



Oifig an Stiúirthóir Cúnta Náisiúnta,
Foireann Míchumais Náisiúnta,
An Chéad Urlár - Oifigí 13, 14, 15,
Áras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,
Páirc Náisiúnta Teicneolaíochta,
Caladh an Treoigh,
Luimneach.

Office of the Assistant National Director,
National Disability Team,
First Floor- Offices 13, 14, 15,
Roselawn House, University Business Complex,
National Technology Park,
Castletroy,
Limerick.

28th January 2025

Deputy Jerry Buttimer,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: jerry.buttimer@oireachtas.ie

Dear Deputy Buttimer,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ: 2014/25

To ask the Minister for Health to provide an update on the life plan for intellectually disabled or autistic children to parents who are now older and want to put services in place for their children for their future.

HSE Response

Wherever possible, people with disabilities are supported to live in the community and to access mainstream health and social care services. Specialist disability services focus on providing supports to people with more complex disabilities, and to complement the mainstream health and social care services provided to people with disabilities alongside the rest of the population. The development of specialist services is underpinned by some key principles including:

- Rights-based services aligned with the United Nations Convention on the Rights of Persons with Disabilities
- Services provided in the community where people live
- Early intervention to maximise people's capacities
- Person-centred services supporting people's choice and control
- A strengths-based approach, recognising and supporting the inherent abilities of people with disabilities
- Coherent and integrated services and supports
- Services that are equitable and consistent
- Prioritisation on the basis of assessed need
- Services provided by interdisciplinary teams, networked regionally with other teams, and supported by enhanced services and supports where necessary.



The principle of 'mainstream first' requires that HSE-led services are developed in the context of supporting actions by Government departments in the areas of housing, transport, education, including higher education, employment and social protection.

The HSE is endeavouring to ensure a more equitable approach to the delivery of key services and acknowledges that the needs of people with a disability extend well beyond health service provision. The health service participates fully with other Government departments and services in the development of cross-sectoral strategies to maximise access to services and supports for people with disabilities. In this context, there is a collective effort being made nationally and regionally to fundamentally reform how we deliver services for people with a disability and our commitment to uphold the UN Convention on the Rights of People with a Disability. Under the Transforming Lives policy, this has been a driving force of strong collaborative efforts over many years and where real progress has and continues to be made.

Disability Service Provision

The HSE provides and funds a wide range of specialist disability services to those with physical, sensory, intellectual disability and autism. Services focus on supporting and enabling people with disabilities to maximise their full potential, as independently as possible. Current policies are based on the principles of person-centredness to ensure insofar as possible, that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community as possible. Services are provided in a variety of community and residential settings in partnership with service users, their families and carers and a range of statutory, non-statutory, voluntary and community groups. Specialist Disability services are delivered through a mix of HSE direct provision as well as through over 400 voluntary Section 38 and 39 funded service providers, and private providers. The range of specialist disability services provided to people with disabilities includes:

1. Residential
2. Respite
3. Day Services & Rehabilitative Training
4. Assisted Living Services (Home Support & Personal Assistant Services)
5. Early Intervention and School-aged Services - Progressing Disability Services for Children & Young People (0-18 years)
6. Multidisciplinary supports
7. Aids and Appliances
8. Neuro-Rehabilitation Services
9. Financial Allowances
10. Miscellaneous Support Services

The HSE acknowledges the significant role, work and the challenges faced by aging parents/family carers in the provision of care and sustaining individuals in their local communities.

People with disabilities are living longer and healthier lives. The change in demographics, increased life expectancy and changing needs for those with both a physical and sensory disability, and an intellectual disability has led to a significant increase in the need for disability services across all settings.

As people with an intellectual and/or physical disability age, they may have additional care needs which require input from a range of services across the HSE. These services include acute and community services such as Primary Care Services, Older Persons Services and Mental Health Services.

As outlined above, collaborative working is required across the wider health and social care setting with the aim of improving access to services for all people with disability.

The Disability Capacity Review Report shows that, overall, the disability population is expected to grow up to 2032, with a change in the overall age structure that will affect demand for disability services. The central projection forecasts that the number of adults with a disability would grow by around 10% to 2027 and by 17% in 2032 over the 2018 level.

Critically, the number of older adults is set to rise, driving up demand for full-time residential services when parents or natural support networks are no longer in a position to continue to care at home.



This changing age profile and change in demographics observed in the data over the past four decades, has implications for service planning; as there is a continuing high level of demand for services designed to meet the needs of older people with intellectual disability, in addition to support services for ageing care givers.

Disability Support Application Management Tool (DSMAT)

HSE Disability Services has introduced a system called the Disability Support Application Management Tool (DSMAT), which provides a list and detailed profiles of people (Adults & Children) who need additional funded supports in each CHO.

DSMAT captures detailed information on home and family circumstances and a detailed presentation profile of the individuals. This enables Community Healthcare Organisation (CHO) areas to record and manage requests for support and to ensure that the application process is equitable and transparent.

It is important to note that in the absence of a statutory, legislative framework providing entitlement to services, the DSMAT is not a chronological waiting list. Rather, it is a support to the CHO area to feed into its decision making process around prioritisation of services, subject to budgetary constraints.

This means that services are allocated on the basis of greatest presenting need and associated risk factors.

It is important that the family/ carers of individuals with an intellectual disability that they are supporting to live in the local community, engage and collaborate with the local HSE Disability Services/ or Service provider to discuss and plan for the future care needs and requirements of the individual with an intellectual disability.

Information regarding local HSE Disability Services can be obtained at:

<https://www.hse.ie/eng/services/list/4/disability/>

Action Plan for Disability Services 2023-2026

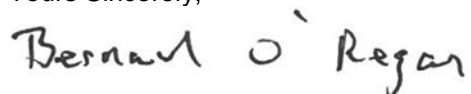
The Action Plan for Disability Services 2024-2026, sets out a three year programme designed to tackle the deficits highlighted in the *Disability Capacity Review to 2032*, which identified the demand for specialist community-based disability services arising from demographic change and considerable levels of unmet need.

Specifically, the Disability Capacity Review projected a need for a minimum of an additional 1,900 residential places by 2032 under a minimum projection and an extra 3,900 in order to return to levels of provision prior to the beginning of the 2008 recession. Moreover, the central projection of the Capacity Review suggests that adults with intellectual disabilities requiring specialist services will increase by a sixth between 2018 and 2032, with fastest growth for young adults (up a third by 2032) and over 55s (up a quarter). These projections include an average of approximately 90 new residential places that will be needed each year from 2020 to 2032 to accommodate changes in the size and age structure of the disability population.

The Action Plan is designed to provide additional funding for developments that will help build capacity within services, so that the benefits of these funding increases will be felt directly by the service user. This will also help the HSE in dealing with some of the key cost-drivers in service delivery, such as high-cost emergency residential placements, giving greater flexibility and control when planning services.

Each CHO continues to actively respond to the needs of people in their areas within the resources available.

Yours Sincerely,



Bernard O'Regan
Assistant National Director
National Disability Team

