



**Inclusion Ireland**  
The National Association for People  
with an Intellectual Disability.

# Budget Submission 2024



**JUNE 2023**

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# About Inclusion Ireland

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

We work towards the full inclusion of people with an intellectual disability by supporting people to have their voices heard and advocating for rights under the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of Respect, Inclusion, Equality, Voice and Choice

# Foreword

As we enter the planning phase for Budget 2024, it is important to take stock and reflect on the real-world issues facing people with intellectual disabilities and their families. Each year, Inclusion Ireland consults widely through survey and focus groups to understand what is happening for children and adults with intellectual disabilities in communities across Ireland.

Our findings paint a picture of the real lived experience of people. The process also gives us an opportunity to put forward strong arguments for change, both in the budget process itself and also in what gets recognition and is prioritised by Government. It is our view at Inclusion Ireland that whatever funds are made available should be about advancing the human rights of people with intellectual disabilities as equal citizens. What is also clear is that creativity and a more radical view of support is required, the old ways simply do not work for people anymore.

The traditional ways (group models and segregation) lead to further devaluing of people and the creation of systems which separate and other. What we need is a budget which is focused on equality, human rights and belonging. The limitations of annual budgeting are also clear. If we only deal in 12-month timeframes, we can only really respond to what is in front of us, rather than careful planning with people and their families in ways that are meaningful for them over time. Annual budgets further create “emergency” responses, multi-annual budgets provide at least some hope for people’s future. We fully recognise that issues cannot be addressed overnight, but we should be able to see incremental change over time.

Budgeting should be about hope, not crisis planning. The thousands of people waiting for a home of their own, the people living well below the poverty line with the cost of disability sky rocketing, the children waiting on lists to access services all deserve a budget that recognises their fundamental human rights and a hope for a different, more inclusive future.

We call on Government to listen to the words of people echoed throughout this budget submission and to respond by putting forward a budget that acknowledges the right of people with intellectual disabilities to live equal, dignified lives into 2024.

**Derval CEO Inclusion Ireland June 2023**

# Key messages

Inclusion Ireland believes that persons with intellectual disabilities have waited long enough to have their rights fulfilled, five years after Ireland ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

While Budget 2023 implemented some actions reacting to the cost-of-living crisis, more needs to be done to make sure that disabled people and their families live dignified lives.

Budget 2024 provides an opportunity to invest in people. Significant reports and strategies were published throughout 2021 and 2022 namely:

- The Cost of Disability Report
- The Disability Capacity Review
- The Housing Strategy for Disabled People 2022-2027

As of yet, only one implementation plan has been published - The Housing Implementation Plan - which was published on the 22nd of June 2023. Without a plan we lurch from crisis to crisis, when what we need is to have creative and rights-based supports in place for people.

Inclusion Ireland consulted with people with intellectual disabilities and their families. We received 615 responses to the survey: 115 were from people with intellectual disabilities, 252 were family members of disabled children, 228 were family members of disabled adults.

# Budget Survey 2024 - Top Priorities

## **The top 3 priorities for people with intellectual disabilities are:**

- Housing and Independent Living Support
- Money and the Cost of Disability
- Employment and Training

Transport was also highlighted in the comments as one of the concerns for people.

## **The 3 top priorities for family members of a child with an intellectual disability are:**

1. Access to Services
2. Education
3. Cost of Disability

## **The 3 top priorities for family members/supporters of an adult with an intellectual disability are:**

1. Housing and Independent Living Support
2. Employment and Training
3. Access to Services





## Key messages

Additional funding made available in Budget 2024 should only be provided if the services/supports are compliant with UNCRPD. Creative, community based, rights compliant approaches are what is needed by people with intellectual disabilities. It is beyond time to move on from outdated models such as traditional day services and institutionalised approaches. Individualised supports, personalised budgets and services which take their lead from people with intellectual disabilities are the way forward. We need investment in these approaches.

None of our recommendations will be possible without a comprehensive, creative workforce planning strategy particularly focused on disability services and supports. This strategy has to incorporate immediate actions (pay parity for section 38/39, graduate retention strategies) as well as address more medium to long term supply issues (increasing third level places, looking at apprenticeship models, a better overall pay deal for workers at front line, better working conditions). If this strategy is not prioritised, many of the systemic issues facing disabled people and their families will not have a hope of being addressed. We must care for the carers, otherwise community-based supports like home support and personal assistance (PA) supports and personalised budgets will be decimated.

# Summary of Inclusion Ireland Asks

You will find below a summary of Inclusion Ireland asks in plain English. For more information, look at the recommendation section for each topic.

## **Housing and independent living support**

Start a plan to support the remaining residents from congregated settings and people in nursing homes into a home of their own in the next five years. This plan would include:

- More people to have access to a personalised budget
- Training of all staff working with disabled people in services about UNCRPD and rights
- Provide funding for organisations which have experience of delivery on community and rights-based approaches
- A review of the system to have better access to personal assistance hours. Personal assistance should be based on needs, not diagnosis.

## **Access to services**

A strategy is needed to recruit more people as up to 1 in 3 posts are vacant in therapy teams. The strategy also needs to look at how we hold on to staff who are working on the teams.

- Increase the money available for personalised budgets.
- Provide full time individualised services to people who only have access to “day services” on a part-time basis. Make sure that money towards “day services” is for more creative, individualised supports in line with New Directions Policy.

## **Cost of disability**

- More money for the disability allowance (€291.50) so people are not living in poverty.
- Create a permanent cost of disability payment.
- Create a special fund for equipment, technology and other essential assistive aids and appliances for people with higher support needs and their families.



## **Education**

The new version of the EPSEN Act should be supported by a long-term plan to move towards a fully inclusive model of education over the next 10 years. This includes:

- Reduction of class sizes to under 20 pupils by reducing teacher/pupil ratio
- The National Council for Special Education (NCSE) is given annual funding for 39 therapy posts each year as part of SIM (School Inclusion Model). Make this funding permanent so people are hired for a longer period, not just for a year. Children with higher support needs (no matter where they go to school) should be able to access therapies.
- Give teachers and Special Needs Assistants (SNAs) better training about disability and rights.
- Train educators and school staff against the use of seclusion and restraints.
- Make sure that disabled children have access to career guidance.
- Employ more Special Needs Assistants in mainstream schools.

## **Employment**

- Take actions so more people with an intellectual disability have jobs.
- Invest in career guidance at school and transition towards post-school options.
- Invest in job coaches to support employment of people with intellectual disabilities.
- Open wage subsidy scheme to people working less than 20 hours.
- Include job coaches and on-site training for people with intellectual disabilities in Reasonable Accommodations Funds.
- Increase the limit of income disabled workers can earn before they disability allowance and benefits are taken away.
- Create a national platform for employers on the employment of persons with disabilities so they can get advice and support.

## **Supported decision making and advocacy**

- Ensure that the Decision Support Service has enough money and resources to support all people who need help to make decisions.
- Make sure the Decision Support Service is funded to give accessible information to all.
- The State should give money to create an independent advocacy service for children.

# Housing and Independent Living Support - A Full Analysis

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

## The current situation

Around 3500 people are still living in congregated/institutional settings (2,279 according to HIQA Annual report 2022) or unsuitably placed in nursing homes (1,300 according to the Wasted Lives report) while thousands of others are living with families, including older family carers, and have been waiting for many years to move into a home of their own. The latest figures from the National Federation of Voluntary Service Providers show that 1500 people with an intellectual disability are living with family carers aged 70 or older. Only 1455 people with intellectual disabilities were on the housing waiting list at the end of 2022. Given the inaccessibility of the system, we know that this figure vastly underrepresents the real unmet housing needs of people.

A number of barriers were highlighted by Inclusion Ireland and others during the consultation for the new National Housing Disability Strategy 2022-2027. The lack of housing options, the complexity to navigate between the housing and health system to get a housing and support package, the lack of accessible information around the process of applying for social housing and independent living supports.

In addition to these barriers, the Housing Implementation Plan for the new strategy initially expected for June 2022 has just been released, a year late, despite the urgency and despair faced by many disabled people waiting for housing.

According to the plan, only 1826 people with intellectual disabilities were allocated social housing in the whole country since 2016; an average of 260 people per year

If we only take into consideration for people living in inappropriate places and living with their older parents (5500 individuals), it will take close to 20 years to resolve their right to a home. This does not take into account the many other people living with younger family carers and the increase of demands due to the higher needs of the population.

Independent living supports like personal assistance (PA) hours has been highlighted by many organisations as extremely difficult to access. Based on 2018 figures, The Disability Capacity Review estimated, that about 2,500 people get a PA service averaging around 12 hours a week, and around 8,000 people receive home support hours averaging around 7 hours a week. This brings the annual number of hours for all people supported to around 4.5 million.

Beyond the numbers, much of the current model of service provision is outdated and disempowers people with intellectual disabilities. “Services” need to be deeply transformed to better allow the allocation of funds to beneficiaries and their advocates/ families through personal budgets and creative community based models of support.

There is a need for a transition from “service provision” where the disabled person passively “receives” a service towards a person led approach in the way in services are designed, provided, and monitored.

A disabled person should be able to access supports to live independently regardless of their level of impairment or support need once they reach the top of the housing list. The new housing strategy for disabled people has to ensure equity of access to housing, no matter what level of support a person needs, otherwise the strategy is potentially discriminatory.

### **What people told us in the survey:**

- 72% of people with intellectual disabilities said that they were living with their family and 40% of these individuals wanted to move out.
- 51% of respondents who support people with intellectual disabilities said that the person was living with a family member, with 15% of respondents living with a parent over the age of 70.
- Only about a third of people who said they wanted to move house were actually on a housing waiting list. Nearly half of those on the housing list had been on it for more than 5 years including nearly 20% of people who are waiting over 10 years.
- Respondents who support people with intellectual disabilities were asked to identify the main barriers to housing and independent living. Our respondents pointed to a lack of:
  - 41.5% support package/services.
  - 11.5% funding for Personal Assistant hours.



## **Quotes from survey responses:**

“Housing should be available – more wheelchair housing! The Government should help people living at home or living independently by giving more funding to make homes accessible.”

“We want smaller houses to live in with less people”

“More options for independent living supports with people who have disabilities”

“Anyone on Disability Allowance should automatically be put on the social housing waitlist! I have a lifelong disability getting my medical card, disability, free travel was already stressful enough. Also pay student nurses, and pay all healthcare workers more.”

“Better transport and more disability friendly accommodation and access”

“More respite for my parents”

## Budget asks vs Budget 2023 measures

Budget 2023 asks	Budget 2023 measures and HSE service plan 2023
<p>Additional funding of €410 million needed for housing for disabled people (capital and revenue)</p> <p>€64 million to provide additional hours for personal assistance and home support</p>	<p>Additional funding of 29.25 million for Disability Services (not only specifically residential supports)</p> <p>45 additional placements funded to meet the needs. (HSE service plan)</p> <p>€67 million will fund some 12,300 grants to adapt the homes of older people and people with a disability. A further €25 million will support adaptations work to 1,800 existing social homes. The HSE service plan announced over 70,000 additional hours of personal assistant support to people with disabilities at a cost of €1.9 million.</p> <p>Maintain funding for national personalised budgets demonstrator project to 180 participants.</p>

The Disability Capacity Review, published in 2021, called for investments to be made to address the housing support needs of disabled people. However the Housing Implementation Plan has only recently been published. Based on the report and expenditure needed, Inclusion Ireland called the government to allocate €410 million in Budget 2023 to address the needs of people with intellectual disabilities.

Only a part of the additional funding of 29.25 million for Disability Services has been allocated to improve the capacity of residential care and homes for people with intellectual disabilities. Due to the lack of clarity and breakdown of Budget measures related to this, it is not possible highlight a specific number. This year's HSE service plan with 43 additional residential places funded falls far short of the requirements for homes and housing for people with intellectual disabilities. The aim of the service plan to provide an additional 43 residential placements in "response to the current needs" is a blatant underestimation of the actual current needs. At this rate, it would take nearly 90 years to move out the 3500 people from congregated settings and nursing homes not to mention the countless others living with their families and sometimes older family carers.

Finally, the announcement of an additional 70,000 hours /1.9 million euros of Personal Assistance hours falls far short of requirement. In comparison, we can note that the Disability Capacity Review highlighted that an additional 10 million euro should be spent every year for personal assistance and home support to address the additional cost due to demographic changes. This goes without mentioning the current unmet needs that were unknown by the report but deemed “substantial”.

## **Recommendations**

Set out a plan that is fully costed and funded to support the remaining residents from congregated settings and inappropriately placed in nursing homes into community settings over a five-year period. This plan would entail:

- A number of places for services available
  - 450 residential places for people coming from congregated settings
  - 300 places for people moving out from nursing homes
  - 90 new supported living packages to match demographic changes
  - 20% increase from current levels of provision of personal assistance hours and home support
- An increase in the number of personalised budget arrangements allocated so that people can continue to live in their own homes and/or with family members leading self-directed lives outside of “traditional/residential” arrangements.
- Ensure the training of all staff working with disabled people in services around the UNCRPD and a rights based, inclusive and community first approach.
- Fund organisations which have a track record of delivery on community and rights-based approaches.
- Capacity building/training and support must be made available to individuals who require it to support their independent living. This should include managing a home budget, home maintenance, community inclusion, using transport, etc. Funds should be made available to provide this practical support.
- Review the criteria to grant access to personal assistance hours. Personal assistance should be based on needs, not diagnosis.

# Access to Services - A Full Analysis

Article 25 of the UNCRPD highlights the obligation of Ireland to the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Additionally, article 26 states that Ireland should support people with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

## Context

For children:

The Children's Ombudsman has recently called on the Government to spend surplus budget income on services for "vulnerable children", including those in care and with disabilities.<sup>5</sup>

As of March 2023, 10,696 children have been waiting for over 12 months for initial contact with a Children's Disability Network Team (CDNT), an increase of 836 since December, and 17,157 were waiting in total.<sup>6</sup>

A survey led by Inclusion Ireland in 2022 on progressing Disability Services received more than 1000 responses from family members. It highlighted that:

- Over 50% of the families of children surveyed are not in receipt of any service.
- 85% reported that they have waited or continue to wait for more than a year. Of these families, 27% were waiting 2-4 years, 16% were waiting, 4-6 years and 5% for 6 years or more.
- 48% of families cited difficulties with communication from the services as one of their top 3 issues with the service.
- 19% of families mentioned concerns about quality of service.

For adults:

The Disability Capacity review published in 2021 highlighted the gaps in terms of access to a range of different services. According to the report there are 600 people in congregated settings with no access to a day service or supports outside the home and 3,000 people who get a partial day service.



While the Disability Capacity Review was necessary to outline the blatant lack of existing disability services and support, it should not lead to massively fund an outdated model of service provision that is not fully respectful of people's rights. Otherwise for more money, we are in danger of getting more of the same; people with disabilities with little choice and control over their lives. We need to stop funding exclusion and look towards funding truly inclusive, person led models of support.

Some of the funding allocated to services must be redirected to people themselves to ensure they have full control over the support they receive. Funding should support the innovation and development of more user-led budget like personalised budgets, community led housing.

### What people told us in the survey:

- In our 2024 pre-budget survey, there were 252 responses by family members/parents. Of those surveyed, the top concern at 42% was access to services.
- Family members of children with intellectual disabilities commented on the wait time for services, the lack of joined up thinking between health and education, the need for better management of Children's Disability Network Teams and expressed strong support for in-school therapies.
- More than half of the people with intellectual disabilities surveyed reported long delays in seeing a dentist, a hospital consultant and accessing mental health services.
- In terms of the quality of service, the following three accommodations were identified as being equally important:
  - Meeting the same staff every time
  - Having more time for appointments
  - Having accessible information to help people understand what is happening



## Quotes on Access to Services:

"As a carer for my son, the services are non-existing... he needs SLT, OT etc... but nothing... always waiting lists for everything and us parents having to fight all the time .. the government needs to step up to help as a matter of urgency... Staffing is a huge problem, something must be done, sooner rather than later as our kids are suffering"

"My children are both linked with services, one of them received one hour of intervention in the past three years, the other not even that. They told us it's because of staff shortage. Increase the capacity in services."

"Put therapists in the school classroom. Collaboration is the name of the game- not the false collaboration that currently exists- get therapist into the key learning environments."

"More money needs to be spent on the cost of travel for people with disabilities in rural areas"

"Government should make transport easier for people. Make Easy to read information about transports in booklets."

## Budget asks vs Budget 2023 measures

Budget 2023 asks	Budget 2023 measures
<p>Implement the recommendations of the Disability Capacity Review:</p> <ul style="list-style-type: none"> <li>• Increase of €54 million on therapy services for children and adults</li> <li>• Increase of €30 million in individualised supports for people personal assistance and home support.</li> <li>• Increase of €30 million euro in the current spending on "day services".</li> </ul> <p>A comprehensive strategy is needed to address the workforce planning issues and up to 1/3 of post vacancy on therapy teams</p>	<p>€29.25 million for Disability Services (including residential) has been allocated to improve the capacity of day services, Progressing Disability Services</p> <p>HSE service plan 2023: commitment to spend additional €25 million including</p> <ul style="list-style-type: none"> <li>• 1,250 new day service placements for school leavers and graduates of rehabilitative training</li> <li>• 11.7 million to address backlogs in Disability services in relation to Assessments of Need</li> </ul>

As mentioned above, only a part of the additional funding of €29.25 million for Disability Services has been allocated to improve the capacity of day services, Progressing Disability Services. Due to the lack of clarity and breakdown of Budget 2023 measures related to this, it is not possible to highlight a specific number.

Continued implementation of the Access and Inclusion Model (AIM) is needed to ensure that more than 5,000 children with a disability can access and meaningfully participate in the ECCE Programme;<sup>8</sup>

The 2023 Waiting List Action Plan has an overall budget of 443 million to address the challenges of waiting. The only clear information we had on this was the 11.7 million to address backlogs in Disability services in relation to Assessments of Need.<sup>9</sup>

The Health Service Executive (HSE) further describes the measures included in the increase from Budget 2023: “We will spend an additional €25.0m on disability services including over 70,000 additional hours of personal assistant support to people with disabilities and 1,250 new day services placements for school leavers and graduates of rehabilitative training in line with New Directions policy.”<sup>10</sup> These measures fall short compared to the disability capacity review and organisations’ estimate of what the investments that would be required

## **Recommendations**

- A comprehensive strategy is needed to address the workforce planning issues and up to 1/3 of posts vacancy on therapy teams. This must include retention as well as recruitment issues as an urgent priority.
- Increase the funding available for personalised budgets to increase the current national demonstrator project
- Provide full time individualised services to people who only have access to “day services” on a part-time basis. Make sure that any additional funding towards “day services” is for more creative, individualised supports in line with New Directions Policy.

# Cost of Disability - A Full Analysis

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”.

## Context

### Survey on Income and Living Conditions (SILC)

The recent Survey on Income and Living Conditions (2022) highlighted a deterioration of living conditions in Ireland. In this survey 13.1% of people were at risk of poverty in 2022, compared with 11.6% in 2021 and 5.3% of people were found to be living in consistent poverty, up from 4.0% in 2021.

The survey more specifically focused on people unable to work due to long standing health problems, including disabled people. The survey underlined that one in five people in this group are living in consistent poverty (compared to 5.3% in the general population) which constitutes the highest rate amongst all the disadvantaged groups. Moreover, one in three persons (35.2%) are at risk of poverty (compared to 13.1% in the general population). Finally, this group has one of the lowest rates of disposable income(€18,144).

## Income

The current rate for the Disability Allowance is €220. This amount, while increased in successive budgets, is still substantially lower than the poverty threshold which was €291.50 per week in 2021.

The Covid pandemic has highlighted the important role Ireland’s social protection system can play in protecting people from poverty, through the Pandemic Unemployment Payment (PUP). However, the considerable gap between the €350 of the PUP set in 2020, before the current inflation, and the current rate of €220 for the disability allowance sends a clear signal that disabled people are not seen as equals to other Irish citizens.

The comprehensive, government commissioned “Cost of Having a Disability in Ireland” report was published in 2021 and it estimated that the total annual additional cost of disability for people with intellectual disabilities is €13,107.12 Care and assistance was one of the highest average costs (€541) that people with an intellectual disability could not afford, together with adequate housing (€505) and transport (€384). Other areas like mobility (€193), communications (€185) and medicines (€107) were also highlighted.<sup>13</sup>

72% of the respondents with intellectual disabilities in the cost of disability report stated that they would earn more if they did not have a disability. They reported that without their disability, they could earn from 21,523 to 25,203 (depending on the level of support needs they have).

The top 3 cost of living challenges identified by people with an intellectual disability were:

- Electricity and gas bills
- Rent
- a Social Life

For supporters of adults with intellectual disabilities, the 3 main financial burdens due to their role of carers were:

- accessing therapists (79%),
- reduction or interruption of work (62%)
- and energy costs (36%)
- It was closely followed by transport (33%), equipment and aids (33%) and dietary requirements (32%).

When those who support adult with intellectual disabilities were asked if they have struggled in the last year to pay bills:

- almost 70% said they had, with over 20% of those stating that this was always the case.
- 56% of supporters said that this was a cause of stress and poor health in their household.
- 40% of our respondents report that they rarely or never have access to mental health services. It is difficult to see how people will benefit from the recently implemented Mental Health Services for People with Intellectual Disability Model (MHID) which promised that a tiered model of integrated support would be prioritised.

## Quotes from the survey:

"If the basic cost of living was decided at €350 for Covid Payments why is the disabled person's cost of living worth so much less."

"I think they should give disability people more money for living - Double disability allowance! It needs to be more than the €350 minimum that was the pandemic payment because being disabled is more expensive."

"Provide a living wage/benefit & services so I can learn to live independently"

## Budget asks vs Budget 2023 measures

Budget 2023 asks	Budget 2023 measure
<p>Establish a cost of disability payment of €50 per week for every disabled person as well as increase the disability allowance by €20 per week for those who receive it.</p> <p>Invest 10 million euro in a special fund to support grants to cover expenses of people with higher support needs.</p>	<ul style="list-style-type: none"> <li>• Autumn cost of living double payment (extra 220 euros in October)</li> <li>• €500 one payment in November</li> <li>• Christmas bonus (extra 220 euros in December)</li> <li>• €200 cost of living payment</li> <li>• €12 increase of the Disability Allowance</li> </ul>

A set of measure was voted to alleviate the cost-of-living crisis faced by many in Ireland. This included two double weekly payments, a 500 euros off payment, a 12e increase per week of the disability allowance.

While these measures were welcomed, especially the increase of the disability allowance that nearly matched our recommendations, they only addressed partially in a short term/reactive manner the economic struggle faced by many people with an intellectual disability and the systemic barriers forcing people to remain living in poverty. Moreover, a once-off payment seems to be more rooted in the charity approach of disability while the permanency of a payment would send the signal that compensation for the extra cost of disability is a right and should not depend on the budget available from one year to another. The extra costs for equipment, medical bills, services and therapies remain the same or even rise year upon year.



### **Reaction of a self-advocate after Budget 2023 announcement:**

"I know we will get 12 more euro each week with a 500 euros one off payment and a double week in November and at Christmas. I still can't work more hours to make more money. If I do I will lose some of my allowance. I need a cost of disability payment because of the cost of living crisis. My disability will never disappear."

One-off payments will not solve the consistent poverty faced by disabled people. Inclusion Ireland together with other organisations have long been advocating for the permanent cost of disability payment. As the cost of disability report expressed in the conclusions:

"The levels of disability payments and allowances should be changed to reflect the very different costs of disability by severity and type of disability."

### **Recommendations**

- Increase the rate of the disability allowance to match it with the poverty threshold (291.50e).
- Create a permanent cost of disability payment to ensure that the extra cost is recognised on the long-term, not through once-off payment.
- Establish a special fund for equipment, technology and other essential assistive aids and appliances for people with higher support needs and their families who face the highest cost of disability.

# Education - A Full Analysis

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.

## Context

20 years after it was initially passed, the Education for Persons with Special Educational Needs Act (EPSEN Act) has yet to be fully commenced. In the current public consultation Inclusion Ireland highlighted the immediate need to commence those parts of the Act that would entitle children to have:

- An educational assessment of their needs
- The development of an Individual Education Plan (IEP) based upon this assessment.
- The delivery of the education supports detailed in the plan.
- An independent appeal process.

Inclusion Ireland also highlighted the need to review parts of the Act that are contrary to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This is especially true for section 2 of the Act that currently allows for exceptions to inclusive education “if not in the best interests” of both the child with special educational needs and in the best interest of other children with whom the child is to be educated.

In 2022, the Children’s Ombudsman received over 1800 complaints, a third of these being about school or education issues. Bullying and special education provisions were the most common ones received. The Ombudsman particularly highlighted the difficulty to track how the money is spent due to the lack of clarity around Budget follow up. He declared that “it is not possible to accurately say how much the State spends on children due to inadequate data gathering”. Moreover, he criticised the way money was spent stating that “Last September the Government announced a phenomenal €11bn budget expansion for 2023, but so far this has not been directed towards the key supports and infrastructure needed by children”<sup>18</sup>

## What people told us in the survey

For parents and family members surveyed, Education was the second highest concern at 29%. Here are some trends we were able to identify from their responses:

- Although 91% of respondents replied that they have a school place for their child, only 72% reported that it was a school place with suitable supports for their child.
- Of the 252 respondents there were 68 comments left in this section. Parents detail the exhaustion they experience in advocating for their child to remain in school.
- Staffing in the schools is stretched.
- Without supports, children do not have access to education.
- Parents detail the travel that their child has to undertake, the lack of communication with the school, a persistent attitude by school management that their child be moved to another school.
- 27% of the respondents indicated that their children have been attending/were attending school on a reduced timetable or for a shorter school day.
- 56% of the respondents said that their child is not going to the same school as other children of a similar age in their neighbourhood/community.
- For those, nearly 60% have to travel for more than 30 minutes, including 17% who have to travel more than 1 hour against 11% (more than 30 minutes) and including 1% for those going to a school in their area.
- 10% of the respondents shared that their child has been secluded or confined in their school.
- Another 10% were restrained or immobilised, implying the use of physical force, mechanical device or medication at school.

Only half of the people with intellectual disabilities who responded, reported getting help from staff in school about their career progression. Less than 10% got a job after leaving school, 30% went to college and 40% went to a day service.



## Quotes from the survey:

"We have no access to services, no education plan for teens with a mild intellectual disability, no future pathway upon turning 18. Nearby, in other regions, in other disability service, children have this support. This is discrimination."

"Plan. Plan that local schools can provide for children. All children ought to attend their local school."

"Require more than two weeks of token education in a special school or in a unit for training teachers."

"Have equality in the same school like a hand full of disabled people in the same room with other people in schools"

## Budget asks vs Budget 2023 measures

Budget 2023 asks	Budget 2023 measures
<p>15 million for a fully costed plan for the provision of therapeutic supports within schools</p> <p>Provision of comprehensive, rights-based training for teachers and SNAs</p> <p>Outcomes of the review of the EPSEN Act and a detailed report on actions regarding the legislative elements of inclusive education.</p>	<ul style="list-style-type: none"> <li>• An additional 660 mainstream teachers, including a reduction in primary staffing schedule one point from 24:1 to 23:1.</li> <li>• 12 million for an additional 1,194 Special Needs Assistants (SNAs)</li> <li>• 12 million for an additional 686 teachers for special education working in special classes and special schools</li> <li>• 6 million for additional teachers to reduce the primary staffing schedule</li> </ul>

## Recommendations

Ensure that the amended EPSEN Act is supported by a multi annual and fully costed plan to move towards a fully inclusive model of education over the next 10 years. This would entail:

- Reduction of class sizes to under 20 pupils by reducing teacher/pupil ratio
- Availability of therapeutic supports within school environments. This is almost non-existent at present. The National Council for Special Education (NCSE) is given annual funding for 39 therapy posts each year as part of the School Inclusion Model (SIM). We call for this funding, at a minimum, to become regularised in budget 2024 and for a pathway to be created towards the wider roll out. Children with higher support needs (no matter where they go to school) should be able to access therapies.
- Provision of comprehensive, rights-based training for teachers and Special Needs Assistants (SNAs) this should include universal design for learning, rights based approaches for supporting children in crisis and how to make sure the school environment is accessible for all children.
- Funding to train educators and school staff against the use of seclusion. Restraint should never be used as an intervention with a child as it breaches their fundamental rights.
- Provision of career guidance to disabled children across all settings.
- Additional SNAs in mainstream schools.

# Employment and Training - A Full Analysis

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.

## Context

People with disabilities experience multiple barriers to accessing employment, including financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity. Ireland has the one of the lowest rates of employment for disabled people (32.6%) and it gets even lower for people with intellectual disabilities (17%). At the European level according to Eurostat, Ireland has the lowest rate of employment for disabled people. In comparison, the employment rate for those aged 15-64 was 72.8% in Q1 2022.

In the cost of disability report mentioned above, the lowest figures for average annual income from employment are reported by respondents with intellectual disabilities (€12,553). One of the main recommendations of this report is to increase employment opportunities for disabled people in order to tackle the poverty they face.

The low income is closely linked with the impossibility for disabled workers to work more than a certain amount hours without seeing part or the entirety of their disability allowance and associated benefits (medical cards, travel card) taken away. While the income disregard has been increased over the past couple of years, this limit constitutes a barrier for people to take on jobs and earn a decent and meaningful income out of it.

### What people told us in the survey:

- Only half of the respondents with intellectual disabilities reported that they got help from the staff at school (formal or informal career guidance) to choose what they wanted to do after school while another half did not have access to this support.
- 40% of people with intellectual disabilities surveyed said that they had a job. Nearly 70% of these said that they would like support for more on the job learning, and a third of them indicated that they would need more support with transport.
- Nearly half of those who don't have a job said that on the job learning and support would be the most important thing to help them while a third indicated that support with interviews and better transport would be important for them in getting and keeping a job.



### **Quotes from the survey:**

"Being kept on work experience for a long time with no offer of paid contract or full-time work"

"I want to be able to get a job and work part time and get help in it"

"Get me a job!"

"Get the support if you don't have a job and make sure you are paid in your job"

"Sometimes when you say you have a disability there is no further engagement"

"If employed you need the right support to do the job well"

"If I get a pay rise I lose a lot of important benefits, travel and medical expenses can cost a lot"

"My medical needs turn employers off because of insurance concerns"

"I need someone to guide me at work"

"Limited access to employment options for individuals I support. Public bodies have not met their 6% employment targets. No onboarding solutions in government bodies of individuals I support to access meaningful employment."



## Budget asks vs Budget 2023 measures

Budget 2023 asks	Budget 2023 measures
Invest in job coaches to support employment of people with an intellectual disability.	
Open wage subsidy scheme to people working less than 20 hours.	
Invest further in established and successful Ability programs to enable more employment opportunities for people.	Increase the earnings disregards on both Disability Allowance and Blind Pension by €25, from €140 to €165 per week.
Lead an awareness raising campaign for people with intellectual disability and employers on the Reasonable Accommodation Fund (RAF).	€1 million expansion of the Reasonable Accommodation Fund to support people with disabilities in the workplace.
Recruit more Support Officers to oversee the use of RAF and train them around supporting disabled people appropriately.	

## Recommendations

- Set real and meaningful targets for people with intellectual disabilities in particular, given the low levels of employment.
- Invest in career guidance at school and transition towards post-school options.
- Invest in job coaches to support employment of people with an intellectual disability by expanding the ability programs and other employment projects for disabled people
- Open wage subsidy scheme to people working less than 20 hours.
- Job coaches and on-site training for people with intellectual disabilities should be included in reasonable accommodations funds.
- Increase the income disregard for disabled workers.
- A dedicated, centrally based national resource of peer advice and information for employers on the employment of persons with disabilities should be established.

# Supported Decision Making and Advocacy - A Full Analysis

## Context

### Reform of assisted decision making

8 years after the adoption of the first version of the text in 2015, the Assisted-Decision Making Act (ADMA) finally commenced on the 26th of April 2023. The new Decision Support Service (DSS) also became operational at the same time. This service will need to meet the needs of 220,000 Irish people who currently have difficulties with decision-making. It will need to be adequately resourced following the initial implementation date both to raise awareness of the general population about its existence and the support it provides as well as to effectively respond to all incoming requests.

### Advocacy for children and young people

Opportunities for children with intellectual disabilities to participate in matters that affect them and have their voices heard are too limited. There are very limited services in existence to advocate for and with them. While advocacy exists for certain groups of children (e.g children in care) there is no representative advocacy for children with intellectual disabilities. Therefore, funding should be allocated to an independent advocacy service for children. Inclusion Ireland are embarking on a research project in 2023 to scope this out further.

## What people told us in the survey

Nearly half of the people with intellectual disabilities surveyed said that they had never heard of the Decision Support Service and a further 26% said that they weren't sure what it was. 25% said that they know a lot about it.

The vast majority of respondents (93%) who are supporting an adult with an intellectual disability mentioned that they advocate for the adult they support. 71% of the respondents in this category stated that they have heard about the Assisted Decision-Making commencement on the 26th of April. However, this falls at 52% when you ask them if they know what the Decision Support Service is. Another 26% said that they heard about it but they do not know what it does. It can be noted that 81% of the respondents highlighted that the person they support need constant help with making important choices. Finally, nearly half of people answering the survey in this group shared that they had concerns or questions about the reform on Assisted Decision Making.

### Quotes from the survey:

"I was told that my daughter is an adult and that I am not included in decision making"

"Government should make transport easier for people. Make easy to read information about transports in booklets."

"No one takes the individual choices and wishes seriously"

"Some organisations won't recognise me as an advocate"

"No one in charge will take responsibility"

"Knowing who to approach to advocate."

### Recommendations

- Ensure that the DSS is adequately funded to support all people who experience difficulties with their decision-making.
- Make sure the DSS is funded to provide accessible information to people with intellectual disabilities.
- The State should commission an independent advocacy service for children.

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- 3 National Housing Disability Strategy 2022-2027, available at <https://www.gov.ie/en/publication/60d76-national-housing-strategy-for-disabled-people-2022-2027/>
- 4 Health Services Executive national service plan 2023, 29 March 2023, p 53, available at <https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2023.pdf>
- 5 Irish Examiner, 16th of May 2023, article can be accessed at [https://www.irishexaminer.com/news/arid-41139820.html?mc\\_cid=48a43952d6&mc\\_eid=c6f2105711](https://www.irishexaminer.com/news/arid-41139820.html?mc_cid=48a43952d6&mc_eid=c6f2105711)
- 6 Tipp Mid West Radio, 24th May 2023, available at <https://www.tippmidwestradio.com/2023/05/24/darmody-family-lauded-for-campaign-work-for-improving-disability-services/>
- 7 This is higher than the amount recommended in the Disability Capacity Review. Inclusion Ireland and other organisations believe that the Review underestimates the level of unmet need for PA as “data on unmet need has not been systematically recorded” (p. 74)
- 8 Budget 2023 expenditure report, 27 September 2022, p72, available at <https://www.gov.ie/en/publication/eb6ec-budget-2023-expenditure-reports/>
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- 13 The Cost of disability in Ireland, 7 December 2021, p87, available at <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>
- 14 The Cost of disability in Ireland, 7 December 2021, p40, available at <https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/>
- 15 Sharing the Vision Implementation Plan 2022-2024, Health Service Executive and Department of Health, 2022. Available at <https://www.gov.ie/pdf/?file=https://assets.gov.ie/219435/7a8c78e1-98ad-4542-9a61-a13195a727d6.pdf#page=null>
- 16 Other measures have been taken in Budget 2023 but these ones are the most relevant to highlight in terms of cost of living measures and direct extra payment received by people with disabilities and others.
- 17 Letter from Secretary General of the DES to the Joint Oireachtas Committee on Education, Further Higher Education, Research, Innovation and Science, November 2020.
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- 19 Other measures have been taken but these ones are the most relevant in terms of cost of living measures and direct extra payment received by people with disabilities and others.
- 20 Census 2016 Reports, Central Statistics Office, available at <https://www.cso.ie/en/census/census2016reports/>
- 21 European Disability Forum report 2023, p31 can be accessed here [https://www.edf-feph.org/content/uploads/2023/05/hr7\\_2023\\_press-accessible.pdf](https://www.edf-feph.org/content/uploads/2023/05/hr7_2023_press-accessible.pdf)
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- 23 The list of measures in the table is not exhaustive and does not necessarily reflect the entirety of budget 2023 measures
- 24 Number raised by the Decision Support Service. Available at <https://decisionsupportservice.ie/news-events/landmark-new-decision-support-service-officially-open-its-doors-public>