

Oifig an Stiúrthóir Cúnta Náisiúnta,

Foireann Míchumais Náisiúnta, An Chéad Urlár - Oifigí 13, 14, 15, Àras 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.

20th March 2025

Deputy Marie Sherlock, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: marie.sherlock@oireachtas.ie

Dear Deputy Sherlock,

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: 12000/25

To ask the Minister for Children; Equality; Disability; Integration and Youth to list the organisations funded by the HSE and her Department that work with sufferers of acquired brain injury; the supports available to them for each year from 2019 to 2024, in tabular form; and if she will make a statement on the matter.

HSE Response

Health Services are provided based on the assessed needs of the individual rather than by diagnosis. It is this clinical assessment that determines the appropriate pathway for services, including Primary Care, Disability Services, Older Persons Services and Mental health Services as appropriate to their care needs. This applies to all people who present to Health Services, including individuals with acquired brain injury (ABI).

The list of service provision includes:

- Acute Hospital Services
- Mental Health Services
- The National Rehabilitation Hospital.
- A range of multi-disciplinary services at local level providing rehabilitation in the community to people with ABI
- A range of long term assisted living supports, usually contracted by the health service from the non-statutory sector.
- Rehabilitative training services, also usually contracted by the health service from the non-statutory sector.

These services are provided directly by the health service and a number of non statutory organisations across Disability Services, General Community Services, Acute Hospital Services and Services for Older People.



With regard to Disability services, the HSE funds a range of community services and supports to enable each individual with a disability, to achieve his or her full potential and maximise independence, including living as independently as possible. Services include Residential and Respite Services, Day Services and Rehabilitative Training, PA and Home Support Services, Therapeutic Supports, and Neuro-rehabilitation Services.

Disability services focus on enabling people with disabilities to achieve their full potential, living ordinary lives in ordinary places, as independently as possible, while ensuring that the voices of service users and their families are heard, and that they are fully involved in planning and improving services to meet their needs.

Importantly, the needs of people with a disability, including acquired brain injuries, extend well beyond health service provision, and the health service will participate fully with other governmental departments and services in the development of cross-sectoral strategies to maximise access to services and supports for people with disabilities.

Organisations providing support to people with acquired brain injuries

The HSE works in partnership with organisations including Section 38, Section 39, Out of State and For Profit organisations to ensure the best level of service possible is provided to people with a disability, and their families, within the available resources. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers. The relationship between these providers and the HSE is governed by way of a Service Arrangements (SA) or Grant Aid Agreement (GA) via the Community Healthcare Organisations/ Regional Health Areas. The HSE currently manages 1,045 Service Arrangement or Grant Aid Agreements with an approximate total of 419 organisations.

Organisations which provide services to people affected by an acquired injury including brain injury are funded through Disability Services, Primary Care, Mental Health, Health and Wellbeing and Social Inclusion.

Within Disability Services, the following organisations are also funded to provide services for individuals with disabilities as a result of an acquired brain injury. These include but <u>are not limited to</u>;

- Headway Ireland (HI):
- The Cheshire Foundation Ireland:
- Irish Wheelchair Association:
- Enable Ireland
- Acquired Brain Injury Ireland
- The Rehab Group

The table below provides information regarding the funding for these organisations since 2019.

Table 1: Funding

Organisation Name	2019	2020	2021	2022	2023	2024
Headway Ireland	€2,308,891	€3,341852	€3,907,116	€4,381,291	€5,013,017	€5,482,885
The Cheshire Foundation Ireland	€30,078,999	€30,498,695	€35,390,902	€31,953,649	€31,508,007	€31,462,537
Irish Wheelchair Association	€40,854,600	€46,177,853	€45,805,671	€54,132,622	€54,422,527	€55,843,816
Enable Ireland	€44,331,001	€45,744,845	€50,303,951	€54,800,522	€60,043,593	€63,965,281
Acquired Brain Injury Ireland	€12,733,689	€13,585,809	€14,710,632	€16,884,298	€18,299,654	€19,392,133
The Rehab Group	€15,311,100	€16,377,099	€17,308,814	€19,016,125	€22,843,888	€96,705,055

As mentioned above, disability services are provided based on the assessed needs of the individual rather than by diagnosis. There are many more organisations who are providing services to people with ABI depending on the assessed needs of the individual and if the supports provided by those organisations can meet the needs of those individuals.



Note re SPG: Please note:-The funding Information contained in the table above is from the SPG system is as at the date indicated, and represents the funding arrangement allocations entered by the operational system. SPG is not a finance or payment system and figures will fluctuate on a continuum as updates on governance arrangement are uploaded

Supports provided by the HSE and its funded provider organisations for people with an ABI.

Personal Assistant and Home Support Services

The HSE provides a range of assisted living services including Personal Assistant and Home Support Services to support individuals to maximise their capacity to live full and independent lives.

PA and Home Support Services are provided either directly by the HSE or through a range of voluntary service providers. Services are accessed through an application process or through referrals from public health nurses or other community based staff. Individuals' needs are evaluated against the criteria for prioritisation for the particular services and then decisions are made in relation to the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. As with every service there is not a limitless resource available for the provision of services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

Day Services

Day Services are a key component of support services that enable people to live within the community. The New Directions Policy, which was published in 2013, outlines the manner in which adults with disabilities receive disability day services. This policy is underpinned by the values of person centredness, community inclusion, active citizenship and quality.

This policy is in line with the UN Convention on the Rights of People with Disabilities which articulate the rights of people with disabilities to avail of the whole range of public services that are available to all citizens of the state. The guiding principle for HSE funded day services is that supports will be tailored to individual need and will be flexible, responsive and person-centred.

There are now 19,524 individuals with a disability in receipt of day services, together with a further 2,046 in Rehabilitative Training services.

These services are provided at 1,091 locations around the country by 97 service provider agencies.

Community Funded Schemes

The Community Funded Schemes is a collective name for all of the many products, supports, supplies, appliances and aids that are provided through community services. There is an extensive range of assistive technology products and services provided to hundreds of thousands of individuals living with a wide variety of different medical conditions or disability, under the CFS.

The HSE currently spends in excess of €250m per annum on these products and services. The scale of the programme is extensive and many thousands of items are provided from community based services across the country. Every PHN, continence advisor, clinical nurse specialist, occupational therapist, physiotherapist, dietician, speech and language therapist, podiatrist and orthotist, who prescribes an appliance, a sip feed, a prosthetic, oxygen or one of the many thousands of items used to support service users in the community, has a role to play in delivery of these extensive services.

The budget for CFS sits within the Primary Care function of the CHO's. Based on satisfying the eligibility criteria, people living with disabilities are like other people living with a broad range of medical conditions, eligible for Medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence. The HSE provides assistive devices to thousands of people with disabilities to enable them to maintain their health, optimise functional ability and to facilitate care in their primary care setting.



Respite Services

The HSE and its funded Agencies provide respite care to people with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

Residential Services

Residential services make up the largest part of the Disability funding disbursed by the HSE – over 60% of the total budget – and approximately 90 service providers provide residential services to 8,662 individuals throughout the country. The bulk of these are provided by the 50 highest funded agencies (comprising both Section 38 & Section 39 organisations) – some 6,356 places, or 74%. The HSE itself provides 1,063 or 12% of the places. While 1,219 places or 14% are provided by Private-for-Profit agencies.

Neuro Rehabilitation Implementation Framework

The Neurorehabilitation Strategy would support access to services based on clinically assessed need rather than diagnosis. Assessment of need would include an assessment of ability to participate in an active rehabilitation programme. In some instances, an active addiction could impact on an individual's ability to participate in a rehabilitation programme and this would be taken into account.

Advocacy Services

An additional support and service for people with acquired brain injury include advocacy services such as the National Advocacy Services and SAGE. Please see:

https://advocacy.ie/

Supports for young persons (Under 65 years of age) in Nursing Homes who have a disability such as an Acquired Brain Injury.

The HSE established a dedicated funding stream as part of the National Service Plan to enable people under the age of 65 years living in Nursing Homes to move to homes of their choosing in the community, with support. This initiative is in line with the Programme for Government and the UNCRPD, as well as Time to Move On Policy and the Ombudsman's Report into the placement of persons under 65 years of age in nursing homes.

In 2019, the Ombudsman commenced a systemic investigation into people under 65, living in nursing homes (NHs), and in May 2021 "Wasted Lives: Time for a better future for younger people in nursing homes" was published.

The Ombudsman's research suggests that nursing homes in general are designed for frail older people in the latter stage of their life. They are therefore not equipped to provide the rehabilitation that a younger person living with a disability may require, nor do they provide a social model of care focused on enabling the people concerned to return to their communities. Such a model of care is essential to implement the Transforming Lives Programme and to meet the commitments under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The Ombudsman's report details a series of findings and nineteen recommendations covering a range of themes including funding, informed consent, quality of life, access to services, navigating the system and policy and human rights.

National and Regional U65 Structures and Supports

In response to the Ombudsman's report, the HSE is co-ordinating a programme of work at both the Health Regions (HRs)/CHO operational and at national levels, to progressively address the Wasted Lives Report review and implement the report's recommendations for which the HSE has accountability.



Nationally, the Implementation Steering Committee (ISC) oversees the programme of work. The membership represents, Acute Services, Older Persons services, Disability and Primary Care Services, along with Clinical Leads and representatives for people with lived experience. The ISC meets on a bi-monthly basis.

Additionally, there is an U65 Programme Office and the Implementation Project Team. The implementation programme has been divided into 5 work streams with 5 work stream leads.

The work streams are as follows:

- 1. Quality of life and model of service development
- 2. Funding and personal finances
- 3. Services access and navigation
- 4. Informed consent policy and human rights
- 5. NH U65 survey (previously SRF project)

At local Health Regions/CHOs, there is an identified U65 lead per CHO, who is responsible for progressing U65s transitions and working with individual disability case managers. The operational activity is supported by two U65 Trackers. Firstly the U65 Operational tracker which manages the U65 programme within each CHO and provides data on U65 operational activity for the National Office. Secondly, the U65 Finance Tracker, which manages and provides governance over the U65 budget within the CHO and Nationally.

Transitions to the Community

At end of January2025, 2 people under the age of 65, who were residing in nursing homes, were supported to move into more appropriate community settings.

In addition, based on the data we have from the U65 Operational Tracker, there has been in total 99 transitions since the project commenced.

The majority moved to community residential placements including sheltered living, specialised and residential placements, with other individuals moving to their own home.

There are individuals who are in active planning for potential discharge to the community in the short to medium term. These individuals are at different stages of the case management process as follows:

Most individuals are at pre-approval stage i.e. their business case preparation is in progress.

- Some are ready to move but are awaiting Home support staff availability.
- Some individuals are in active transition planning including; working with potential service providers, sourcing suitable housing, planning adaptions to the home, recruitment of staff etc. and will be the next group to transition in the immediate to medium term

Individuals who need to continue in their Nursing Home placement have benefitted from Enhanced Quality of Life Supports (EQLS) funded by the U65 programme. These supports include: Personal devices, Transport, Social Care, Vocational, Therapeutic supports and PA hours.

For the majority of those continuing a NH placement, the reason is due to their current personal will and preference. Disability services recognise that the issue of will and preference is changeable and that there needs to be planned engagements with individuals to better understand their reasons why they may wish to stay.

This is followed by those who are staying due to their assessment of needs requirements. (There are also a number of people who have complex medical and social care needs that require intensive nursing and medical care that cannot be provided in a home setting or by family members. This might include people who have conditions such as Acquired Brain Injury or early onset dementia)

Bearing in mind the uniqueness and complexities of each person's situation, choice, social and medical/care needs and requirements, all options must be explored and considered.



Due to the work of the U65 Integrated Steering Committee, the Health Region/CHO disability teams and the U65 project team, there is a greater awareness across Acutes, Older Persons and Disability services of the need to prevent U65s being placed in NHs.

The U65 Model of Service directly addresses the issue of alternatives to nursing homes, including specialised residential options and other disability service options including home support.

Yours Sincerely,

Gerry Tully Assistant National Director, Access and Integration, Adult Disability Services

