



**Oifig an Cheannaire Oibríochtaí,**  
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
31-33 Sráid Chaitríona, Luimneach.

**Office of the Head of Operations,**  
Disability Services/Social Care Division,  
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369  
Suíomh Gréasáin/Website: <http://www.hse.ie>

29<sup>th</sup> June 2023

Deputy Neasa Hourigan,  
Dail Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.  
E-mail: [neasa.hourigan@oireachtas.ie](mailto:neasa.hourigan@oireachtas.ie)

Dear Deputy Hourigan,

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: 28888/23**

*To ask the Minister for Children; Equality; Disability; Integration and Youth the supports and services available to adults with special needs to continue to live independently in the community following the death of a parent who had previously cared for them; and if he will make a statement on the matter.*

**HSE Response**

People with disabilities are thankfully living longer. This requires planning ahead and putting in place the required services that can assure ageing parents that their loved ones will have the supports they need when the family are no longer in a position to offer support.

The proportion of people with intellectual disabilities aged over 60 living at home with family members (23% in 2017) seems unsustainably high. As people with intellectual disabilities get older, their ageing parents or other family members have much less capacity to care for them at home, both because of increasing support needs of a person ageing with a disability, and because the primary carer may also be experiencing significant health issues.

A majority of over-60s who are at home are living either with ageing siblings, or with a parent likely to be aged in their eighties or older.

There is a high risk that these caring arrangements will break down when a parent is hospitalised or passes away, or an ageing sibling can no longer manage. Societal change is also likely in years to come to see a reduction in the availability of siblings to act as primary carer.

Societal change, 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.

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.



It is important to recognise also that the needs of people with a disability 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.

In this context, the HSE has produced the attached Guidance Document- *Supporting People with Disabilities to access Appropriate Housing in the Community, October 2020*. This document has been developed as a resource for service providers and other stakeholders who are supporting people with disabilities to move to their own homes in the community. It is recommended that this document is read in conjunction with the Housing Options document published by the Housing Agency, which provides a guide to the social housing options available. There are plain English and easy read versions of this document available at:

<https://www.housingagency.ie/housing-information/social-housing-options>

With regard to people with disabilities, including the service user whose parent and caregiver has regrettably deceased, the Assisted Decision-Making (Capacity) Act 2015 (the Act) gives each person the right to be assisted to make decisions with legally recognised supports regardless of disability or any condition which may affect their decision-making capacity. The Act recognises each person's right to make autonomous and independent decisions for as long as possible.

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. While this does include residential care services, it also includes community/home based supports such as day supports, respite services and personal assistant and home support services.

### **Living independently in the community**

The HSE provides and funds a wide range of disability services to those with physical, sensory, intellectual disability and autism. Disability 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.

In 2023, Disability Services is allocated c. €2.6 billion to provide a range of services throughout the country and is spent in line with nationally agreed policy for disability services, whilst at the same time endeavouring to maximise value. Non residential services include Respite Services, Day Services and Rehabilitative Training, PA and Home Support Services and Therapeutic Supports.

### **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. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

### **PA Service**

The independent living philosophy underpinning the Personal Assistant service concurs with the approach that people with a disability should be empowered to live independently. The philosophy of independent living espouses living like everyone else, i.e. having the right to self-determination, to exert control over one's life, to have opportunities to make decisions, take responsibility and to pursue activities of one's own choosing, regardless of disability.

The role of a Personal Assistant (PA) is to assist a person with a disability to maximise their independence through supporting them to live in integrated settings and to access community facilities. The PA works on a one to one basis, in the home and/or in the community, with a person with a physical or sensory disability. A vital element of this personalised support is the full involvement of the individual (service user) in planning and agreeing the type and the times when support is provided to them, supporting independent living must enhance the person's control over their



own life. Article 19 of the UN Convention states that disabled people should live where they wish and with whom they wish. That they should enjoy a range of community support services including personal assistance. That they should enjoy community life and its opportunities on an equal basis to non-disabled people and they should not be subject to isolation or segregation.

## **Home Support**

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.

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 home support 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.

In the normal course of service delivery, there will be ongoing reviews throughout the year to ensure that if needs change the service provided will address this change within available resources. An individual's PA or Home Support hours may be adjusted following a service review where service demand can result in one individual's service being reduced in order to address priority needs of other people with disabilities within that community.

Currently, each CHO has a process to manage applications and referrals for PA and Home Support Services. While many individuals are adequately provided for by their current level of support, it is also the case that many would benefit from more support hours if they were available.

The delivery of PA and Home Support Services remained steady during 2022; PA Services was above the National Service Plan target by +2.7% and Home Support Services was +8% above target for the year. The figures for quarter 1, 2023 were also largely in line with national targets.

The HSE acknowledges the role of PA Services in supporting the person with a disability to realise the entitlements set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCPRD). As Ireland has now ratified the UN Convention it will be necessary to have a policy on the provision of PA services with an agreed definition, criteria for accessing the service, assessment process and an indication of the level of support that can be provided.

In this context, the HSE is in the process of establishing a Working Group on PA Services; work is underway to develop the Terms of Reference and proposed membership of the Working Group which is planned to commence in early Quarter 2, 2023.

The HSE has contributed to the development by Government of the Capacity Review of the Disability Sector (2020) and the draft Disability Action Plan 2023 – 2026. These set out the future service needs and how they might be addressed. They incorporate the dual development goals to (a) increase the range of hours available to individuals already in receipt of some PA support and (b) increasing the hours available to make the service available to more people.

This report will be used by the Working Group being established to improve this important service, as well as making a valuable contribution to the service planning process.

## **Intensive support packages**

In 2021, €6m in funding was allocated to Intensive Support packages. 497 intensive support packages were put in place; this included 437 new packages and 60 packages approved in 2020 against additional Q4 funding, which were maintained in 2021.



In 2022, Disability Services developed 18 new intensive support packages and 19 new supported living packages.

In accordance with the National Service Plan 2022, the HSE will deliver 120,000 additional hours of personal assistant supports and 30,000 additional hours of home supports to expand and enhance supports for people to live self-directed lives in their own communities.

The HSE is committed to protecting the level of Personal Assistant and Home Support Services to support 10,000 individuals to maximise their capacity to live full and independent lives and in 2022 the targets set in the NSP were exceeded with the delivery of 1.75 million hours of PA Services (above the target by +2.7%) and 3.37 million hours of Home Support Services (+8% above target for the year).

In accordance with the NSP 2023, the HSE has been allocated funding to provide a range of supports including:

- Support 18 delayed transfers of care in line with the Winter Plan. This includes new residential places and home care packages.

Whilst there is currently no centrally maintained list of people awaiting Home Support services, each Community Health Organisation Area would be aware of the presenting needs within each of the geographic areas. Following referral and assessment, available resources are allocated to clients with highest level of need.

### **New Directions - Day Services**

Day Services are a key component of support services that enable clients to live within the community. Currently day services are transitioning to a new approach outlined in the policy *New Directions*. This policy is underpinned by the values of Person Centredness, Community Inclusion, Active Citizenship and Quality. This strategy is in line with the National Disability Inclusion Strategy and the UN Convention on the Rights of People with Disabilities both of 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.

New Directions, which was published in 2013, contains a radical change to the manner in which adults with disabilities receive disability day services. The approach to adult day services charts new territory and outlines that all the supports available in communities be mobilised so that people have the widest possible choices and options about how they live their lives and how they spend their time. It places a premium on making sure that being part of one's local community is a real option. It recognises that people with severe and profound disabilities may need specialised support throughout their lives. The guiding principle for all future HSE funded day services is that supports will be tailored to individual need and will be flexible, responsive and person-centred.

A structure to implement New Directions was established in 2015 and a number of key work streams were developed and implemented to support the sector with the significant change programme involved in delivering the policy. These are as follows: -

- **Information Management:** - a case management system with details of all service users in receipt of day services was developed and implemented in 2017. This system provides up to date information regarding the quantum of service received by each individual, the location at which they receive their supports and the organization providing their support needs.  
A Learning Hub has been developed on HSeLanD with a complete suite of documentation for service providers and service users to support the implementation of New Directions.
- **Person Centred Planning Framework:** - A National Person Centred Planning Framework was developed in 2018, demonstrated in a number of provider organisations during 2019 and is now in the process of being implemented across all 1,000 day service locations nationally.

Service Providers are currently evaluating their practice against the framework and developing action plans to address gaps. A series of Training Webinars was delivered during 2021 to support the sector with this work. An e Learning module to support, Service Users, Families and Advocates participate in the person centred planning process has been commenced and is due for completion in 2021.

- **Interim Standards for New Directions:** - The development of a set of Interim Standards for Adult Disability Day services commenced in 2016. A process of Continuous Quality Improvement was developed to support



the implementation of the Interim Standards. The EASI process - **Evaluate, Action, Service Improvement** was implemented throughout all approximately 1,000 day service locations during 2019 with a target to embed continuous quality improvement as the delivery culture within each day service. This process is ongoing and in 2022 it is planned to develop a monitoring system to establish the sector's compliance with the Interim Standards.

- **RT/School Leaver process:** - Since 2015 a national process has been developed and implemented to provide for the needs of approx. 1,800 young adults that leave school or rehabilitative training annually and require a HSE funded day service. This process includes profiling of individual need the allocation of resources in line with that profiled need. The HSE structure that supports the delivery of adult disability day services has been strengthened in all areas and now comprises a day service team under the management and direction of a Day Services Coordinator.

Currently almost 19,000 people are in receipt of disability Day Service supports at 1,041 locations around the country. These supports are provided by approximately 95 service provider agencies.

## **Respite Services**

The HSE and its funded Agencies provide respite care to children and adults 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.

## **Disability Support Application Management Tool (DSMAT)**

While there is no centrally collated information on applications for respite and residential respite services, the 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.

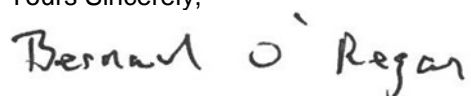
DSMAT captures detailed information on home and family circumstances and a detailed presentation profile of the individuals. This enables Community Healthcare Organisation (CHO) areas to record and manage requests for support and to ensure that the application process is equitable and transparent.

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 areas 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.

Applications for services entered into the DSMAT tool by CHO areas are primarily categorised as Residential or Non-Residential. Non-Residential services may include Respite, Home Support Hours, Personal Assistance or combinations thereof.

Yours Sincerely,



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

