



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

# **Pre-Budget Submission 2022**

## **Invest in People with Intellectual Disabilities**

**June 2021**

**This document is written in font 12 Verdana in line with Inclusion  
Ireland plain English guidelines**

# Key Messages

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- People with intellectual disabilities and their families identified housing, the extra costs of disability and education as their most important issues for Budget 2022
- The Government must invest in building accessible, affordable homes for people with disabilities
- A clear pathway to support services must be developed for people with intellectual disabilities so they can live in homes in the community
- An individual, non means tested Cost of Disability payment must be introduced to address the poverty affecting people with disabilities
- Fund the recruitment of job coaches for Intreo offices to provide 'on the job' support to enable those with high support needs to obtain and maintain employment
- Invest in teachers and the physical infrastructure to reduce maximum class sizes to less than 30 pupils and over time to less than 20 pupils per class.
- Review the EPSEN Act 2004 in line with the UNCRPD and commence it without further delay.
- Invest resources to ensure that there is full accessibility across transport services. Attention should be paid to accessible information as well as physical access.
- Invest the resources needed for 2022 to cover both operational and project costs in order to fully operationalise the Decision Support Service and fully commence the Assisted Decision Making (Capacity) Act 2015

# The voices of people with lived experience

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*"People think your opinions don't matter when your disabled"*

*"Tired of being considered 'difficult' for trying to get services"*

*"Consideration of the complex needs of a high support family member in order for them to actual live outside of the family home"*

*"Not enough accessible housing"*

*"What happens to our son when we are gone"*

*"We struggle financially constantly."*

*"Bring in a cost of disability payment. Proper, assessed and non means tested."*

*"Parents shouldn't have to fight for their child's education it should be a given"*

*"Too late for my son he is an adult now"*

*"Need for more support around employment for people with disabilities"*

## About Inclusion Ireland

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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.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

# Introduction

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Inclusion Ireland believes that persons with intellectual disabilities should live self-determined lives and Budget 2022 provides an opportunity to invest in people. Budget 2022 must be a platform to create a more equal & just society and to further develop pathways into a life in the community for people with intellectual disabilities.

In putting together this submission we consulted with people with intellectual disabilities and their families. We received 311 responses to a survey and found that the three most interacted with issues from that survey were housing, cost of disability and education.

This submission identifies 4 key action areas informed by our consultations and the relevant UNCRPD Articles. These are to:

1. Provide accessible homes and supports so people can live in the community
2. Address poverty and the extra costs of disability
3. Invest in community inclusion
4. Support equality and participation

## 1. Provide accessible houses and supports so people can live in the community

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Article 19 of the UNCRPD reaffirms the right of people with disabilities to live independently and be included in the community with the supports needed.

Issues affecting people with disabilities include the lack of available accessible houses, being at an increased risk of poverty, difficulties navigating the social housing application process due to its inaccessible nature, and also issues regarding decision-making when they enter into tenancy agreements.

### **Pathways to supports**

One of the biggest barriers is access to support services that facilitate independent living, and the absence of a defined and transparent pathway to applying for these supports. When asked about housing in our survey,

26% of responses said they needed housing and supports. Many people report being unable to get access to a social housing home due to the unavailability of support services, while others who need supports in their home have no way of applying for these supports<sup>1</sup>.

This points to a clear breakdown in collaboration between the Department of Housing, Local Government and Heritage, The Department of Health and the HSE regarding coordination and funding of support services, and this must be addressed as a matter of urgency.

### **Accessibility of houses**

People with disabilities have reported that in their interactions with local authorities and disability service providers, there is a difficulty in acquiring accessible homes. This is not helped by a lack of data on accessible properties. 25% of responses to our housing survey question highlighted the need for accessible housing for them and their families.

Through our advocacy work, Inclusion Ireland is aware of people being placed highly on the priority waiting list for a house, only to then find there are no available homes that are accessible to their requirements. This is despite a commitment from the NDIS on accessible housing and universal design and the publication by the National Disability Authority (NDA) of Universal Design Guidelines for Homes in Ireland<sup>2</sup>.

To address this, Part M of the Building Regulations needs to be reviewed so that the accessibility standard for new builds will be higher.

### **Deinstitutionalisation and community living**

The UNCRPD is clear in its opposition to institutional living and on the right of persons with disabilities to a life in the community. Article 19 reaffirms the “equal right of all persons with disabilities to live in the community, with choices equal to others’ and to “full inclusion and participation in the community”<sup>2</sup>.

It is therefore imperative that the Irish State ceases with the continued use of institutions which are a clear breach of domestic and international rights, and increases funding to accelerate the deinstitutionalisation process that should have been completed by the end of 2018.

### **Recommendations**

- Ring-fence funding for accessible homes and support services to be made available for people with disabilities who have been allocated

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<sup>1</sup> Inclusion Ireland (2019) Housing for People with Intellectual Disabilities, The lack of supports for Independent Living

<sup>2</sup> Article 19, UNCRPD

housing through local authority or Approved Housing Body (AHB's), or those who may need support to rent privately.

- Develop a clear pathway to apply for supports to live in your own home.
- Invest in building accessible social housing units, and require that any new build housing for use by local authorities will be universally designed and accessible to all
- Increase funding to accelerate the move of the 2841<sup>3</sup> remaining residents from institutions to homes in the community with the appropriate supports, within the next 5 years

## 2. Address poverty and the extra costs of disability

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The UNCRPD is clear on the need to eradicate poverty for persons with disabilities. Article 28, which is concerned with an adequate standard of living and social protection, requires States to “ensure access by persons with disabilities...to social protection programmes and poverty reduction programmes”.

In Ireland, people with disabilities are more than three times as likely to experience consistent poverty as the general population<sup>4</sup>. Persons with disabilities also face additional costs such as specialist disability aids, home adaptations, higher energy costs or an increased need for taxis due to inadequate public transport and these costs are estimated as being between €207-€276 per week<sup>5</sup>.

In our Pre-Budget survey, people cited the numerous additional costs that they have in their life due to disability. Just over half (51%) of people cited additional costs putting a financial strain on their lives. Many of their extra costs related to everyday items such as extra heat, extra transport but also to paying privately for inadequate state supports such as speech therapy and medical items. A small number of people also cited the significant premium of disability aids.

Over a quarter of respondents (27%) said the cost of motoring was an issue. Many people have to travel by car because public transport is not available or if available is not suitable. Many respondents described the

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<sup>3</sup> HIQA Annual Report 2020.

<sup>4</sup> In 2017, 24% of people with disabilities experienced consistent poverty as compared with 6.7% of the general population.

<sup>5</sup> Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

cost of purchasing and keeping a car on the road as a real problem, particularly if a larger or adapted car is a necessity.

61% of respondents counted a raised payment, tax allowances or a cost of disability payment as one of their top three ways to address disability poverty rates.

Recent research carried out by Indecon through tender from the Department of Social Protection is to be welcomed. It is hoped that it will help to determine what the drivers of extra costs are for persons with disabilities in an Irish context and how the extra costs can be addressed.

## Recommendations

- The Department of Social protection must publish the Cost of Disability research
- Introduce an individually assessed, non-means tested cost of disability payment to offset the additional costs associated with having a disability and alleviate poverty among the disability community

# 3. Invest in community inclusion

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## Employment:

Article 27 of the UN Convention on the Rights of Persons with Disabilities affirms the right of persons with disabilities to work, on an equal basis with others.

People with disabilities experience multiple barriers to accessing employment, including financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity.

When asked about employment in our Pre-Budget survey, the most prominent concern arising was the need for employment supports (33%). Recent research by Inclusion Ireland indicates that those with complex needs can obtain and keep a job, with the right supports.<sup>6</sup> A job coach can be one such support. This is supported by the Comprehensive Employment Strategy which sets out the value of individualised support

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<sup>6</sup> Magee, C., Murphy, T., Turley, M., Feely, M., García Iriarte, E., McConkey, R. and Inclusion Ireland (2019). 19 Stories of Social Inclusion – Ireland: Stories of belonging, contributing and connecting. <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1673/19-stories-socialinclusion-ireland.pdf>

from a job coach in supporting people with intellectual disabilities to find and keep jobs<sup>7</sup>.

The Ability Programme funds projects that are aimed at supporting young people with disabilities who are not currently job ready through the provision of a range of person-centred supports. The projects are due to cease in mid-2021, and should be evaluated to assess what has worked and what hasn't and those projects that have demonstrated positive outcomes for people with intellectual disabilities should be mainstreamed.

The progress of the Ability Programme and any potential future roll-out nationally of this programme would be supported by developing capacity within Intreo offices across the country. Such a step is supported by Action 2.2 of the Second Action Plan of the CES which outlines that capacity must be built to support people with disabilities to get into and maintain employment<sup>8</sup>.

## Recommendations

- Ring-fence funding to mainstream the good practice and learning arising from the evaluation of the "Ability Programme".
- Fund the recruitment of job coaches for Intreo offices to provide 'on the job' support to enable those with high support needs to obtain and maintain employment
- Invest in an advertising campaign for the 'Reasonable Accommodation Fund' to ensure that employers and people with disabilities are aware of the support available

## Education:

Article 24 of the UNCRPD places obligations on the Irish government to ensure that people with disabilities are not excluded from education on the basis of disability and can access education on an equal basis with others.

In recent years, the Department of Education and Skills (DES) has significantly increased the spending on special education. However, much of this additional spend is on segregated education and many children with disabilities continue to be excluded from mainstream education.

When asked about education in our Pre-Budget survey, the most important issue (20%) for the respondents is the general lack of places at

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<sup>7</sup> Government of Ireland (2015). Comprehensive Employment Strategy for People with Disabilities 2015-2024

<sup>8</sup> Comprehensive Employment Strategy Phase Two Action Plan 2019- 2021

schools for children with additional education needs. More investment is required to provide the appropriate supports so that children and young people with disabilities receive an inclusive education and are supported to reach their full potential.

### **Class sizes**

Large class sizes are one of the biggest challenges facing teachers in supporting children with disabilities and are a key barrier to the delivery of inclusive education<sup>9</sup>. Large classes of 30 pupils plus, leaves little space for the kind of differentiated strategies necessary to support the diversity of learning needs, leaving teachers feeling stressed that they were not doing their best for either SEN students or the class as a whole. The ratio must be reduced to ensure equality and a quality education system that serves all children.

### **EPSEN and Education Act**

When enacted in 2004, the Education of Persons with Special Education Needs (EPSEN) Act 2004 represented a fundamental shift in how the needs of children with special education needs would be met. The Act provides for educational assessments and independent appeals. Under the Act it was envisioned that a child would have access to a statutory assessment of supports and an individual education plan.

### **Recommendations:**

- Invest in teachers and physical infrastructure to reduce maximum class sizes to less than 30 pupils and over time to less than 20 pupils per class. All teachers need to be adequately trained to work with a spectrum of children with disabilities.
- Review the EPSEN Act 2004 in line with the UNCRPD and commence it without further delay.

## **Transport**

Article 9 of UNCRPD places an obligation on States Parties to ensure persons with disabilities can access transport in urban and rural areas on an equal basis with others. It requires states parties to take measures to identify and eliminate barriers to accessible transport.

### **Accessible transport**

During Inclusion Ireland consultations on Budget 2022, issues frequently raised include: information such as timetables not being in accessible

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<sup>9</sup> ASTI finding in their survey <https://www.asti.ie/news/latest-news/lack-of-training-no-planning-time-largeclasses-key-challenges-to-inclusive-education>

formats, inaccurate display or lack of audio systems, unstaffed bus and train stations and poor upkeep of existing accessibility features, such as ramps and lifts. These issues can be a significant barrier to people with intellectual disabilities travelling independently.

The Comprehensive Employment Strategy (Action 2.12), aims to develop the passenger assistance scheme where an assistant supports people to use public transport and plan journeys on Dublin Bus, Luas and DART. The scheme aims should be extended nationwide as it would support people with intellectual disabilities to use public transport.

### **Rural transport**

A common issue arising from our consultations was the lack of public transport services in rural areas. The availability and accessibility of rural transport is a significant issue for people with intellectual disabilities as the absence of an accessible service leads to an increased isolation and a sense of being cut off from services and community supports. Many reported they have no access to any form of public transport, while others spoke of the difficulties posed by the long distance to bus stops or train stations, infrequent services or service provision and planning which is undependable.

The National Transport Authority's (NTA) first strategic plan for the Local Link Rural Transport Programme (2018-2022) outlines key actions relating to 'Access for All'. These include accessibility requirements to be specified in service contracts; analysis of accessibility levels across all contracted operators following a retendering of existing rural services; and ensuring feedback from disability representative groups and key stakeholders is used to inform a best practice approach to accessibility in the Rural Transport Programme.

### **Recommendations:**

- Invest resources to ensure that there is full accessibility across transport services. Attention should be paid to accessible information as well as physical access.
- Further develop and extend the Passenger Assistance scheme nationwide, extending it and rolling it out in rural areas in conjunction with the Local Link Rural Transport Programme.
- Resource the Local Link Rural Transport Programme to ensure actions are fully implemented within the required timeframes and in consultation with people with disabilities

## 4. Support equality and participation

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### **Assisted Decision-Making**

The Assisted Decision-Making (Capacity) Act 2015 was enacted at the end of 2015 but has yet to be fully commenced. A key part of the process of fully commencing the Act involves the establishment of the Decision Support Service (DSS). This is a commitment as part of the National Disability Inclusion Strategy, and although the DSS was established in October 2017, progress has been very slow.

When asked about decision-making in our Pre-Budget survey almost one third of responses highlighted the need to commence the Act as soon as possible. Full commencement of the Act is essential to ensuring that individuals with disabilities have the support to exercise decision-making and choice in their lives.

In 2021, Ireland will report on its compliance with the United Nations Convention on the Rights of Persons with Disabilities, following ratification in March 2018. The full commencement of the 2015 Act and operationalisation of the DSS plays a key role in the State's compliance with the Convention, in particular the right to legal capacity (Article 12).

### **Recommendations**

- Invest the resources needed for 2022 to cover both operational and project costs in order to fully operationalise the Decision Support Service and fully commence the Assisted Decision Making (Capacity) Act 2015

Inclusion Ireland receives support from the Scheme to Support National Organisations (SSNO) for this work. The SSNO is government funding administered by Pobal.



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