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Dear Deputy Tully,

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: 36389/23**

*To ask the Minister for Health to detail the location of all services available for adults with cerebral palsy here; and if he will make a statement on the matter.*

**HSE Response**

Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood and is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.

The symptoms of CP vary from person to person. A person with severe CP might need to use special equipment to be able to walk, or might not be able to walk at all and might need lifelong care. A person with mild CP, on the other hand, might walk a little awkwardly, but might not need any special help. CP does not get worse over time, though the exact symptoms can change over a person's lifetime.

Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability. Services are provided following individual assessment according to the person's individual requirements and service needs.

Based on the individual's presentation and degree of severity of symptoms, individuals are referred and treated in Acute Services and/or Primary Care or the Multidisciplinary Adult Disability Team.

The HSE provides and 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 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. Services are provided either directly by the HSE or through a range of voluntary



service providers. Voluntary agencies provide the majority of services in partnership with and on behalf of the Health Service Executive.

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

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 (UNCRPD). 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.

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.



## 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 over 8,000 individuals throughout the country. The bulk of these are provided by the 50 highest funded agencies (comprising both Section 38 & Section 39 organisations) – some 6,360 places, or 77%. The HSE itself provides 1,085 or 13% of the places. While 834 places or 10% are provided by Private-for-Profit agencies.

The HSE developed a Residential Capacity Database to capture the number of residential placements / contract capacity per the service arrangement between the nine CHO areas and the service provider agencies. The end of April 2023 position indicates that there were 8,296 residential places for people with a disability. A number of new emergency residential places have been added to the residential base, which results in a capacity increase. However, it should also be noted that Residential Capacity will also reduce during the year as a result of the loss of places in congregated settings due to deaths, which cannot be re-utilised. This is in keeping with Government policy, which is to move away from institutionalised settings (i.e. Time to Move On from Congregate Settings) where the State is actively implementing a policy that will have a bed reduction impact. In addition, “in-year” capacity (bed) levels will also be impacted negatively as a result of regulatory requirements; that is, where an inspection outcome leads to capacity being reduced.

The table below shows the number of residential places available at end of June 2023, broken down by CHO Area. This is the latest data available.

CHO Area	Residential Places Available June2023
CHO 1	690
CHO 2	866
CHO 3	809
CHO 4	1,117
CHO 5	909
CHO 6	550
CHO 7	1,181
CHO 8	932
CHO 9	1,260
<b>Grand Total</b>	<b>8,314</b>

## Disability Support Application Management Tool (DSMAT)

While there is no centrally collated information on applications for disability 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,

Bernard O'Regan

**Mr Bernard O'Regan,  
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Community Operations**

