



## Information Brief 2

### Community Living and Housing for People with Disabilities

- 1. Key Statistics**
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#### 1. Key Statistics

- Over 8,000 people with disabilities in Ireland still live in residential centres.
- Over 93% of disability residential centres inspected by the Health Information and Quality Authority (HIQA) since November 2013 failed to comply with national standards – with one in seven not meeting any standards at all.<sup>i</sup>
- Between 2008 and 2014, 600,000 home help hours were cut.<sup>ii</sup>
- Almost 4,000 people with disabilities in Ireland are in need of social housing.<sup>iii</sup>

## 2. The Lived Reality – The Issue in Short

1. Over 8,000 people with disabilities in Ireland still live in residential centres across the country. Similarly, more than 1,000 young people – including those with disabilities - are living in long-term care in Ireland, including nursing homes.
2. Segregated congregated settings are outdated and dangerous places for people to live. The list of adverse reports from HIQA keeps growing. The forms of abuse include slapping, kicking, shouting, force feeding and the over prescribing of heavy medication to control people.
3. There is a serious funding dilemma between the HSE and HIQA. The urgent state of affairs in residential centres is clearly reflected in the HSE's submission to the Department of Health seeking €250 million to move people with disabilities to community based care.<sup>iv</sup> At the same time, however, it has been revealed that the HSE has told the Department of Health that HIQA should be mindful of the HSE's lack of resources when issues reports and recommendations.
4. When people leave disability residential settings to live in the community, there is a distinct lack of community supports available. This often means that people are isolated and effectively institutionalised in their own homes.
5. Massive cut backs to home help hours and a rapidly increasing waiting list for PA services mean that people are lacking basic supports to be able to live independent, fulfilling lives.
6. The roll-out of individualised funding models like Direct Payments to people with disabilities remains slow with no national framework for their implementation and investment.
7. Almost 4,000 people with disabilities are in need of social housing.<sup>v</sup>

8. Households with income over €60,000 are not eligible for funding support for housing adaptations.<sup>vi</sup> If the grant is awarded, it can take two years to come through meaning people with disabilities often find themselves accepting unjust and demeaning living situations.

### **3. Community Living and Housing in More Detail**

Government's disability policy clearly supports community living, independence and personalisation of services for people with disabilities – this, however, is translating far too slowly into practice.

Living in the community opens opportunities to enjoy freedom, dignity and choice for people with disabilities, empowering them as active citizens with control over their own lives. Now is the time to make this reality for everyone.

#### **Continued Institutionalisation**

Over 8,000 people with disabilities in Ireland still live in residential centres across the country. Similarly, more than 1,000 young people – including those with disabilities – are living in long-term care in Ireland, including nursing homes.<sup>vii</sup>

One of the most pressing issues of recent months concerns this group of people: we can no longer tolerate the hugely disturbing human rights abuses and living arrangements of people with disabilities in residential centres, perhaps known more informally for a long time but concretely laid out in recent, often disturbing Health Information and Quality Authority (HIQA) findings.

Over 93% of disability residential centres inspected by HIQA since November 2013 failed to comply with national standards – with one in seven not meeting any standards at all.<sup>viii</sup> This urgent state of affairs is clearly reflected in the Health Service Executive (HSE) submission to the Department of Health (DOH), seeking €250 million to move people with disabilities from these centres to community-based models of care.<sup>ix</sup>

At the same time, however, it has been revealed that the HSE has told the department that HIQA should take note of the HSE's lack of resources when issuing

reports which are critical of individual centres, and that the DOH should make the “necessary arrangements” with HIQA so the watchdog’s findings “have regard” to this funding. It explained that it has achieved as much as is possible in “decongregating” from existing resources.<sup>x</sup>

Investment in the reform of residential services for people with disabilities is evidently needed now more than ever, not only to facilitate the implementation of HIQA recommendations but to fundamentally change the very culture of these services.

HIQA recommendations must be site-specific, practicable and resource-efficient. The focus should be on reconfiguring existing resources to ensure a safe, comfortable and stimulating environment. Most importantly, the attitude and behaviour of those staff whose actions amount to human rights abuses must be addressed and profoundly altered, while the expectations of residents must be raised so that they understand and value their rights to independence, individuality, dignity and equality.

### **Lack of community supports**

Although, more people are leaving disability residential settings to live in the community, the distinct lack of community supports available to them is a huge and telling issue. Some people, for example, have moved to rural areas that simply do not have the infrastructure available to support them to be independent and to enjoy a decent quality of life – such as opportunities for socialising, strong transport links to towns, or locally-based therapies and services. This results in people being isolated and effectively institutionalised within their own home and within the community.

## Cutbacks to Home Help and Personal Assistant (PA) Supports

Home Help and PA supports enable people with disabilities to live independent, fulfilling lives in their own homes and communities. For too many people, this support is being continually reduced and cut back, or is just not being made available at all. For example:

- Between 2008 and 2014, 600,000 home help hours were cut.<sup>xi</sup> Close to 1,700 people are waiting for home help services.
- Increasing need and demand is seeing the waiting list for PA services grow to 207, and home help services to 296.<sup>xii</sup>

This is only set to get worse, as more people with disabilities move from institutions into the community, leading to a likely increase in demand for personal support services. As people live longer and their expectations of the supports they're entitled to rise, this demand will intensify again.<sup>xiii</sup>

There is currently no legislation or official policy underpinning the right to PA supports for people with disabilities. This isn't good enough – the huge difference they make to people's lives is well-known and consistently proven. A PA receives instructions from the person with a disability and works to support them in being as independent as they can be. PA supports promote and strengthen a person with a disability's right to individual choice, flexibility and Independent Living, empowering them to participate equally and to take control of their own life.<sup>xiv</sup>

However, PA is often grouped in the same category as Home Supports, reflecting a fundamental lack of understanding regarding the purpose and meaning of a PA service. There is also evidence to suggest that PA services have been diluted in recent years; for example, in some instances, they are used to incorporate assisted care, supplementing that provided by families, and a bias towards physical care tasks, rather than those assisting participation in social activities.<sup>xv</sup>

Equally, Home Help services are underperforming for many, with some people reporting that they receive as little as 15 minutes of support per day. Others claim that home support is used to supplement access to PA, again indicating the lack of understanding between different services and their respective objectives.

### **Slow introduction of self-directed living supports**

Government has committed to promoting community inclusion for people with disabilities and establishing individualised funding models which support this. These commitments are laid out in numerous policies<sup>xvi</sup> but delivery is slow and piecemeal.

Support for individualised funding models, like Direct Payments, among people with disabilities and their families is huge<sup>xvii</sup> as opportunities for increased autonomy, choice and control, as well as more flexible and quality supports are long-awaited. Support extends further, demonstrated by a letter sent to Health Minister, Leo Varadkar, by 25 of the larger service providers outlining their support for individualised budgets.<sup>xviii</sup> Inclusion Ireland has also called for the allocation of 8-15% of the block grants currently being given to service providers to go towards individualised, person-centred, community-based models of support.<sup>xix</sup>

Despite widespread support, as well as the leadership of a few non-for profit initiatives, barriers towards the implementation and roll out of individualised models remain. Currently, there is no national framework to support these mechanisms; there is a lack of investment in existing demonstration projects; there is a need for more information and consistency within the HSE, across its various areas and among staff; while people with disabilities and families remain unaware that this is being developed as an option.

Demonstration models developing different approaches to and models of individualised budgets need to be continued to be supported and resourced. While all stakeholders, particularly the HSE and service providers must work together to realise this policy. Self-directed supports – or individualised funding models – embrace the full inclusion and self-determination of people with disabilities and their families. Implementation of the VfM Review in particular, means a seismic shift in how disability services are funded and provided, moving choice and control from professionals and service providers to people and families with disabilities themselves. This will advance delivery of services and supports with much greater efficiency, transparency and accountability.

### **Inadequate housing**

People with disabilities should be supported to live in their own home and in their own communities. Like everyone else, they are entitled to live in basic comfort and with dignity, in houses that can accommodate their various and personal needs so that they do not have to suffer barriers in the home as well as in the community.

However, almost 4,000 people with disabilities in Ireland are in need of social housing.<sup>xx</sup> At the same time, the maximum income threshold on the Housing Adaptation Grant for People with a Disability scheme was reduced from €65,000 to €60,000, meaning that households with income over €60,000 are now ineligible for funding support. Equally, the income bands on payable grants were significantly restricted in 2014, following 42% cuts to the scheme since 2010.

Delays in the approval and awarding of these grants, meanwhile, mean that some people find themselves accepting unjust and demeaning situations, like being forced to disassemble one's wheelchair in order to get it through the front door<sup>xxi</sup> or having



to sleep on a couch in the family sitting room due to a minimum two-year waiting list for this grant to come through.<sup>xxii</sup>

If the dearth of inaccessible housing continues, many people with disabilities who are perfectly capable of living independently with support will have no other option but to live in institutions. Many people are vehemently refusing to accept this option and will continue to do so, even though this can result in inappropriate living conditions.

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<sup>i</sup> Irish Times, Analysis, Available at <http://www.irishtimes.com/news/social-affairs/inspectors-find-failings-in-every-hse-disability-care-home-1.2315327>

<sup>ii</sup> Social Justice Ireland (2014) Budget 2015

<http://www.socialjustice.ie/sites/default/files/attach/publication/3573/budget2015analysisandcritiqueprint.pdf>

<sup>iii</sup>Housing Agency (2013) *Summary of Social Housing Assessments 2013: Key Findings*. Dublin: Department of the Environment, Community and Local Government

<sup>iv</sup> <http://www.theatnetwork.com/health-service-executive-seeking-e250-million-for-community-based-care-for-people-with-disabilities/>

<sup>v</sup> Housing Agency (2013) *Summary of Social Housing Assessments 2013: Key Findings*. Dublin: Department of the Environment, Community and Local Government

<sup>vi</sup>

[http://www.citizensinformation.ie/en/housing/housing\\_grants\\_and\\_schemes/housing\\_adaptation\\_grant\\_for\\_people\\_with\\_disability.html](http://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/housing_adaptation_grant_for_people_with_disability.html)

<sup>vii</sup> Department of Health (2015) Long-Stay Activity Statistics 2013, Available at [http://health.gov.ie/wp-content/uploads/2015/04/long\\_stay\\_2013.pdf](http://health.gov.ie/wp-content/uploads/2015/04/long_stay_2013.pdf)

<sup>viii</sup> Irish Times, Analysis, Available at <http://www.irishtimes.com/news/social-affairs/inspectors-find-failings-in-every-hse-disability-care-home-1.2315327>

<sup>ix</sup> <http://www.theatnetwork.com/health-service-executive-seeking-e250-million-for-community-based-care-for-people-with-disabilities/>

<sup>x</sup> [http://www.irishtimes.com/news/health/improving-homes-for-intellectually-disabled-to-cost-57m-1.2344875?utm\\_source=twitterfeed&utm\\_medium=twitter](http://www.irishtimes.com/news/health/improving-homes-for-intellectually-disabled-to-cost-57m-1.2344875?utm_source=twitterfeed&utm_medium=twitter)

<sup>xi</sup> Social Justice Ireland (2014) Budget 2015

<http://www.socialjustice.ie/sites/default/files/attach/publication/3573/budget2015analysisandcritiqueprint.pdf>

<sup>xii</sup>HRB (2014) Table 3.4 Future Requirement for Personal Assistance and Support Services. These figures are an under-estimation of the true need of services due to the voluntary nature of the database, and because need and future need is self-reported.

<sup>xiii</sup>Disability Federation of Ireland (DFI) (2014) *Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities*. p.13

<sup>xiv</sup> <http://www.theatnetwork.com/wp-content/uploads/2014/05/T-Direct-Payments-Glossary.pdf>

<sup>xv</sup>Disability Federation of Ireland (DFI) (2014) *Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities*. p 24

<sup>xvi</sup> The Programme for Government 2011-2016, *New Directions Review of HSE Day Services and Implementation Plan 2012-2016: Personal Support Services for Adults with Disabilities, Value for Money and Policy Review of Disability Services* (2012).

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<sup>xvii</sup> At an event organised by Áiseanna Tacaíochta (ÁT), an organisation facilitating Direct Payments in Ireland, in December 2014, attendees were asked if Direct Payments has a future in Ireland – 77% strongly agreed and 23% agreed. While 85% of people strongly agreed with the statement that people with disabilities should be supported to support themselves, with 14% agreeing.

<sup>xviii</sup> Inclusion Ireland drafted the letter and secured the agreement and signatures of representatives from 25 disability service providers.

<sup>xix</sup> Susan Mitchell (06/09/2015) Sunday Business Post

<sup>xx</sup> Housing Agency (2013) *Summary of Social Housing Assessments 2013: Key Findings*. Dublin: Department of the Environment, Community and Local Government

<sup>xxi</sup> <http://utv.ie/News/2015/05/28/Limerick-teen-still-waiting-for-wheelchair-ramp-38075>

<sup>xxii</sup> <http://www.thejournal.ie/george-chalkley-2304120-Sep2015/>