also noted that the numbers served by each non-profit organisation needs to be monitored so that allocations do not get out of line with services provided. The need to ensure that funding to agencies in respect of individual clients is not duplicated was also highlighted.

### **Social Housing Rights**

Social Housing may be available to disabled people who are in need of housing but who cannot afford to buy their own homes. Local Authorities are the main providers of social housing in Ireland although voluntary and community organisations also provide social housing to people with disabilities.

#### Local Authorities

People with disabilities may be able to apply for Local Authority Housing. Local authorities in Ireland provide social housing for those in need of housing who cannot afford to purchase their own homes.

Local authority housing is allocated according to a scheme of letting priorities, as required by S. 11 of the Housing Act 1988. The sectoral plan drawn up by the Department of the Environment, Heritage and Local Government highlights that under s. 11, housing authorities may set aside a proportion of dwellings becoming available for letting for persons of a specific category, including persons with disabilities.

S. 9 of the Housing Act 1988<sup>69</sup> requires housing authorities to make 3-yearly assessments of the need for the provision by the authority of adequate and suitable housing for those in need of such accommodation and unable to provide it from their own resources. In making this assessment the housing authority is to have regard to, among others, persons who are disabled.

The most recent local authority assessment of need was carried out in 2008. The results indicated that at 31 March 2008 just over 56,000 households were in need of social housing support, a significant increase from the 2005 assessment where 43,000 households were identified as in need of social housing support.

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<sup>68</sup> Report available at [http://audgen.gov.ie/documents/vfmreports/52\\_DisabilityServices.pdf](http://audgen.gov.ie/documents/vfmreports/52_DisabilityServices.pdf)

<sup>69</sup> Available at <http://www.irishstatutebook.ie/1988/en/act/pub/0028/index.html>



Detailed figures from the 2008 assessment are not yet available, but the Minister for Housing, Urban Renewal and Developing Areas, Mr. Michael Finneran reported that special needs households (older people and people with a disability) showed a substantial increase in the 2008 assessment.<sup>70</sup> The March 2005 assessment reported that 480 households (just over 1% of the total) were included in the category “disabled or handicapped persons”.<sup>71</sup>

In relation to local authority social housing, respondents to the survey carried out as part of the CIB and DFI Report stated that in their opinion there was an insufficient supply of accessible and adaptable local authority housing and as with the general population, people with disabilities can be on the waiting list for several years, particularly those living with parents and relatives. Furthermore, in the opinion of some respondents, local authority waiting lists are incomplete in that some people with disabilities do not apply for local authority housing because they do not believe they have a chance of succeeding.<sup>72</sup>

### Voluntary Sector Social Housing

Voluntary Housing Associations and housing co-operatives also provide social housing for people who cannot afford to buy their own homes. This is mostly funded by the State. The Irish Council for Social Housing published the results of a survey of its members in 2007<sup>73</sup> which revealed that 82 housing associations are providing 2,064 units of social housing for people with disabilities across 267 schemes. 56% of the units were described as housing people with an intellectual disability, with 24% being provided for people with physical disabilities. A number of housing associations that were providing accommodation to people with disabilities were also providing a wider range of services and support to tenants. Of the 82 organisations providing accommodation for people with disabilities, 65 were in receipt of HSE funding, although in a number of cases it was the services the organisations link into to provide support for tenants and not the housing itself that was funded by the HSE.

The ICSH Survey identified a number of significant challenges for the voluntary social housing sector. These included the lack of suitable sites and properties for tenants with disabilities, with members being forced to consider land outside towns, which although cheaper, would present problems for tenants with disabilities. The issue of limited capital funding for accommodation for people with disabilities was also raised with many feeling that these limits restricted the quality of housing that could be provided.

The results of the survey carried out as part of CIB and DFI Report also identified funding as a key challenge facing voluntary and community organisations providing accommodation for people with disabilities. Other points made by survey respondents on voluntary social housing included the fact that access to accommodation in voluntary social housing schemes can be arbitrary, depending on factors such as geographical location, advocacy and personal contacts.<sup>74</sup>

### **Personal Assistance Services**

Assisted living or personal assistance services are central to the independent living movement in Ireland as elsewhere and can facilitate disabled people if they want help to live in their own homes. A Personal Assistant provides a person with a disability (known as a Leader) with assistance to help them carry out everyday tasks.

<sup>70</sup>Department of the Environment, Heritage and Local Government website, ‘Minister Finneran publishes results of the Local Authority Housing Needs Assessment’, 10/12/08,

<http://www.environ.ie/en/DevelopmentandHousing/Housing/SocialHousingSupport/LocalAuthorityHousing/News/MainBody.19070.en.htm>

<sup>71</sup>Housing Needs Assessment 2005 detailed results available at

<http://www.environ.ie/en/Publications/StatisticsandRegularPublications/HousingStatistics/>

<sup>72</sup>‘The Right Living Space’, p. 26.

<sup>73</sup>‘Enhancing Housing Choices for People with Disabilities in the Community’, available at

[http://www.icsih.ie/eng/services/publications/icsih\\_publications/enhancing\\_choices\\_for\\_people\\_with\\_disabilities\\_in\\_the\\_community](http://www.icsih.ie/eng/services/publications/icsih_publications/enhancing_choices_for_people_with_disabilities_in_the_community)

<sup>74</sup>‘The Right Living Space’ at p. 28.



The services are provided in the individuals' homes and communities, facilitating community participation, access to education/employment and improved quality of life. The nature of the services provided by a PA varies according to the Leader's individual needs. Tasks may include personal care, domestic support, social support, overnight or weekend services or assistance for access to employment or education.

The survey conducted as part of The Right Living Space Report noted a number of issues identified by survey respondents in relation to PA services in Ireland. In the first place, the overall funding available for PAs was felt to be insufficient with many people who were getting a PA service in need of more hours. Furthermore it was difficult to get people to work as PAs on a part-time or limited hours basis.<sup>75</sup>

The operation of the PA service will be discussed in more detail below.

### **Home Help**

People with disabilities in Ireland may also be able to avail of home help services to help them live in their own homes. Home help services are provided by the HSE to assist people to remain in their own home and to avoid going into long-term care. The HSE may provide the home help services directly or alternatively, make arrangements with voluntary organisations to provide them. Home help is not provided in a uniform manner across the country and although the service is generally free to medical cardholders, in some circumstances the recipient of the service may be asked to make a contribution towards the costs. A local public health nurse will assess an individual's need for the service and then process the application to the Local Health Office. Home helps usually assist people with typical household tasks such as shopping, cleaning and laundry, although they may also provide help with personal care. Home helps provide a set number of hours assistance every day or week.

The survey conducted as part of The Right Living Space Report raised a number of points such as waiting periods in some areas, the difficulty getting cover if a home help is sick or on holidays, and the perception by some families of people with disabilities that the service is only available to people over 65, with the result that they do not actively seek the service. The fact that people with home help requirements are not able to access a service flexible enough to meet their specific needs was also raised as an issue.<sup>76</sup>

### **The Housing Adaption Grant and The Mobility Aids Grant Scheme**

Schemes such as the Housing Adaption Grant and Mobility Aid Grant may also facilitate people with disabilities living independently in their own homes.

On October 1 2007, the Housing Adaptation Grant and the Mobility Aids Grant Scheme replaced the older Disabled Persons and Essential Repairs Grants. The CIB and DFI Report highlighted some of the concerns raised by respondents to the survey carried out as part of the project in relation to the older schemes. These included complaints about delays in having grant applications processed and work carried out and also that the grant was inadequate to cover adaption costs.

The new Housing Adaption Grant is available where changes need to be made to a home to make it suitable for a person with a disability or mental health difficult to live in. The Mobility Aids Grant Scheme provides grants for works aimed at addressing mobility problems in the home. The Housing Adaption Grant and The Mobility Aids Grant Scheme will be discussed further below.

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<sup>75</sup>Ibid p. 33.

<sup>76</sup>Ibid.



## **What support is available to family members who provide practical help to disabled people in their own homes?**

Some supports, such as the carer's allowance and carer's benefit, may be available to family members who provide practical help to disabled people in their own homes.

### Carer's Allowance

Carer's Allowance is a payment made to a person who is looking after someone who is in need of full time care and attention, including a person with disabilities in need of such care.

The allowance is means tested and the recipient of the payment must live with the person they are looking after or be contactable quickly by a direct system of communication between their home and the home of the person they are caring for. The Carer must care for the person on a full time basis and the person being cared for must be aged over 16 and not normally live in a hospital, home or other institution.<sup>77</sup>

### Carer's Benefit

Carer's Benefit is a payment made to insured persons in Ireland who leave the workforce to care for a person in need of full-time care and attention. Carer's Benefit can be claimed for a total period of 104 weeks for each person being cared for. The right to Carer's Leave from employment under the Carer's Leave Act 2001 compliments the Carer's Benefit. Carer's Leave entitles employees to leave employment for up to 104 weeks to provide full time care for those in need of full time care and attention. The leave will be unpaid but those who avail of such leave will have their jobs kept open for them for the duration of the leave.<sup>78</sup>

## **Who decides how much support is provided to each person or family and how is this assessment done?**

Part 2 of the Disability Act 2005 provides for an independent assessment of the health and education needs of persons with a disability and the subsequent drawing up of service statements.

At present only children under the age of five are entitled to an assessment under the Act although it is intended that the assessments will be rolled out to other age groups so that all people with disabilities will be able to avail of an assessment by 2011.

A Protocol for Co-operation between the HSE and Local Authorities<sup>79</sup> was developed in June 2007 focusing on children under five years who have been assessed under Part 2 of the Disability Act and are identified as likely to require housing support. The protocol was developed pursuant to section 12 of the Act which provides for the exchange of information between the HSE and public bodies for the purpose of assisting a person with disabilities when applying for personal or individual services provided by the body. The Protocol requires that the relevant Housing Authority provide all appropriate information regarding the full range of housing support options available to the person with the disability who has been assessed under Part 2 of the Disability Act 2005, or if appropriate to a specified person, or to the Liaison Officer responsible for the arrangement of the service provision.

The Protocol currently only applies to those under the age of five. The contribution of the Protocol towards enhancing access to housing for people with disabilities and by extension to opportunities for independent living cannot be accurately assessed until Assessments under Part 2 of the Disability Act are rolled out to other age categories.

<sup>77</sup>Information available from Department of Social and Family Affairs at <http://www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/CarersAllowance/Pages/ca.aspx>

<sup>78</sup>Information available from Department of Social and Family Affairs website at <http://www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/CarersBenefit/Pages/carb.aspx>

<sup>79</sup>Details of the Protocol can be found on the Department of the Environment, Heritage and Local Government at <http://www.envron.ie/en/DevelopmentandHousing/Housing/SpecialNeeds/PeoplewithaDisability/>



### **What mechanisms exist for measuring the quality of community based assistance and services and their impact on quality of life?**

There are no formal mechanisms in Ireland for measuring the quality of community based assistance and services or their impact on quality of life.

The Health Information and Quality Authority<sup>80</sup> was established in 2007 under the Health Act 2007 with a mandate to set standards for health and social care services and to monitor compliance with these standards. In May 2009, HIQA published Standards for Residential Services for People with Disabilities,<sup>81</sup> developed for the purposes of the registration and inspection of residential services for people with disabilities.

Standard 1 concerns the Autonomy and Participation of persons with disabilities and seeks to ensure that each individual exercises choice and control over his/her life and over his/her contribution to his/her community. As part of this, the standards require that an individual who decides to move from a residential service is assisted in the preparation for the move and facilitated to do so through the provision of information on services and supports available and, where appropriate, the provision of training in the skills required for independent living.

However, the standards have not been implemented due to costs and have not been formally adopted by the Ministry of Justice and put on a statutory basis.

### **Can people move from one part of the country to another and still receive this type and level of support?**

Funding for support services for independent living in Ireland does not attach to the individual but rather to the organisation providing the service.

As a consequence, an individual in receipt of, for example, a certain number of PA hours in one part of the country would be required to reapply for support if they moved elsewhere (which can take time). In addition the availability of services may vary in different parts of the country and the same supports may not be available in the location that the person with the disability moves to.

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<sup>80</sup>Website at <http://www.hiqa.ie/>

<sup>81</sup> Available at [http://www.hiqa.ie/functions\\_sh\\_ss.asp](http://www.hiqa.ie/functions_sh_ss.asp)



#### 4.1: PERSONAL ASSISTANCE SERVICES

Personal Assistant Services in Ireland are funded by the Health Services Executive (HSE) or through the FAS Community Employment (CE) Scheme.

PA services are however generally administered by voluntary or community organisations. Two service packages are available to Leaders. With the self-directed or leader-managed package the person with the disability acts as the leader or service manager. This involves recruiting his/her own PAs, organising their weekly rosters, returning their timesheets, arranging holiday cover, etc. The leader can consult the service coordinator when necessary. With the supported package, the service coordinator takes responsibility for some or all of the management, delivery and operation of the service. With both options the Leader will have significant input regarding who is employed as their personal assistant. The Leader will provide most of the PA's training, although the service provider will provide essential health, hygiene and safety training.

Individuals can apply directly to service providers to access PA services or alternatively they can contact the Disability Area Manager in their local HSE area.

Currently there is no system of direct payments for PA services in Ireland. David Egan in a 2008 Report on Issues Concerning Direct Payments in the Republic of Ireland<sup>82</sup> notes that some people with disabilities believe that they could obtain better value for money and better personal outcomes from a Direct Payment, as a direct payment would allow funding to follow service users rather than the service provider. This would ensure that "choice, control and funding" would lie with people with disabilities.<sup>83</sup>

Some service users and their organisations have made sporadic calls for a system of service delivery in Ireland based on Direct Payments. The Irish Wheelchair Association in its strategic plan 2008-2011 commits to working with members to explore alternative models of Assisted Living Services including direct payment options.<sup>84</sup> The Microboards Association of Ireland in a 2008 Evaluation of The Microboards Project recommended that a pilot study of direct payments should be undertaken to determine their effectiveness in an Irish context.<sup>85</sup> In October 2008, a number of groups were involved in organising the "Taking Control" Conference on the issue of Individualised Funding.<sup>86</sup> The organisations involved included Autism LifeCare Trust, Down Syndrome Ireland, Inclusion Ireland, the National Parents and Siblings Alliance, the National Institute for Intellectual Disability-Trinity College Dublin, Partners for Change, RehabCare and the Sisters of Charity of Jesus and Mary/Muiriosa Foundation. The conference heard from speakers involved with services in Ireland and of the steps being taken to introduce individualised funding in Ireland. Speakers from the UK, Australia and Canada also contributed, telling of their experiences in those countries.

As of yet, there has been no official response from Government to these calls for the introduction of a Direct Payments option.

In relation to PA services, these are funded by the HSE or Community Employment Schemes.

The person with a disability wishing to access a PA service will make an application for funding to the HSE or CE Scheme and once funding is allocated to the individual, they will enter into negotiations with service providers to provide them with a PA service. The service user can demand full transparency in relation to the application of this funding, but there is anecdotal evidence that such transparency is not being achieved.

<sup>82</sup> Available from <http://www.dublincil.org/Documents/DP%20Report.pdf>

<sup>83</sup> Ibid.

<sup>84</sup> Full text available from [http://www.iwa.ie/Docs/agm/iwa\\_strategic\\_plan.pdf](http://www.iwa.ie/Docs/agm/iwa_strategic_plan.pdf)

<sup>85</sup> Available at <http://www.microboards.ie/training-and-events-page.html>

<sup>86</sup> Information available from <http://www.inclusionireland.ie/TakingControlConferenceOct2008.asp>



***As part of the Multi-Annual Investment Programme 2006 – 2009 announced under the Disability Strategy the HSE committed to put in place 250,000 hours Personal Assistant/Home Support per annum for persons with physical or sensory disabilities.***

Some of the main providers of PA services in Ireland include:

The Centres for Independent Living<sup>87</sup>

The first Irish Centre for Independent Living (CIL) was established in Carmichael House, Dublin, in 1992 by and for people with disabilities, with the main aim of ensuring that people with disabilities achieved Independent Living, choice and control over their lives and full participation in society as equal citizens. There are now 24 CILs nationwide.

Centres for Independent Living generally provide PA services to those with physical and sensory disabilities between the ages of 18 and 65. A member of staff will carry out a full assessment of the individual's requirements and the individual will then be placed on the waiting list for the service. There are now 24 Centres for Independent Living around Ireland.

The Irish Wheelchair Association<sup>88</sup>

The IWA provide personal assistants to individuals with a physical or sensory disability. The services are provided in the individuals' homes and communities facilitating community participation, access to education/employment and improved quality of life. The IWA has centres across Ireland.

Enable Ireland<sup>89</sup>

Enable Ireland employ and train personal assistants to help service users with accessing support in their local community. According to their website these services are 'particularly developed in the Galway and Meath region where people can access a personal assistant to support them in accessing things such as training and education, employment, social and leisure pursuits and independent living'.

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<sup>87</sup><http://www.dublincil.org/>

<sup>88</sup><http://www.iwa.ie/about/Default.aspx>

<sup>89</sup><http://www.enableireland.ie/>





## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

### Housing Adaptation Grant

This grant is available to assist in the carrying out of works necessary to render a house more suitable to the accommodation needs of a person with a disability. Local authorities administer the grant. The types of work allowable are varied and may include the provision of access ramps; stair lifts; downstairs toilet facilities; accessible showers, adaptations to facilitate wheelchair access; extensions; and any other works which are reasonably necessary for the purposes of rendering a house more suitable for the accommodation of a person with a disability.

The grant is means tested and applicants are assessed on the basis of household means. The proportion of the costs covered by the grant operates on a sliding scale. A maximum grant of €30,000 to cover 95% of costs is available where the maximum yearly household income is less than €30,000 with 30% of costs covered where income is between €54,000 and €65,000. No grant is payable where the maximum yearly household income is over €65,000.

In 2008, €71.405 million was allocated for the funding of the Housing Adaptation Grants<sup>90</sup>, with 79.57 million allocated in 2009. Local authorities paid 12,094 individual grants to private houses under the schemes in 2008.<sup>91</sup>

### Mobility Aids Grant Scheme

This grant covers basic adaptations to the home to address mobility problems for older people or people with a disability. Local authorities administer the grant.

It is not possible to apply for both the Housing Adaptation Grant and the Mobility Aids Grant Scheme.

A maximum grant of €6,000 may be available to applicants where the maximum yearly household income is less than €30,000. The grant can cover 100% of the necessary works. A variety of types of works can be carried out under the grant and may include the provision of grab-rails, access ramps, level access showers and stair-lifts.

### Workplace Equipment Adaptation Grant

This grant is available to disabled persons, who have been offered employment or are in employment, and require a more accessible workplace or adapted equipment to do their job and covers the costs of adapting premises or equipment. FAS<sup>92</sup> administer the grant. Possible adaptations for which a grant may be given include minor building modifications such as ramps or modified toilets, alarm systems with flashing lights and equipment adaptation such as voice synthesisers for computers or amplifiers for telephones. A maximum grant of €6,348 is available towards the cost of adapting or purchasing equipment, or upgrading adapted equipment that was previously funded.

<sup>90</sup>Department of the Environment, Heritage and Local Government website, 'Minister Finneran announces funding of over €79.5 Million for Private House Grants for Older People and People with a Disability', 21/05/08

<http://www.environ.ie/en/DevelopmentandHousing/Housing/News/MainBody,17428,en.htm>

<sup>91</sup>Department of the Environment, Heritage and Local Government website, 'Minister Finneran announces funding of over €1.4 Million for Private House Grants for Older People and People with a Disability', 06/05/09

<http://www.environ.ie/en/DevelopmentandHousing/Housing/News/MainBody,20132,en.htm>

<sup>92</sup>Website found at <http://www.fas.ie/en/>



## **PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE**

### **The Centre for Independent Living<sup>93</sup>**

The first Irish Centre for Independent Living was established in Carmichael House in 1992 by and for people with disabilities with the main aim of ensuring that people with disabilities achieved Independent Living, choice and control over their lives and full participation in society as equal citizens. The Centre for Independent Living established the first personal assistance programme in Ireland, enabling people with disabilities to take greater control of their lives. This pilot project was known as INCARE and ran for two years, providing 15 people with severe disabilities with personal assistants. Following on from the success of INCARE, CIL Carmichael supported the development of 24 Centres nationwide.

Many of the regional CILs also provide additional services such as advocacy services, note taking services for university students with disabilities and accessible transport services.

### **Galway Centre for Independent Living<sup>94</sup>**

Galway Centre for Independent Living was established in 1994 by individuals with disabilities and other interested parties and was the first Centre to be opened outside of Dublin. The Centre was originally funded through FAS through the operation of the Community Employment scheme. In 2000 the Centre received some limited funding from the then Western Health Board. Over the years, the level of funding has slowly increased. The Galway Centre for Independent Living Value Statement includes a commitment to providing user-driven services that are relevant and meaningful

As well as providing Personal Assistant Services, Galway Centre for Independent Living also provides services in access consultancy, accessible transport, audio and Braille duplication and computer training.

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<sup>93</sup>Information on the Centre for Independent Living available from website at [http://www.dublincil.org/introduction\\_and\\_overview.html](http://www.dublincil.org/introduction_and_overview.html)

<sup>94</sup>Information on the Galway Centre for Independent Living available at <http://www.gcil.ie/>



## ***Glossary of Acronyms***

**CIB** - Citizens Information Board (formerly Comhairle): The CIB is responsible for supporting the provision of information, advice and advocacy on social and civil services.

**CIL** – Centre for Independent Living: established by and for people with disabilities, with the aim of ensuring that people with disabilities achieved Independent Living, choice and control over their lives and full participation in society as equal citizens.

**DFI** - Disability Federation of Ireland: The DFI is the national support organisation for voluntary disability organisations in Ireland who provide services to people with disabilities.

**FAS** - Foras Aiseanna Saothair: FAS is the National Training and Employment Authority in Ireland, responsible for providing vocational training and employment services for people with disabilities.

**HIQA** - Health Information and Quality Authority: HIQA is responsible for driving quality and safety in Ireland's health and social care services and for ensuring standards in disability services.

**HRB** - Health Research Board: The HRB is the lead agency in Ireland supporting and funding health research.

**HSE** - Health Service Executive: The HSE is responsible for providing Health and Personal Social Services for those living in the Republic of Ireland.

**ICSH** - Irish Council for Social Housing: The ICSH is the national housing federation representing housing associations across Ireland.

**IHRC** – Irish Human Rights Commission: The IHRC was set up under the Human Rights Commission Act 2000 and keeps under review the adequacy and effectiveness of law and practice in the State.

**IWA** - Irish Wheelchair Association: The IWA is an important provider of services to people with limited mobility in Ireland.

**LRC** – Law Reform Commission: The LRC is an independent statutory body established to keep the law under review and to make recommendations under revision.

**NDA** - National Disability Authority: The NDA is the lead state agency on disability issues, providing independent expert advice to Government on policy and practice.

**NESC** - National Economic and Social Council: The NESC analyses and reports on strategic issues relating to the efficient development of the economy and the achievement of social justice.

**NESDO** – National Economic and Social Development Office: established under the National Economic and Social Development Act 2006, NESDO incorporates the National Economic and Social Council (NESC), the National Economic and Social Forum (NESF) and the National Centre for Partnership and Performance (NCPD).

**NIDD** – National Intellectual Disability Database: The NIDD measures the specialised health services currently used or needed by people with an intellectual disability

**NPSDD** – National Physical and Sensory Disability Database: measures the specialised health services currently used or needed by people with a physical or sensory disability.



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