

National Federation of Voluntary Service Providers

Over two thirds of disability services in Ireland are provided on behalf of the State by the voluntary sector. The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is the national umbrella organisation of not-for-profit agencies providing direct supports and services to people with intellectual disability and autism in Ireland. Across 53 organisations, our members support more than 26,000 children and adults and their families, providing services and supports throughout the lifespan.

We advocate for the full implementation of the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** and work with all key stakeholders to collaboratively identify and progress the actions needed for these rights to become reality for people with disabilities across Ireland.

Priorities in your Manifesto and the Programme for Government

As we look ahead to a new Government, it is essential to prioritise implementing the positive framework of disability policy and legislation already in place in Ireland. Implementation requires long-term, planning and a coordinated whole-of-government approach and commitment to equality for people with disabilities from the outset.

People with disabilities and autism in Ireland need you to actively progress inclusion of these key priorities in your Manifesto and the Programme for Government.

- 1) A **whole-of-government approach** to the implementation of the UNCRPD across all departments, including the continuation of the **Cabinet Committee** on Children, Education and Disability to oversee integration.
- 2) Address the urgent and pressing **unmet needs** of people with intellectual disabilities and autism as set out in this paper and in the Disability Capacity Review.
- 3) Address the **crisis in sustainability of disability services** to ensure there is capacity to provide the required supports.
- 4) Ensure the **full implementation of existing plans and policies**, including the Action Plan for Disability Services 2024-2026, National Housing Strategy for Disabled People 2022-2027 and the Time to Move on from Congregated Settings Report 2011:
 - a. Introduce a fully resourced, planned and co-ordinated approach to providing housing and supports to live in the community
 - b. Support access to employment and education (including an urgent uplift to the Wage Subsidy Scheme)
 - c. Prioritise access to early intervention and staffing of children's disability teams
 - d. Review transition planning for school leavers, the banding and profiling mechanisms of costing; and transport provisions for Day Service supports.
 - e. Increase the availability of respite and short-break services.
- 5) To support the implementation of existing plans and policies, commit **to multi-annual funding** for Disability Services.
- 6) Invest in **innovation** and **assistive technology**.
- 7) Ensure access to **mainstream healthcare** for people with intellectual disabilities and autism.
- 8) Prioritise the funding of **nationally agreed pay awards** and **pay parity** for all staff.
- 9) Progress the positive work undertaken to consult on the **New National Disability Strategy**– progress to finalise, publish and implement this Strategy.
- 10) Progress cohesive, collaborative, and urgent planning at national level to address the **recruitment and retention crisis in disability services**.

Critical challenges in supporting people with intellectual disabilities and autism

Level of unmet need

Housing, Housing Supports and Respite (short break) services

Article 19 of the UNCRPD sets out State obligations to *uphold the equal right of all persons with disabilities to live in the community, with choices equal to others, and to take measures to facilitate this right and the full inclusion and participation in the community*; including having the opportunity to choose where to live and with whom; providing a range of in-home, residential and community supports to enable living and inclusion in the community, to prevent isolation and segregation, and ensuring access to responsive mainstream services for people with disabilities. The Time to Move on from Congregated Settings Report (2011) rightly set out an alternative vision to congregated living. However, successive budgets have provided very limited funding for emergency residential placements and no funding for planned residential placements or other housing options - creating a distressing crisis for people with disabilities, ageing carers and disability service providers.



Current level of unmet need for housing, housing supports and respite:

- The Capacity Review of Disability Services highlighted an unmet need for residential support of up to 2,300 places¹. The National Ability Supports System (NASS) data identifies 1,434 people in immediate need²
- Over 2,000 people are living in congregated settings³
- 1,242 people under 65 are living in nursing homes⁴
- 1,965 people live with primary carers over the age of 70 (471 of these are over the age of 80)
- 1,212 people require overnight respite (short break) services
- The number of places which need an enhancement in the next 12 months (e.g additional hours/days or additional support):⁵
 - 1,604 (21%) of residential places
 - 862 (13%) of assisted living services
 - 197 (16%) of day respite places
 - 1,125 (27%) of overnight respite places

Impact of lack of planned housing, housing supports and respite

- Ireland is not meeting its obligations under article 19 of the UNCRPD. People with intellectual disabilities and autism currently have no means of realising their rights to housing and supports other than through an emergency.
- Due to the lack of planned residential places many adults with intellectual disabilities and autism are living with and receiving support from elderly family carers. The Health Research Board found in 2023 that 1,494 of primary carers of people engaging with disability services were aged between 70-79 years and 471 were aged over 80 years and over. Currently, this only changes for most people when their situation becomes an emergency often as a result of the primary carer passing away.

¹ gov.ie - Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032 (www.gov.ie)

² HRB Bulletin, National Ability Supports System (NASS), Overview of people engaging with disability services, 2023

³ Action Plan for Disability Services 2024-2026

⁴ HSE Response to PQ: 28493/24

⁵ HRB Bulletin, National Ability Supports System (NASS), Overview of people engaging with disability, 2023

Crisis residential placements often occur after the loss of elderly family carer or home breakdown and becomes further traumatising as these placements can be far away from an individuals' community, therefore incurring for individuals a loss of their primary carer, their home, their usual service and supports and community of origin all at one time. This is a very traumatic and expensive way of delivering residential services, resulting in poor outcomes for the person and the State.

- Urgent need for residential services is putting pressure on respite services. In 2023, 26 people received 260 or more nights each of overnight respite. Of those, 13 received 365 nights of overnight respite.⁶ This reflects situations reported by our members where respite beds are being used as a substitute for residential placements during emergencies. As a result, availability of breaks reduces, wait times for respite increase, leaving some individuals and families with disabilities with no access to respite or short breaks at all.
- The lack of cross-departmental coordination and consistency of approach is limiting access to housing for people with disabilities. Our members report people with intellectual disabilities being offered suitable accommodation that they cannot accept as they are unable to access the necessary associated supports or having staff supports in place but no access to housing.
- There are critical barriers to the operation of the Capital Assistance Scheme (CAS), the main funding source for housing for people with disabilities. There is an urgent need for a review of CAS and for access to other funding streams such as Capital Advance Leasing Facility (CALF) to be made available for housing for people with disabilities.

Day Services

There have been significant developments in the provision of day service supports to adults with disabilities in Ireland since the publication of 'New Directions: The Report of the National Working Group for the review of HSE Funded Adult Day Services' in 2012. Disability day services have seen a sustained investment programme for school-leavers across the past decade; the development of Interim Standards in 2016; and the implementation of a wide range of initiatives to support people with disabilities in how they access day service supports across the country. However, there remain key challenges and barriers to the provision of services in line with the UNCRPD.

Current level of unmet need:

- 3,468-day service places require an enhancement (for example, additional hours/days or additional support)⁷
- Significant unmet need in terms of access to therapeutic supports including physiotherapy, occupational therapy and speech and language therapy

Impact of unmet need in day services

- In the austerity years of 2008, 2009, and 2010 the budgets of service providers were significantly reduced and in 2012, agencies were asked to accept individuals into day services with little or no funding provided. Therefore, historically there has been a severe shortage of funding in relation to specific cohorts of people who were brought into the services. Though funding has been brought in for school leavers entering day services since 2015, this legacy of insufficient funding still impacts the people using services and providers today.
- Investment is needed to address the ageing transport fleet in disability services, and clarity is urgently required on which Department holds the funding responsibility for transport to ensure safety and accessibility.
- The HSE New Directions policy for day services does not include providing direct employment supports for people using the service, however mainstream Intreo services are not resourced to provide specialised supports for people with ID and autism. This gap in support provision leaves many people without access to employment.

⁶ HRB Bulletin, National Ability Supports System (NASS), Overview of people engaging with disability services, 2023

⁷ HRB Bulletin, National Ability Supports System (NASS), Overview of people engaging with disability, 2023

- As the lifespan of people with intellectual disabilities has increased – which is a hugely positive trend, there is a rise in the number of older adults with intellectual disabilities who have significant support needs. People with intellectual disabilities statistically experience age-related conditions at a younger age than the general population. As a result, many individuals with intellectual disabilities experience changing needs that require adaptations and/or additional supports in their day and residential services.
- More generally (inclusive of day and residential supports) there is no standardised, fair and transparent pathway to access the additional supports required due to ageing. Services apply for additional funding but may not receive it and there is no mechanism to appeal. Services continue as long as they can manage to meet the additional supports needs of the person without the additional funding, however if they are unable to do so, this can result in an inappropriate admission to a nursing home due to a lack of alternatives.
- Day Service providers report a myriad of sustainability challenges including, staffing levels, banding levels for those entering services, rising inflation, non-pay costs, and increased cost associated with regulation.

Children's Services

Children's disability services provided through the Children's Disability Network Teams are facing substantial challenges, resulting in high levels of unmet need. Beyond difficulties in accessing assessments and corresponding interventions, there is also a shortage of appropriate school placements, planning for the transition to adulthood, and career guidance for children with intellectual disabilities and autism. These gaps in support come at a crucial stage in a young person's life, where timely interventions and comprehensive support are essential to fostering development and empowering them to reach their full potential.

Unmet need in children's services

- Over 16,500 children are awaiting their first appointment with a Children's Disability Network Team (CDNTs)⁸
- Immediate need for additional therapy posts for CDNTs and future workforce planning for CDNTs - Children's Disability Network Teams have a national average vacancy rate of 34%, i.e. 700 posts, with some teams experiencing over 60%.⁹
- 9,924 Assessment of Need (AON) overdue for completion as of end of Q1 2024,¹⁰ demand continues to grow every year with a 25% increase in 2023.¹¹
- Transition planning and supports are needed for young people transitioning to further and higher education, employment and/or adult services.
- Requirement for the development of a range of appropriate school placements
- Implementation of the National Access Policy required to integrate the provision of services across Primary Care, CAMHS and CDNTs is required.

Impact of unmet need in children's services¹²

- Children with intellectual disabilities and autism need timely access to early intervention to reach their full potential. Young people need access to transition planning and career guidance to support them to plan their lives after leaving school. However, students and their families are facing significant challenges accessing these supports.
- Our members are predicting challenges meeting the needs of the growing population of children presenting with autism. The draft Autism Innovation Strategy reports that nearly four in five autistic people (79%) are under the age of 18 years. This indicates the need for planning and delivery of children's services to be firmly rooted in practices that are inclusive and supportive of autistic children. However, current barriers and levels of unmet need are hampering their ability to plan and meet the needs of this cohort of people.

⁸ Roadmap for Service Improvement 2023-2026

⁹ Roadmap for Service Improvement 2023-2026

¹⁰ HSE Response to PQ: 28813/24 & PQ: 28837/24

¹¹ HSE Response to PQ: 28813/24 & PQ: 28837/24

Sustainability Crisis facing Service Providers

The developments set out in the Action Plan for Disability Services 2024-2026 are essential to meeting the significant current unmet need and progressing the rights enshrined in the UNCRPD. It is also essential that long-term planning for the future and innovation in how we provide services are prioritised. However, not-for-profit disability service providers (which provide 70% of disability services on behalf of the State) are currently facing a sustainability crisis, which is threatening their ability to respond to the required new developments and sustainably maintain existing services.

Factors affecting the ongoing sustainability of services are complex and include the concurrent challenges of:

- demographic growth in terms of people requiring disability supports;
- the increased supports associated with ageing and changing support needs;
- the increasing complexity of the support needs of young people presenting (including those who have not had adequate early intervention due to challenges in the CDNTs);
- the needs of people who entered day, respite and residential services several decades ago with inadequate funding to meet current regulatory and person-centred standards;
- the financial impact of regulation introduced without a coordinated financial impact assessment;
- increased support costs with the development of rights-based services;
- ongoing inflationary pressures and an increase in non-pay costs;
- the higher cost and poorer outcomes of meeting needs on emergency rather than planned basis, and
- the impact of recruitment and retention challenges in both Section 38 and 39 organisations.

Impact of Sustainability Crisis

- Some of our members are facing financial deficits; whilst others are facing non-compliance with regulation due to budget constraints; and many are facing both of these issues.
- Many organisations are facing untenable levels of risk.
- Consequently, organisations are finding it challenging to recruit and retain suitably qualified voluntary Board members.
- Ultimately, the worst consequences are experienced by people with disabilities and their families, particularly those who cannot access services, have increased or complex support needs.

70% of disability services in Ireland are provided on behalf of the State by the voluntary not-for-profit sector. Without addressing the sustainability crisis, service providers will not be able to maintain current supports or develop urgently required services.



Moving Forward: Future planning and policy implementation

Policy Framework

The past decade has seen the development of a highly positive framework of policy and legislation focused on disability in Ireland. These include:

- Progressing Disability Services for Children and Young People programme (2009-onwards);
- Time to Move on from Congregated Settings Report (2011);
- New Directions Personal Support Services for Adults with Disabilities (2012);
- Disability Capacity Review (2021);
- National Housing Strategy for Disabled People (2022-2027);
- Assisted Decision Making (Capacity) Act (2015 – commenced 2023);
- Roadmap for Service Improvement 2023 - 2026 Disability Services for Children and Young People;
- Autism Innovation Strategy (2024); and
- Disability Action Plan for Disability Services (2024-2026).

In 2024, Ireland also acceded to the Optional Protocol of the UNCRPD - which is a strong indication of the State's commitment to the rights of people with disability. The Department of Children, Equality, Disability, Integration and Youth are also leading out on the development of the new National Disability Strategy which should be launched during the term of the next Government.

A coordinated whole of government approach and a commitment to provide the leadership, collaborative working and sufficient investment is required to implement these progressive policies, laws, and frameworks.

This coordinated approach will be pivotal to reducing the overall levels of unmet need with many of the actions identified as necessary in the National Federation's priorities for the Programme for Government already contained in the pre-existing policy framework.

Political Framework

There are many roles, structures and groups at Government and Departmental level that are essential to monitoring Ireland's implementation of the aforementioned policies and to ensure the protection and realisation of rights for people with disabilities. In the Programme for Government, it is essential that the elements of cross-departmental working are maintained. These include:

- A dedicated Minister for Disability
- The Cabinet Committee on Disability
- The Joint Committee on Disability Matters

Resourcing the Framework of Policies and Legislation

To reduce the levels of unmet need and implement the positive framework of policy and legislation, the appropriate levels of funding and resourcing will be required. According to the Disability Action Plan 2024-2026, *"The planned improvements will call for additional current expenditure of over 25% over the current levels over the three years of the plan"*. Certainty is also needed in terms of funding into the future. Providing the disability sector with funding over a three period would provide the certainty required to deliver on nationally agreed policy priority areas including realisation of the rights contained in the UNCRPD, person-centred planning, innovation in service delivery, and greater use of assistive technology.

In addition to the funding required to meet specific policy objectives, addressing the sustainability crisis facing voluntary service providers is essential to safeguarding both current and future supports for people with disabilities and autism in Ireland. Currently, the voluntary sector provides 70% of services to people with disabilities and autism on behalf of the State. The independent Boards that govern our member organisations are responsible for delivering services in line with the State's policy direction and in accordance with extensive governance and regulatory requirements. Importantly, they also hold the independent responsibility for managing the financial affairs, viability and risk profile of their organisations. In this capacity, they are responsible for highlighting the financial fragility and serious strategic risk the State is taking if the sustainability crisis facing services is not addressed. Without precise and targeted actions from the next Government to address the issues raised by the Voluntary Sector, the delivery of existing services will be at significant risk and the capacity for the development of new services will not in place.

Conclusion

Ireland is well-positioned to tackle the significant levels of unmet need, address the sustainability crisis facing disability services, and advance the implementation of crucial policies aligned with its commitments under the UNCRPD.

Given the serious concerns highlighted in this submission, we urge you to share these messages widely within your networks, make them a focal point in the upcoming General Election, and prioritise them in the next Government's agenda.

Your commitment to tackling these urgent issues is vital to making substantial progress for people with disabilities across Ireland.

If you need any further information or have any questions, please contact info@fedvol.ie

National Federation Members

Across 53 organisations, our members support more than 26,000 children and adults with intellectual disabilities and autism and their families, providing services and supports throughout the lifespan.

- Ability West
- Ard Aoibhinn Centre
- Aurora
- Autism Initiatives Ireland
- Avista
- Beam Services
- Brothers of Charity Services Ireland – Clare Region
- Brothers of Charity Services Ireland – Limerick Region
- Brothers of Charity Services Ireland - South East Region
- Brothers of Charity Services Ireland - Southern Region
- Brothers of Charity Services Ireland - West Region
- Cairdeas Centre
- Camphill Communities of Ireland
- Carriglea Cairde Services
- Cheeverstown House
- Children’s Sunshine Home / Laura Lynn
- Clann Mór Ltd.
- CoAction West Cork
- Cope Foundation
- Cumas New Ross
- DARA
- Delta Centre
- Drumlin House
- Gatehouse Day Services Drogheda
- Gheel Autism Service
- Holy Angels Day Care Centre
- KARE
- Kerry Parents & Friends Association
- L’Arche Ireland Secretariat
- Moorehaven Centre
- Muiriosa Foundation
- Peacehaven
- Peamount
- Praxis Care
- Prosper Group
- Reach Ability
- RehabCare
- SOS Kilkenny Ltd.
- St. Aidan’s Service
- St. Catherine’s Association
- St. Christopher’s Service
- St. Cronan’s Association
- St. Hilda’s Services
- St. John of God Community Services
- St. Joseph’s Foundation
- St. Margaret’s Centre IRL-IASD
- St. Michael’s House
- Stewarts Care
- Sunbeam House Services
- WALK
- Waterford Intellectual Disability Association
- Western Care Association
- Windmill Therapeutic Training Unit