



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Housing for people with intellectual disabilities

**The lack of supports for independent living
November 2019**



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About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

As part of this submission Inclusion Ireland held consultations with people with disabilities and family members of people with disabilities. Their quotes are included as part of this submission.

Introduction

At present there are approximately 66,000 people with an intellectual disability living in Ireland. These people live in a variety of different housing circumstances; some within the service provision system, and the majority outside of it. There is an increasing amount of people with disabilities moving into community-based housing from large, institutionalised settings, and many more living at home with family members. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is clear in its message that people have the right to be living independently¹ in the community², and it is important that the right supports are in place for people to realise their rights.

This paper aims to explore the current housing context for people with intellectual disabilities in Ireland with a focus on social housing provision and the private rental market. The paper will examine the policy context

¹ Living independently can mean different things to different people. Some people will require more supports than others, but these supports should be assessed and allocated in a person-centred way.

² Article 19, Convention on the Rights of Persons with Disabilities (CRPD)

for housing in Ireland in relation to disability, the barriers people with intellectual disabilities come up against in accessing houses and the supports necessary for people to live independently in the community, before examining potential models of housing that could improve the housing situation for people.

1. The Policy Context

In looking at the housing disadvantages experienced by people with intellectual disabilities, it is important to examine the policy context within which this experience is framed. There are multiple policies related to disability and housing, some of which overlap.

The National Disability Inclusion Strategy 2017 - 2021

The National Disability Inclusion Strategy 2017-2021 (NDIS) is the whole of government, overarching policy framework on disability. While it includes some actions on de-congregation, universal design, local authority application processes and housing adaptation grants, it defers to the National Housing Strategy for People with a Disability (NHSPWD).

The timeline for the National Housing Strategy for People with a Disability was originally 2011-2016 but the NDIS notes that this has been 'affirmed and extended' to 2020.

The National Housing Strategy for People with a Disability

The government's overarching framework for housing policy in Ireland is Rebuilding Ireland. Rebuilding Ireland makes little reference to people with disabilities and instead defers to other policies specific to disability, chiefly the National Housing Strategy for People with a Disability. This strategy "sets out the Government's broad framework for the delivery of housing for people with disabilities through mainstream housing options"³.

The NHSPWD also makes reference to the government's de-institutionalisation policy and says the Department of Housing, Planning and Local Government will provide ring-fenced funding of €10 million in 2016 under the Capital Assistance Scheme (CAS) specifically for people with disabilities transitioning from congregated settings. However, just €2.3 million of this funding was drawn down in 2016, meaning all

³ Rebuilding Ireland: Action Plan for Housing and Homelessness

available funding has not been used to move people from congregated settings.

Within the NHSPWD there is reference to the National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities. The guidelines are meant to provide direction for local authorities in developing their own individual allocation schemes. However, each local authority is free to develop their allocation processes as they see fit which means there are variances in allocations across local authorities.

Importantly for people with disabilities, the guidelines note that people with a disability “shall not be deemed adequately housed when their current address is a congregated setting, institution, hospital/nursing home, community based group home, or when they, although an adult, remain in the family home due to their personal circumstances and/or support needs.”⁴

The guidelines also refer to the issue of housing supports and note that while a person may have support needs to enable them to move to their own home, “these supports do not need to be in place at the point when a person is making a social housing support application and the circumstances should not affect the housing authority’s assessment of need.”⁵

Time to Move On from Congregated Settings – A Strategy for Community Inclusion

‘Time to Move on from Congregated Settings – A Strategy for Community Inclusion’, published in 2011, focused specifically on 4,000 people in 72 centres which it called ‘congregated settings’. This was defined as ten or more people sharing a single living unit or where the living arrangements are campus-based. Publication of the strategy was considered a milestone and established a national policy for a new approach to community living for persons with disabilities.

Despite the “compelling case for action” described in the strategy, action has been very slow. The strategy was clear in recommending that all congregated settings would be closed within 7 years (by 2018). However,

⁴ Key message 14, National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities

⁵ Key message 3, National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities

according to the latest figures, there are at present approximately 2136 people with disabilities still living in institutional settings in Ireland⁶. Today persons with disabilities experience segregation, human rights abuses and deprivation of liberty by virtue of remaining in these congregated settings, and through its inaction, Ireland is possibly in breach of several international rights covenants as well as domestic and Constitutional law⁷.

The International human rights framework

The United Nations Convention on the Rights of Persons with a Disability (UNCRPD) makes reference to housing, and with Ireland's recent ratification of the Convention in March 2018, there is an increasing obligation on Ireland to reflect the principles and Articles of the Convention in its policy and budget decisions.

Article 19 of the UNCRPD reaffirms the right of people with disabilities to live independently and be included in the community with the supports needed⁸. Article 28 also states that State parties must ensure equal access by persons with disabilities to public housing programmes⁹.

The right to adequate housing is recognised in international human rights law as part of the right to an adequate standard of living¹⁰. The International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the right of everyone to an adequate standard of living, including "adequate food, clothing and housing, and to the continuous improvement of living conditions."

While the right to housing as enshrined in the ICESCR has limited enforceability in Ireland at present, equality legislation (The Equal Status Acts 2000-2015) prohibits discrimination in access to goods and services, including housing and accommodation.

⁶ Time to Move on from Congregated Settings: A Strategy for Community Inclusion

⁷ Deinstitutionalisation in Ireland; a failure to act, 2017.

⁸ Article 19, UNCRPD.

⁹ Article 28, UNCRPD

¹⁰ General comment No. 4 at paragraph 1, Committee on Economic social and Cultural Rights

2. The Housing Context

As it currently stands, the statistics available on the numbers of people with intellectual disabilities in housing and the types of housing they live in, is not comprehensive. However, the National Intellectual Disability Database (NIDD) does give a good indication on this context despite only taking into account people who are already engaged in some type of disability service. The NIDD does not include people who have not yet come into contact with disability services.

According to the NIDD, 55.5% of adults with an intellectual disability live in a home setting; 6.2% in independent setting; 22.2% in community group homes; and 10.2% in residential centres (See Figure 1.1). For those under 18 years of age, 99% of them live in a home setting¹¹.

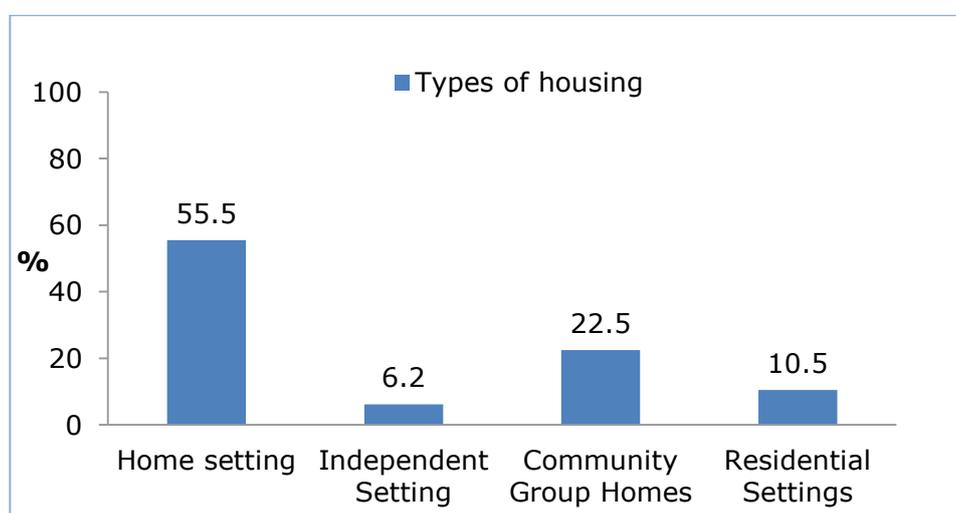


Figure 1.1 Type of housing adults are living in (NIDD)

The NIDD illustrates that housing - outside of the informal setting of the family home - for people with intellectual disabilities in Ireland has been dominated by the provision of residential services either in large-scale institutional settings or more recently by group home settings. This type of housing provision has been dominated almost exclusively by disability service providers; many of whom are in the position of being responsible for providing both the housing and the supports for the individual.

People living in residential services and congregated settings

According to the most recent figures from the NIDD, there are 7,530 people availing of full-time residential supports; such as community group homes. The 'A Time to Move On from Congregated Settings' report

¹¹ Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings

published by the Health Service Executive in 2011 found that many people with disability living in congregated settings live isolated lives, segregated from the community and family; many experienced institutional living conditions where they lack basic privacy and dignity. The report proposed a new model of accommodation and support in the community.

The report set a target of closing all institutions in 7 years (by 2018). At the time there was slightly over 4,000 people living in institutions. The government has scaled back transition plans and set a new target of reducing the amount of residents by 1/3 by 2021.

In effect this means that there are 2136 people on a waiting list to move into the community from congregated settings. This is in addition to the approximate 1500 younger people inappropriately placed in nursing homes¹². These people also require appropriate community based housing and supports.

People living with family members

While there is not robust data available on the number of people with intellectual disabilities living at home with family members, the NIDD does give us some indications on this group. Of the 28,388 people with an intellectual disability registered on the NIDD, 15%, or 4,255 people aged 35 or over are living in a home setting¹³ – many of which would be with family members. These numbers indicate an ageing demographic of people with an intellectual disability reliant on family members for both their housing and support needs.

This is a group who are not adequately housed in their own right, and of which there seems to be no forward planning of accommodation as family members grow older. With this form of housing comes informal care giving from family members; supports which are not being covered by the HSE or other service providers. This informal support has many effects, with some people having their independence constrained by this ongoing dependence on family support, while others have their independence promoted by family members.

Providing this informal support can be challenging and limiting for family members and can be particularly distressing for parents as they age and

¹² The situation of younger people with disabilities living in nursing homes in Ireland - phase 1, 2018.

¹³ Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings

their capacity to provide care and support diminishes. In a sample of 18 of their organisations, the National Federation of Voluntary Service Providers found that 183 people are living with a carer over the age of 80, and 473 lived with a carer aged 70-79¹⁴. By the HSE's own admission, these people are not a priority when it comes to housing¹⁵.

This also raises problems in the future for these people when their family members pass away. Many people with disabilities and their family members are trying to plan in advance in order to avoid crisis situations, but the current social housing application system and the lack of a clear process to apply for supports, makes it very difficult for people with disabilities – and in particular people with intellectual disabilities - to avail of housing.

Local Authority (LA) and Approved Housing Body (AHB) Housing

Local authorities are the main providers of social housing in Ireland. The allocation of social housing is determined by eligibility and need, with rents based upon the household's ability to pay.

Approved Housing Bodies are independent, non profit organisations. They provide affordable rents for those who cannot afford to pay private rental rents, or for particular groups such as older people, or people with a disability. In order to be housed by an AHB, you must normally be already registered on the housing waiting list.

Figures from 2017 illustrate the number of people on the Social Housing Assessments list, and those who were then allocated housing. In 2017, there were 85,799 people waiting for social housing support¹⁶, with 7,943 people being allocated houses through local authorities and Approved Housing Bodies¹⁷.

¹⁴ National Federation of Voluntary Service Providers, 2019.

¹⁵ Regional Health Forum, Agenda Item No.5, Reply to Question, Ref 23.07.19/13/14/15

¹⁶ Housing Agency, Summary of Social Housing Assessments 2017.

¹⁷ Rebuilding Ireland, Social Housing Delivery 2017

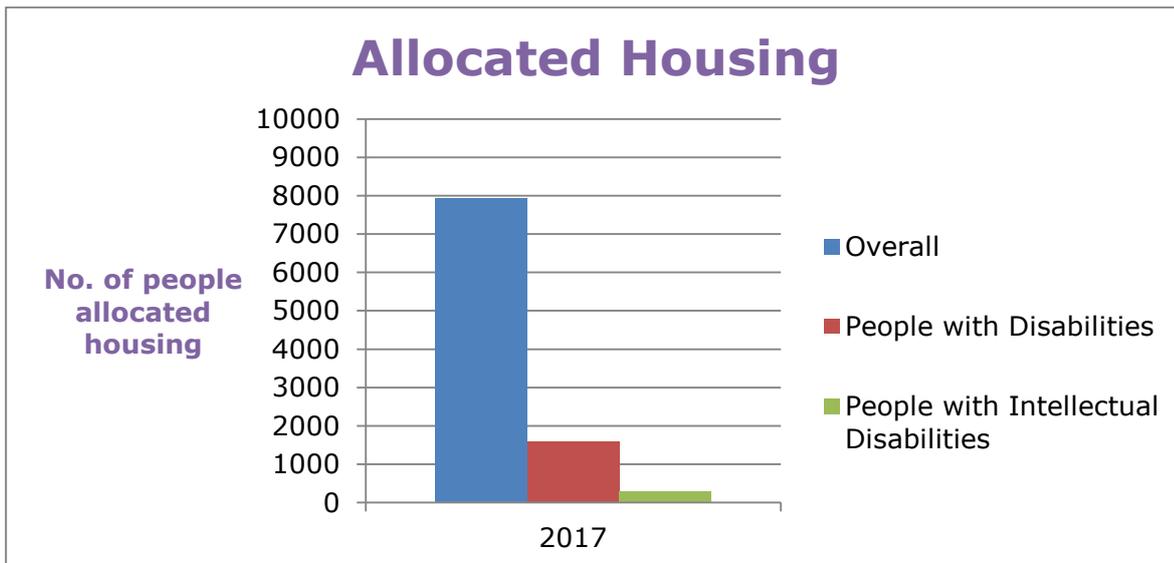


Figure 1.2 Local Authority Housing Allocations 2017

Of this figure of 7,943, 20% of these were people with a disability (See figure 1.2), and just 199 people or 2.5% were those with intellectual disabilities¹⁸. The majority of those people were individuals moving from congregated settings as per the Time To Move On from Congregated Settings policy. These allocation figures would indicate that people with intellectual disabilities living at home with family members, and applying through local authorities are not being successful in getting social housing.

These figures would also suggest that demand for social housing in general is significantly outnumbering need with just 9% of people on the social housing list being allocated homes through local authorities and approved housing bodies. Additionally, in 2018, people with an intellectual disability represented over 2% of the social housing waiting list¹⁹. Census 2016 found that there were 66,611 individuals with an intellectual disability in Ireland, representing 1.4 per cent of the total population.²⁰ This indicates that people with disabilities are a group in Irish society who is over-reliant on social housing support (discussed further on page 12).

Of the 85,799 people on the waiting list, 1,571 are people with an intellectual disability. However, figures from the NIDD illustrate that there are 10,865 people over the age of 18, and 4,255 people over the age of 35 living at home with family members²¹. As mentioned previously, these figures are people already availing of disability services and do not take

¹⁸ Housing Agency, 2017

¹⁹ Housing Agency. (2018) Summary of Social Housing Assessments 2018.

²⁰ Census 2016

²¹ Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings

into account those who are not using any disability services. This would indicate that there are a large number of people with intellectual disabilities not on the social housing waiting list.

With many people with intellectual disabilities still living at home with family members, including those who have not applied for social housing support – due to the various obstacles, it is likely that the true number of people with intellectual disabilities in need of housing is much higher than those on the social housing waiting list.

The private rental market:

According to the Central Statistics Office (CSO), in the 2016 Census there were 57,314 people with intellectual disabilities in all types of private housing, with 7,268 of those being people with intellectual disabilities living in private rented accommodation²². This figure is inclusive of children with an intellectual disability living with their parents who are renting private accommodation.

The current housing market in Ireland has a significant effect on people with intellectual disabilities. The lack of houses on the market, particularly in urban areas such as Dublin city, means people with disabilities face extra barriers in finding rented accommodation. According to a recent report there were just 2,700 properties for rent nationwide on daft.ie; this being the lowest ever number of stock on the market²³. This was followed by a further report that highlighted the prices people are facing in the rental market, with the average national rent being €1,403 per month, with areas of Dublin as high €2,224 per month²⁴. This lack of stock isn't exclusive to the urban areas, nor is the rising cost of rents with this phenomena occurring in rural areas.

As referenced below in our consultation, people with disabilities regularly report facing discrimination when it comes to renting. There are also few accessible houses on the rental market at any given time for people with disabilities, and many report of the problems with the Housing Assistance Payment (HAP). This can take the form of landlords refusing to accept tenants who want to avail of HAP²⁵.

²² CSO, 2016

²³ The Daft.ie Rental Price Report An analysis of recent trends in the Irish rental market 2019 Q1

²⁴ The Daft.ie Rental Price Report An analysis of recent trends in the Irish rental market 2019 Q3

²⁵ Irish Legal News <https://www.irishlegal.com/article/homeless-man-wins-circuit-court-discrimination-case-over-landlord-s-refusal-of-hap-tenants>

There is also the added concern that availing of HAP as a tenant results in the person being removed from the social housing waiting list. However, people can apply to be placed on the transfer list and, if they do it within two weeks of receiving the letter confirming the HAP payment, will still have their time on the waiting list counted, which means that if a regular social housing unit becomes available, they would be considered for a transfer across²⁶.

What people in our consultation said about renting privately:

"It's too expensive to rent in the private rental market".

"If you want to leave and live by yourself or friends there's no support to do this. Everyone is just thinking of service provider houses."

"People don't have the choice to rent themselves."

"I looked at 5 houses and only one accepted us. I think this was because I had a disability."

"Once we were told that there was a greater risk of fire with us – because we had a disability- so they wouldn't take us."

Homelessness:

According to the Census 2016 there were 6906 total homeless persons; with 1871 homeless being persons with a disability, and 213 being homeless persons with an intellectual disability. This means that people with a disability are 13.5% of the general population but 27% of the homeless population²⁷. Similarly, people with an intellectual disability are 1.4% of the total population and 3.1% of the homeless population. This represents a gross inequality for people with disabilities.

These figures don't take into account what is often referred to as 'the hidden homeless', those who are couch surfing or are living at home with family members, and are not adequately housed in their own right. Recent research²⁸ has also shown that people with disabilities are more

²⁶ Citizens Information, 2019.

²⁷ CSO

²⁸ Discrimination and Inequality in Housing in Ireland Set Out in New Research, 2018 (ESRI)

than twice as likely to report discrimination in relation to housing, and are among the most disadvantaged groups in Ireland when it comes to housing.

Children with intellectual disabilities

Through our advocacy work we have come across many families who have children with intellectual disabilities and the barriers they come up against in finding appropriate housing. Some families describe receiving little support from local authorities in relation to getting accessible housing for their children.

In some cases, the changing circumstances of families mean that houses allocated through local authorities are no longer suitable for the children, as the children's needs have changed. Families in these situations have reported that they have faced resistance from local authorities in finding more suitable accommodation, which has resulted in children living in conditions that are detrimental to their needs.

3. Barriers facing people

Affordability:

Supply and affordability are key drivers of the current crisis in housing, and are core issues that must be addressed within the wider housing context in Ireland. However, increasing affordability of the rental market and increasing supply of social housing, will, in and of themselves, not address the barriers that people with intellectual disabilities experience when they try to claim their right to live independent lives in their communities. These barriers are the focus of this section of the paper.

According to a recent study by the Simon Community, over 90% of homes for rent in Ireland are beyond the reach of people dependent on state benefits²⁹. This includes people with disabilities on Disability Allowance and raises the question as to whether renting in the private rental market is a feasible option for people with disabilities. The current price of rents makes it extremely difficult for people to rent in the private rental market and live independent lives.

²⁹ Locked Out of the Market, Simon Community, March 2019

In Ireland, persons with disabilities are more than three times as likely to experience poverty and deprivation as the general population.³⁰ Persons with disabilities face additional costs such as specialist disability aids, home adaptations, higher energy costs or an increased need for taxis due to inadequate public transport. These extra costs are estimated as being approximately €207 - €276 per week³¹. There is also the added factor of the lack of employment opportunities, with just 17% of people with an intellectual disability in employment³².

According to the ESRI, persons with a disability experience much higher rates of deprivation which means they go without some of the basic necessities for living. The ESRI has also said that "policies that reduce poverty among the general population do not adequately address deprivation experienced by vulnerable groups" and targeted interventions are needed in households where there is a disabled person³³.

Local Authority Allocations

In relation to priority lists for social housing, there appears to be no consistency between local authorities when it comes to what groups constitute priority over others. Each local authority draws up its own rules for deciding the order of priority on their housing list. These are called *allocation schemes* and are generally published on the local authority's website.

For example, Dublin City Council's allocation scheme makes reference to requiring 5% of new developments to make specific provision for disability. In their assessments for social housing support need, DCC make reference to determining "whether the accommodation is unsuitable for reasons of a physical, sensory, mental health and/or intellectual disability within the household".³⁴

Limerick County Council takes a different approach, by outlining the different categories for prioritisation; with disability being one of those categories. As per the Limerick County Council allocation scheme; "4th priority shall be given to applicants in need of housing on disability, medical, compassionate or similar grounds."³⁵

³⁰ CSO. (2017) Census 2016. Survey on Income and Living Conditions (SILC).

³¹ Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

³² CSO (2016)

³³ ESRI, <https://www.esri.ie/news/irelands-deprivation-gap-is-large-and-increased-over-time>

³⁴ Housing Allocation Scheme (Scheme of Letting Priorities), Dublin City Council, 2018.

³⁵ Limerick City and County Council Allocation Scheme 2017.

However, it is unclear exactly how this priority is calculated with other factors, such as time on the waiting list, coming into consideration. This lack of consistency leads to a serious inequity across different local authorities, and could result in people with disabilities residing in one local authority being more likely to receive a house compared to someone

— living in a different local authority.

What people in our consultation said about Local Authorities:

“I applied to go on the housing list. I would want support if I lived in a home.”

“I’ve been trying to apply for housing for a long time. The information was too hard to understand.”

“I have just handed in my application after 2 years of putting it together and finding out what was needed for it.”

Accessibility of information

For people with intellectual disabilities, having access to accessible information in various formats is hugely important. As it stands many people find it difficult to navigate the social housing application process, especially when information is not easy to understand. Through our advocacy work, people with intellectual disabilities have reported that the process for applying to be on the social housing waiting list is strenuous and lengthy. For those with significant support needs, independent advocacy must be available to navigate the system.

From 2017, local authorities developed and made available an easy to read guide to filling out a housing application form. However, this guide has not been widely promoted or advertised by local authorities meaning that many people with intellectual disabilities are unaware of its existence and how to proceed in applying for social housing.

What people said about accessibility of information:

“Information was too hard to understand.”

“I had support from my sister to fill in the form; it was very difficult to follow.”

“It took two meetings to go through the application form with support staff.”

“The process takes so long to fill out forms. ”

“There should be easy to read documents.”

Accessibility of houses

At present there is no data for the amount of accessible houses that have been made available to people with disabilities. People with disabilities have reported that through their interactions with local authorities and disability service providers, they are informed there is difficulty in acquiring accessible homes from the property market.

Through our advocacy work people have reported being placed highly on the priority waiting list for a house, but being unable to receive an adequate home due to many houses being inaccessible for their needs. This is despite a commitment from the NDIS³⁶ (Action 97) on accessible housing and universal design for new homes to be “accessed and used by all persons, irrespective of size, age, ability or disability”. The National Disability Authority advises³⁷ that Part M of the Building Regulations needs to be reviewed so that the accessibility standard for new builds will be higher.

Decision-Making:

At present the Housing Agency is developing a guidance document on the Assisted Decision-Making (Capacity) Act 2015. The aim of this manual is to provide local authority and approved housing body staff:

³⁶ National Disability Inclusion Strategy, 2017-2021

³⁷ National Disability Authority Opening Statement, Meeting of the Oireachtas Joint Committee on Housing, Planning and Local Government Housing for persons with a disability 4 July 2019

- With an understanding of the implications of the Assisted Decision-Making (Capacity) Act 2015 on the provision of housing.
- Facilitate a uniform approach in the adoption of the Assisted Decision-Making (Capacity) Act 2015

As well as taking on board the principles of the Assisted Decision Making Capacity Act, it is also highly important that staff members of local authorities and approved housing bodies should be trained in disability rights, and equality and human rights in order to fulfil their responsibilities under the Public Sector Duty.

The Act - which has not been fully commenced yet - presumes the capacity of individuals and views capacity in functional terms. It has clear implications for people with intellectual disabilities in terms of people's decision-making power to own a house and secure tenancies. At present there is no clearly agreed process for supporting an individual with an intellectual disability to purchase and own a property or to secure a tenancy and fulfil their legal responsibilities as a tenant.

4. Housing and support services

One of the biggest issues emerging from our advocacy work is the absence of joined-up services and the poor collaboration between Government departments regarding the availability and co-ordinated delivery of support services. Typically, services and supports provided to people are based upon the availability of the service and not around the individual needs of the person, where the person lives or with whom the person would like to live with. This lack of co-ordination at national level, is mirrored in disjointed service delivery at local level.

What frequently emerges when talking to people with disabilities and their families is the need for more collaboration between the Department of Housing, Planning and Local Government and the Department of Health and the HSE. Strategic Aim 2 of the NHSPWD aims to address the need for cooperation and the provision of housing and support services. It states that the NHSPWD is

“To develop national protocols and frameworks for effective interagency cooperation, which will facilitate person-centred delivery of housing and relevant support services”

However, there is scant evidence that these frameworks have been developed or are working in any meaningful way. Currently, people with disabilities pinpoint the lack of available supports as one of the biggest barriers to accessing housing. People with disabilities find it difficult to access disability services unless they are in a crisis situation, and there is no clear pathway for a person to attain support services from the HSE in order to live independently in a local authority or rented home.

This is something that can clearly be seen in the recent development of the *Framework for the Management of Residential Supports (including Emergency Placements) in HSE Community Healthcare Organisation Areas*³⁸. This document outlines that the responsibility for the management of residential places for people with disabilities will be directly managed by the HSE and the 9 Community Healthcare Organisations (CHO's). It also says that all people looking for a residential placement will have their information entered on the Disability Supports Application Management Tool (DSAMT).

The purpose of this tool is to assist the HSE in deciding who is most in need of a residential place, with priority being given to people in emergency or crisis situations. The framework makes no reference to local authorities being involved in housing people with disabilities, despite inter-agency co-operation being identified as being central to inclusive housing provision for people with disabilities³⁹. There is also the added factor that the HSE does not keep any records of the people they support that may have applied for social housing, and does not maintain records of those people who may access social housing independently⁴⁰.

For those not already engaged with disability services, gaining access to supports in the first instance is the biggest barrier. There are many people living in communities who do not receive support services from the HSE, and as a result are not in a position to avail of housing from a local authority or an Approved Housing Body in order to live in supported independent living.

If a person with an intellectual disability is not already in receipt of residential support services, there is no clear pathway for them to be assessed for, and gain access to residential support services, irrespective

³⁸ Framework for the Management of Residential Supports (including Emergency Placements) in HSE Community Healthcare Organisation Areas. April, 2019.

³⁹ National Guidelines For The Assessment And Allocation Process For Social Housing Provision For People With A Disability

⁴⁰ Regional Health Forum, Agenda Item No.5, Reply to Question, Ref 23.07.19/13/14/15

of where they are living. There appears to be no formalised process through which people can apply for supports from the HSE Disability Services.

Key Message 3 from the National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities states that people are entitled to assessment of housing need regardless of whether there are support services in place⁴¹. While a lack of available supports should not prevent an assessment taking place, the unavailability of support services results in people being unable to take up a local authority or AHB home.

This absence of available support services may also disproportionately affect people with the highest support needs as they cannot live with low levels of support or without any support. The lack of availability of supports may also be linked to the apparent lack of demand for social housing for people with intellectual disabilities, as discussed earlier in relation to the numbers of those on the social housing waiting list.

The barriers people come up against when trying to access supports may lead to people being reluctant to apply for social housing without the supports being available first. This could lead to a misconception that there is less of a demand for housing for people with intellectual disabilities.

What people in our consultations said about support services:

“You only get the house, not the supports. So really, you don’t get the house at all.”

“The HSE should be linking in with the Local Authorities about people getting supports in houses.”

“I would prefer to be on the Service housing waiting list. The support is more readily available this way. The support just isn’t there if you are on the social housing waiting list.”

“I would need support paying my bills and other financial things like that. It depends on the person what support they might need.”

⁴¹ National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities

5. Giving choice and control to people

This section outlines some potential models of housing and supports that could be implemented that would provide a more person-centred approach to housing for people with intellectual disabilities. These models are:

1. Personal Budgets
2. Housing First Model
3. Cost Rental Model

What people in our consultation said should be done:

“If someone gets a house there should be a person in the HSE where people can apply for support to allow them to take the house and live there.”

“There should be advocacy available for people who are trying to get a house.”

“There should be clear steps and a pathway on how to get a house. There’s a lot of confusion and not enough information out there.”

“People with disabilities should be encouraged to buy homes. I want to buy a house. But there’s no way I could get a mortgage on my part time job income.”

“People with disabilities deserve an opportunity to get a mortgage”

1. Personal Budgets

What is a personal budget?

A personal budget is an amount allocated to a person to cover the cost of providing their care and support needs following an assessment of need or personalised planning process. The aim of a personal budget is clear – to allow a person to decide what services and supports they receive, and who provides those services and supports. They also allow people to imagine a life beyond services, an ordinary life in ordinary places.

Personal budgets can empower people with disabilities and their families – especially those families where the person has high support needs - and give them greater flexibility, choice and control.

Effectiveness of personal budgets

Personal budgets have been in use in other countries for some time. The evidence is clear – while there are ways of implementing personal budgets that may produce better outcomes than other ways, studies show that personal budgets have resulted in a positive impact on physical and mental wellbeing, independence, dignity and feelings of control over one’s own life⁴².

Since a personal budget is about tailoring supports to an individual’s needs and wishes, in principle they can work for anyone that wants one, including those with complex support needs. Young people with complex needs who have a personal budget have reported greater choice and control over the supports they access and the flexibility to design creative and individual supports that allow them to live ordinary, supported lives in their local communities⁴³.

Housing and personal budgets

As mentioned previously, service providers currently control how people’s housing and support needs are provided. However, personal budgets would give people with disabilities more control over many aspects of their life, including their housing and supports needs. A person with a personal budget could decide how their support services are allocated, giving people the opportunity to tailor their support needs around their housing needs.

The current system of resource allocation and funding is inflexible and suits institutions and systems rather than people. The existence of large institutional service providers ensures a system that is less amenable to personal choice and control for those accessing supports. Divesting power, control and the concentration of resources from the institution to the individual, the family, the community is current disability policy. Personal budgets is a key driver of this reform.

Personal budgeting would require greater co-ordination between local authorities and disability services in supporting the individual to avail of their funding. Support is also needed for a range of local brokerage initiatives so that people who would like to avail of this support have the

⁴² Hatton, C. & Waters, J. (2013). The second POET survey of personal budget holders and carers. UK: In Control

⁴³ In Control (2015). Personal health budgets and young people with complex needs. UK: In Control

option to do so. Brokerage services can hold and manage a person's budget and provide information and support to people to plan and manage their own supports and services.

2. Housing First Model:

One potential approach that Local Authorities and AHB's could use is to provide housing for people with intellectual disabilities through the Housing First model that has been successfully used with homeless populations internationally. The key feature of Housing First is the provision of the housing need of the person first followed by wraparound support services thereafter. This model has eight core principles⁴⁴, and of particular relevance to people with disabilities would be the principles of:

Choice and control for residents

This gives people the opportunity to live supported self-directed lives, making decisions about where and how they want to live in their communities.

Separation of housing and supports

This would allow the person to be secure in the knowledge that their home is safe and not contingent on the availability of support. This means that if a person decides to move to a new house that the support can move with them and is not fixed to that property. This separation also gives people the choice and opportunity to cease having support if they feel they no longer require it, without this decision affecting their housing situation.

Person-centred planning

Person-centred planning involves looking at the needs of individuals and planning the provision of support around this person's needs. This type of approach means taking into account that each person's housing needs are going to be different, so a one-size fits all approach is not going to work. This also involves planning with the individual a pathway or set of goals for living independently, so that support services can adapt to the person's needs and not the service dictating to the person.

Flexible support for as long as required

⁴⁴ Housing First Guide: Europe

The flexibility of supports means that if situations arise where a person can no longer live in their house or has to leave their house for a period of time for treatment, that the housing first service will remain in contact. This means there is flexibility in how supports are provided so that services can respond to the needs of what the person needs; whether that be more or less support at a given time.

The provision of housing is the key aspect of the Housing First model. The security of having a home that is not contingent on other issues – such as support or funding – cannot be underestimated. People with disabilities like everyone else would benefit hugely from having a home where they have tenant rights and a private space where they are in control and can make decisions about their own homes.

3. Cost Rental Model

Supply and affordability are key drivers of the current crisis in housing, and are core issues that must be addressed within the wider housing context in Ireland. However, the model of cost-rental housing has been highlighted as a potential solution to these issues.

The National Economic Research Institute (NERI) describe cost-rental as 'a social arrangement where anyone can avail of secure, quality rented accommodation in a way that covers the cost of such accommodation in full but avoids inclusion of a profit margin in the overall cost of renting'⁴⁵. This means that a housing provider raises the finance to provide accommodation and then charges rents that are enough to cover current and capital costs. It would also mean that rents would generally be lower than market rents, and those who cannot afford the cost-covering rent would receive a housing support of some kind.

A number of organisations have put forward proposals to develop a cost rental model as a potential solution to the current housing crisis. According to the Raise the Roof campaign, the 'rental sector is characterised by poor quality accommodation and no security of tenure'⁴⁶. The campaign also calls on government to 'dramatically increase the supply of social and affordable (including cost rental) housing'. The National Economic & Social Council (NESC) describe cost rental as "the best available response to the dynamics of rental systems and housing

⁴⁵ Cost Rental made simple, NERI.

⁴⁶ Raise The Roof, <https://www.raisetherooft.ie/>

markets⁴⁷, and highlights the importance of housing security and affordability as key aspects of the model.

It is clear from the current crisis in the private rented market (as well as the feedback from our consultations) that private rented accommodation, in its current form, is not a reliable means of long term housing for people with disabilities. As well as affordability, private rented accommodation is difficult to access and is precarious in nature, with less than 90% of tenancies available in Dublin falling within the HAP limits.

Inclusion Ireland supports policy proposals to develop a cost rental model and to increase the supply of public housing outlined by the Raise the Roof Campaign and others.

Case Study

Jenny's Story

Jenny lives in her own home in her community.

She recently moved there from a residential disability service and loves living in her own home.

Jenny was supported to make an application for social housing to her local authority by her support worker in a disability service.

Jenny signed a tenancy agreement and pays rent to the local authority.

Jenny has 24-hour support through a disability service to support her to live independently in her home.

Jenny and her support workers worked with the local authority to find a suitable house that was wheelchair accessible.

When a house was identified, careful interagency working and collaboration was required between the local authority and the HSE to ensure that Jenny would have the support that she needed.

Jenny's story is part of 19 stories of social inclusion. Link below – <http://www.inclusionireland.ie/content/books/1736/jennys-story>

⁴⁷ Social Housing at the Crossroads: Possibilities for Investment, Provision and Cost Rental, NESCC.

Conclusion

People with intellectual disabilities, as a group, have largely been removed from the general housing market, both in private renting and in social housing. They face some of the same barriers as everyone else in society in attempting to access affordable housing amidst an ongoing housing crisis. However, there are extra barriers such as the absence of available support services, the lack of accessible houses and availability of accessible information, and the extra costs associated with having a disability.

This lack of planning for housing and supports can be seen in the HSE's failure to record the numbers of people looking for support services, with most allocations of support coming from emergency situations. However, even emergency accommodations are not always accounted for, with many people placed inappropriately in nursing homes. Despite multiple policies for people with disabilities in relation to housing and inclusion in the community, there is a significant gulf between these policies and the practical, lived experience of individuals attempting to access housing. In order to move toward a more inclusive, person-centred approach to housing for people with intellectual disabilities, people themselves must have more choice and control over their housing and supports.

For people with the highest support needs, they may require access to independent advocacy to access housing and the appropriate level of supports required to avail of housing. This can be achieved by models of housing provision that include personal budgets where the person can have a say over how their funding for supports is spent. Similarly, the Housing First model focuses on providing the house, with the support services thereafter. The Cost Rental Model would tackle the issue of affordability and provide long-term housing for people who may not be in a position to purchase their own homes.

Recommendations

- Local Authorities, Approved Housing Bodies and the HSE Disability Services need to develop and publish clear frameworks for co-operation and co-ordination around the issue of residential support services, so that people with intellectual disabilities have a clear pathway to housing and supports.
- HSE Disability Services must introduce a standardised process where people can apply to receive support services, and must record the numbers of people applying. People must be able to receive a full individualised assessment of their 'residential support needs' regardless of their level of disability. Government needs to make funding available for support services to enable people to live independently in their own homes.
- The Departments of Health and Housing must address the real issue of people with intellectual disabilities living at home with aging care givers. A plan must be published to address this issue in respect of the housing and also the support needs of this cohort.
- Personalised Budgets for residential tenancy and support must be introduced, in order to give people more control over how their residential support services are delivered to them. People should have access to advocacy services at the point of negotiating a budget for support, especially people with the highest support needs.
- Local Authorities, Approved Housing Bodies, and HSE Disability Services need to work on implementing a housing model such as Housing First. This would involve separating the provision of housing from the provision of housing supports, with a particular focus on person centred planning and individual pathways towards independent living.
- A Cost Rental model approach to housing should be developed to increase the supply of housing and allow people with intellectual disabilities a pathway to living in affordable long-term housing.
- Government must appoint an independent national oversight group to drive the closure of institutions by publishing a multi-year, fully costed action plan to move the remaining residents out of

institutions into homes in the community with the appropriate supports to lead good lives.

- There needs to be a clear process in place whereby people with intellectual disabilities can secure a tenancy agreement. Staff members working in local authorities and approved housing bodies need training on how best they can facilitate and support this. This is in line with the Assisted Decision-Making (Capacity) Act 2005.
- The housing application processes need to be made more accessible and easier to understand for people with disabilities. For people with more significant support needs advocacy support must be available.
- Research should be commissioned to develop an accurate picture of the extent to which people with disabilities are living in inappropriate / non-UNCRPD complaint or unsustainable settings (including congregated settings, nursing homes, family homes, hospitals). This research should also identify the future housing of this cohort and the support that they will require to live in their own home.
- All new local authority, approved housing body builds must have at least 7% ring-fenced for people with disabilities.



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