



EQUAL CITIZENS

People with intellectual disabilities and autism are equal citizens.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) confirms the equal citizenship of people with disabilities, and places explicit responsibilities on the Irish State to uphold their rights.

Article 19 places a responsibility on the State to ensure:

“that: [...] persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion...”

EQUAL OPPORTUNITIES

The opportunities people with intellectual disabilities and their families need to access are clear:

- for children to be supported to reach their full potential;
- for adults to live at home in the community with appropriate supports (and not in congregated settings or with their parents unless mutually chosen);
- to have pathways and support to find work, education and opportunities to contribute to society;
- to have the necessary and appropriate supports for the changing needs of older adults.



EQUITY of RESOURCES

To meet its obligations to uphold the rights of people with disabilities to participate in life's opportunities as full citizens; the State urgently needs to commit to providing access to the required supports, through a significant resourcing programme in Budget 2024.

Budget 2023 **did not address the urgent and critical needs** of people with Intellectual disabilities:

- The Capacity Review of Disability Services highlighted an **unmet need** for residential support of up to **2,300 places**.
- The implementation plan for this report is more than a year overdue.
- Last year we reported over **1500 individuals living with a parent over the age of 70**; more than **450 over 80 years**.
- A consistent requirement of the HSE in recent years has been the out-turn of 90 residential places just to respond to emergency need. An immediate **emergency need for 315 places** was identified by HSE in December 2022.
- However, in spite of this evidence and with increasing distress being experienced by individuals and their families, **only 43 emergency residential places** were provided in Budget 2023.



EQUAL ACCESS

People with intellectual disabilities and their families are struggling to access essential services:

- Children with intellectual disabilities and autism need timely access to early intervention to reach their full potential. Young adults need access to transition planning and career guidance to support them to plan their lives after leaving school. Families are facing significant challenges to access these supports.
- A spectrum of residential support options is needed – from those who need a small amount of support to maintain independence; to those whose needs require full-time residential supports. There is currently no application process and no system-wide funding or pathway to housing supports, other than through emergency provision.
- This creates an additional acute need for respite services to support individuals and families. Some existing respite supports are unavailable as they are currently needed full-time by people awaiting emergency residential support.
- There are key challenges in accessing supported employment and transport.
- Responding to the changing needs of older adults with intellectual disabilities is critically challenging the sustainability of services, whom are not currently funded by the State to meet these needs.

People with intellectual disabilities have told us that they '**feel forgotten**'; families feel '**abandoned, unheard and lost**'

WHAT is NEEDED to UPHOLD FUNDAMENTAL RIGHTS?

We are calling on Government to make a serious commitment to people with intellectual disabilities and their families in Budget 2024:

- Providing 200 additional multi-disciplinary therapy staff.
- Publishing, resourcing and implementing the overdue *Disability Capacity Review Action Plan*.
- Investing in a significant programme of residential support, beginning in 2024. A minimum of 315 places is immediately required to meet emergency need. Increasing respite supports is needed to meet urgent requirements
- Providing additional funding to support the changing needs of older adults with intellectual disabilities.



SUSTAINABILITY of SERVICES

The State provides 70% of disability services via the voluntary sector. However, the sustainability of services is facing unprecedented threat due to challenges around recruitment and retention; inflationary pressures and resourcing of regulatory requirements. These challenges are having an impact on the quality of life of people supported.

We are calling on Government to **safeguard the sustainable future of disability services** in Budget 2024:

- Appropriately fund the true cost of service provision - provide S38 and S39 providers with the required funding to meet nationally agreed pay awards and inflationary pressures. Inflationary pressures funding provided in 2022 was very welcome and continues to be needed.
- Address the unsustainable pay gap in Section 39 organisations as a matter of urgency – the current disparity is causing an immediate threat to the viability of key essential services.
- Support the cost of compliance with multi-agency regulation.
- Assess and appropriately fund historic day service funding deficits; supported employment; and transport.

With the publication of the *Time to Move on From Congregated Settings* report in 2011, the Irish State **correctly rejected congregated, institutional settings** in favour of **supporting people with intellectual disabilities** to access their rights as **equal citizens** to live an included **life in the community**.

However, whilst moving forward with dismantling the unsuitable congregated model of residential support, **the State has not resourced new, planned residential supports** in the community. This has left people with intellectual disabilities and their families without any route to plan their future.

Instead, the responsibility for support has been left with elderly family carers. People with intellectual disabilities are left with no choice or control in planning where and with whom they will live.

Currently, this only changes for most people when their situation becomes an emergency - when their family carer dies, or their distress becomes so acute that there is a risk to their physical safety or that of their loved ones.

This is **traumatic, expensive** and provides the **worst outcomes** for the **person and the State**.

Last year we highlighted the fact that **over 1500 people with intellectual disabilities** were **living with family carers over the age of 70**, more than **450 of whom** were over **80 years old**. Many more people with intellectual disabilities and autism have a need for residential support and no pathway to access this. **However, Budget 2023 provided just 43 places to address emergency needs, in spite of the many hundreds needing planned access to residential support.**

