



Oifig an Cheannaire Oibríochtaí,
Seirbhísí 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 Head of Operations,
National Disability Services,
First Floor- Offices 13, 14, 15,
Roselawn House, University Business Complex,
National Technology Park,
Castletroy,

10th May 2024

Deputy Colm Burke,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: colm.burke@oireachtas.ie

Dear Deputy Burke,

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 11315/24

To ask the Minister for Children; Equality; Disability; Integration and Youth to confirm if his Department is actively coordinating with disability advocacy organisations and community groups to gather feedback from service users, and to ensure that there is a continuity of improvement in quality of disability home support services; and if he will make a statement on the matter.

HSE Response

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.

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 including PA and Home Support (80%) is delivered through non-statutory sector service providers.

The Home Support service provides domestic and or personal care inputs at regular intervals on a weekly basis. Temporary relief is offered to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability. The service provides support to the parents to enable them to spend quality time with the other siblings in the family. It also supports the individual with the disability in terms of their care plan, with particular attention on the personal needs of the individual. Home supports can be an alternative to residential care, where support to individuals in daily living can avoid the need for full time residential services.

The HSE acknowledges the role and contribution of non-statutory agencies including advocacy organisations in the development and provision of health and personal social services including Home Support services and is committed to the development of effective working relationships as enacted by the Health Act 2004.



Several advocacy organisations including Inclusion Ireland, Disability Federation of Ireland (DFI) and the National Federation of Voluntary Service Providers receive funding to ensure that the voices of people with disabilities are heard when it comes to changes in services and legislation that will improve the quality of life and participation of people with a disability in Irish Society.

Many other non statutory agencies, funded by the HSE also have a role in upholding and protecting the rights and dignity of people with disabilities, although this may not be their primary role and functions.

The role of service users through advocacy in informing health and personal social services provision is well documented. Effective service user involvement enables services to anticipate problems, avoid complaints, develop appropriate and effective service provision and it guarantees that service users will be at the centre of efforts to improve the quality and safety of service provision for many years to come.

Dialogue Forum with Voluntary Organisations

The Partnership Principles was launched on the 3rd April 2023 by Government, the HSE and the Voluntary Organisations.

The Dialogue Forum with Voluntary Organisations was established in late 2019 with the aim of building a stronger, more collaborative, working relationship between the State and voluntary providers (S38/39) in the health and social care sector for the benefit of the people using our health services. Members of the Forum include the Department of Health, HIQA, Mental Health Commission and 8 voluntary representative organisations.

To facilitate regular and structured dialogue between these entities, the Forum has engaged in several activities, including the collaborative development of the Partnership Principles, which serve as a foundation for strengthening the relationship between the State and voluntary organisations. The Principles emphasise the need to place the person at the centre of our partnership and to work on the basis of trust and mutual respect so that coherent planning and good decisions are informed by engagement and participation - harnessing the strengths of both the statutory and voluntary sectors for the benefit of the people using our services.

Service User Involvement in Disability Services

Across the large HSE residential services, each individual setting is progressing the development of a family forum with the support of Inclusion Ireland and putting in place processes to support meaningful engagement by the service users in the design and operation of the services that affect them. This is being managed in a range of ways appropriate to the resident population, such as self advocacy groups, engagement with independent advocates, parent and sibling groups and the roll out of supported self -directed living that enables each person to direct their own life. These developments are in keeping with the National Standards for Residential Services for Adults and Children, and the overall *Transforming Lives* programme across the disability sector that is focussed on delivering person-centred services.

In Childrens Disability Services, the HSE works in partnership with other services providers including, S38 organisations and S39 organisations to deliver services to children with disabilities and their families. Giving voice and opportunities for feedback and input into the development of services, 69 Family Forums have commenced meeting, and in turn, 5 of 9 CHO Family Representatives Groups have commenced with representatives nominated onto the CHO CDNT Governance Group.

The Connect Family Network

The HSE has engaged Inclusion Ireland to establish a national network of family support groups in the disability sector; the Connect Family Network. The Connect Family Network will endeavour to bring about greater participation of persons with a disability and their family members in the design and delivery of disability services and supports.

Research has shown that service and policy development is much more effective when the people who use services are involved from the outset.

The Connect Family Network will not replace any organisation, but will aim to enable a coherent and combined family voice to be heard by service providers and policy makers. Supports to family support groups will include information



provision, facilitation of networking opportunities, capacity building training and support for families to have their voices heard in policy formation and implementation.

The HSE has also commissioned SAGE to pilot a Disability Advocacy model of service in Community Healthcare Organisation Area 5.

National Platform for Self Advocates

The National Platform for Self Advocates is an independent advocacy organization which was set up as a forum for people with Intellectual Disability. Inclusion Ireland facilitated the process of setting up this national platform, although it has its own unique identity and is outside the remit of agencies involved in direct service provision. One of the roles of the Platform was to disability proof national policy from an intellectual disability perspective.

The HSE supports the work of the National Platform for Self-Advocates, but is also very conscious of the need to deliver disability policy on a more sustainable footing given the significant levels of need for increased and more effective services and supports to enable people with a disability to live independent lives in their own community. Hence, it is important that organisations such as the National Platform for Self-Advocates look to other funding streams such as the Department of Rural and Community Development’s Scheme for Community and Voluntary Organisations. The HSE understands that funding of €18.5m over the coming three years has been approved for this Scheme.

Improvement in the provision of Home Support Services

The HSE is committed to protecting the level of Personal Assistant (PA) and Home Support Services available to persons with disabilities. Table 1 below provides data for PA & Home Support Services delivered to people with a disability from 2014 - 2022. The HSE has consistently, year on year, increased the number of hours of PA and Home Support Services delivered to people with a disability.

Table 1: Figures for PA and Home Support Services Delivered to People with a Disability 2014-2022

	2014	2015	2016	2017	2018	2019	2020	2021	2022
PA Services – Number of Hours	1,335,759	1,482,492	1,510,116	1,516,727	1,639,481	1,652,030	1,781,310	1,700,309	1,746,136
PA Services –No. People availing of service	2,224	2,369	2,427	2,470	2,535	2,551	2,673	2,613	2,669
Home Support – Number of Hours	2,614,967	2,777,569	2,928,914	2,930,000	3,138,939	3,036,182	2,939,541	2,949,806	3,369,146
Home Support – No. People availing of service	7,312	7,219	7,323	7,492	7,522	7,321	6,792	6,902	7,164

Activity Data for 2023

As per the National Service Plan 2023, the HSE committed to deliver 3.12 million hours of Home Support Services to 7,326 people. At the end of 2023, the total number of Home Support hours delivered was 3,544,938 which is 13.6% ahead of NSP target of 3,120,000.

The need for increased services is acknowledged and the HSE continues to work with agencies to explore various ways of responding to this need in line with the budget available.

National Service Plan 2024

As per the National Service Plan 2024, the HSE will:

- Improve the delivery of a range of specialist community-based disability services and increase service capacity for people with a disability throughout life in the areas of day, respite, multidisciplinary, residential, home support, neuro-rehabilitation and personal assistant services using the resources available, including:
- Delivery of additional personal assistant hours to support persons with a disability in their own communities, within available funding.



With regard to Home Support, expected activity for 2024, as per the 2024 Service Plan, is 3.48m hours to be delivered to 7,326 people with disabilities.

In addition, the 2024 Service Plan references that a new HSE-led Disability Services procurement framework for home support is planned to be developed and agreed in Q2 2024. Targets may be adjusted accordingly.

This includes engagement with local HSE structures to provide feedback on the Home Support regulations to ensure that these are aligned and supportive of the needs of service users with disabilities.

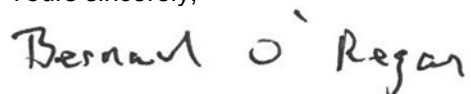
Future Planning

With regard to additional PA and Home Support Services, the Department of Health's 2021 Disability Capacity Review advises that up to €15 million per year by 2032 – equivalent to 600,000 additional hours - is needed to meet the requirements for Personal Assistants and Home Support.

The Action Plan for Disability Services 2024 – 2026 advises that 800,000 extra PA hours and 110,000 extra hours a year is required by 2026 to address shortfall in services and to support individuals with disabilities to live a fuller more independent life and participate in normal activities in the community, in line with UNCRPD Article 19.

Each CHO continues to actively manage applications for support from service users with high levels of acuity/safeguarding risks, through active case-management and inter-agency cooperation.

Yours sincerely,



Bernard O'Regan
Head of Operations - Disability Services,
Community Operations