

#### Oifig an Cheannaire Oibríochtaí,

Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta, 31-33 Sráid Chaitríona, Luimneach.

#### Office of the Head of Operations,

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7th March 2023

Deputy Ivana Bacik, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: ivana.bacik@oireachtas.ie

Dear Deputy Bacik,

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: 8472/23

To ask the Minister for Health his views on the adequacy of transitionary care for adults with intellectual disabilities upon attaining the age of 18 years; and if he will make a statement on the matter.

## **HSE Response**

Each year, the Health Service Executive (HSE) funds specialist disability services for approximately 56,000 people. This includes services provided to around 29,000 adults and children with intellectual disabilities, as well as to service users with physical, sensory or neurological disabilities, or autism. Disability services provided includes Residential, Adult Day Services, Respite, Personal Assistant and Home Support Services to children and adults with disabilities.

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.

With regard to Children's' Disability Services, 91 Children's Disability Network Teams (CDNTs) are aligned to 96 Community Healthcare Networks (CHNs) across the country and are providing services and supports for children aged from birth to 18 years of age. When the young person who has been receiving the services of the CDNT reaches the age of 18 years, or has completed second level school if later and service was extended to his or her 19th birthday, the attached policy (National Policy on Discharge and Transfer) is applicable.

A proposed timeframe for discharge/closure will be discussed in advance with the family. At the time of discharge or closure each young person/family will receive a report which summarises the interventions



and progress achieved and makes any recommendations on future services and onward referrals where appropriate. A copy of the summary is sent to the GP, referrer and relevant others with permission.

In addition, the range of services provided to children and adults and young adults transitioning to adult disability services include as follows:

# • Day Services & Rehabilitative Training Services

Day Services are a key component of support services that enable service users 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.

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.

Since 2015 a national process has been developed and implemented to provide for the needs of approximately 1,800 young adults that leave school or rehabilitative training annually and require a HSE funded day service. This process includes the profiling of individual need and the allocation of resources in line with that profiled need.

In each CHO, the HSE has a Day Opportunities Team that manage the transition process for children moving from educational services to adult disability day services. Each year approximately 1,300 young people are referred for an adult disability day service placement.

The process is one where each child that is deemed to require a HSE funded day services after they finish school, is referred to HSE Day Services approximately 18 months prior to finishing school. The HSE's Day Opportunities Officer arranges with the school and the child's family to carry out a profiling of the young person's support needs. This is usually completed by the end of January in the year that the young person is leaving school. Once the needs of all young people referred are profiled, a report is completed in regard to the funding available for placements based on identified need. Each CHO is allocated their indicative budget for meeting this need in April and during the months of April and May, Day Opportunities staff negotiate placements for those young people referred.

The process should enable confirmation of a placement to the young person and their family by the end of May for a service that will commence in September.

Once a young person's needs are profiled and depending on their needs and abilities, some trialling of day service locations can be agreed between educational services and day service providers and this arrangement can work extremely well particularly when the young person is unclear regarding their choice of service and supports.

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.

The HSE is very much aware of the importance of respite service provision for the families of both children and adults with disabilities and the impact the absence of respite service provision can have on other services being delivered. In this regard, the HSE was allocated funding for additional respite services in 2021 and 2022. This is being used to develop additional centre-based respite services, along with a range of alternative respite projects including Saturday clubs, breakaway schemes, and summer schemes.

The delivery of Respite Services continued to operate during the pandemic, albeit at a reduced capacity due to infection prevention and control and physical distancing requirements. Nevertheless, during 2022, the number of respite overnights (131,057) was 41.6% ahead of the target for the year of 92,555, which is reflective of the easing of restrictions in 2022. The number of day only sessions (28,369) was also significantly ahead of the target of 22,474 for 2022.

## Therapy Services

People with disability, including young adults, can benefit from therapeutic assistance, including Physiotherapy, Occupational Therapy and Speech and Language therapy as well as a range of medical interventions. Therapy services for adults are generally delivered through Primary Care Teams, community therapy services and through specialist adult disability providers.

#### Aids and Appliances

People with disabilities, including young adults, may be eligible for aids and appliances that facilitate and/or maintain mobility and/or functional independence and are responsive to a person's presenting needs at any given time. These assistive devices enable people with a disability to maintain their health and to optimise functional ability.

#### Assisted Living Services (PA and Home Support)

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.

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.

The HSE is committed to protecting the level of Personal Assistant (PA) and Home Support Services available to persons with disabilities. In accordance with the National Service Plan 2022, the HSE planned to 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.



#### Residential Services

Residential services make up the largest part of the Disability funding disbursed by the HSE – over 60% of the total budget of €2.3 billion in 2022.

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 6,399 places, or 78%. The HSE itself provides 1,087 or 13% of the places. While 778 places or 9% 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 area and the service provider agencies. The end of December position indicates that there were 8,282 residential places for people with a disability in 2022. 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 HSE acknowledges that demographic challenges associated with the increase in the number of people living with a disability, the increase in age and life expectancy and the changing needs of people with a disability have all led to the need for increased residential facilities. In this regard, the HSE continues to work with agencies to explore various ways of responding to this need in line with the budget available. The HSE also engages with the Department of Health during the Estimates process to highlight the growing need for residential places for people with a disability and to emphasise the need for additional funding to meet this need.

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

HSE Disability Services has introduced a system called the Disability Support Application Management Tool (DSMAT), which enables Community Healthcare Organisation (CHO) areas to record and manage requests for support and to ensure that the application process is equitable and transparent. The DSMAT provides a consistent listing process for each CHO Area by presenting a detailed profile of the individuals (Adults & Children) including children transferring to adult services on attaining the age the 18 years, who require funded supports outside of the current service quantum.

It captures detailed information on home and family circumstances and a detailed presentation profile of the individuals, including specialised profiles of behavioural intensity, key diagnoses, and complex support needs due to the extent and intensity of intellectual and/or physical & sensory disability. 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 should be noted that DSMAT is not a chronological waiting list. The allocation of service is made on the basis of presenting need and/or associated risk factors. Each CHO continues to actively manage applications for support from service users with high levels of acuity/ safeguarding risks, through lower-cost non-residential interventions such as in-home and Residential Respite, active case-management and inter-agency cooperation.

The DSMAT is used in conjunction with the HSE Framework for the Management of Residential Supports (including Emergency Placements). The Disability Residential Budget is finite, particularly in the absence of multi-annual funding to increase capacity. Therefore, decisions in respect of allocation



of residential placements is based on greatest presenting need and potential associated risk/safeguarding etc. and therefore not on the basis of a chronological waiting list.

It is important to note that the needs of people with a disability including children transitioning to adult services, extend well beyond health service provision, and 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.

Yours sincerely, Bernard O'Regar

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

**Community Operations** 

