



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Oifig an Cheannaire Oibríochtaí,  
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Dear Deputy Murphy

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 21732/21**

*To ask the Minister for Health his plans to recruit advanced nurse practitioners dedicated solely to children with Down syndrome in 2021 and or in 2022.*

#### **HSE Response**

In the health service over the past decades there have been major changes in how services are delivered. Current services are based on the principle of mainstreaming with a clear focus on ensuring persons with a disability have access to the normal range of services and participate in community life as far as possible.

The National Policy on Access to Services for Children & Young People with Disability & Developmental Delay ensures that children are directed to the appropriate service based on the complexity of their presenting needs rather than based on diagnosis. Many children with a disability including those with Down syndrome, who have support needs, can be effectively supported within mainstream child health services. This policy provides a single point of entry, signposting parents and referrers to the most appropriate service (Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties).

The HSE and Service Providers recognise the critical need and importance of disability supports for people and their families, including children with Down's syndrome.

#### **Children's Therapeutic Services**

A number of service improvements are being introduced that, when implemented, will help improve access to services for children with disabilities and developmental delays. The overall programme of improvement is the ongoing roll out of Progressing Disability Services for Children and Young People (PDS). The HSE is establishing a total of 91 Children's Disability Networks across the nine CHOs, each comprised of one specialist inter-disciplinary Children's Disability Network Team (CDNTs) to work with children aged from birth to 18 years with complex disability needs. This requires the reorganisation of all current HSE and HSE funded children's disability services into geographically-based CDNTs.

PDS is doing this by forming partnerships between all the disability organisations in an area and pooling their staff with expertise in the different types of disabilities to form the CDNTs. These teams will provide for all

children with significant disability, regardless of their diagnosis, where they live or where they go to school. This reconfiguration of services under PDS is in line with Health Service Reform and the implementation of Community Healthcare Networks under Sláintecare.

Progressing Disability Services for Children and Young People Programme (PDS) is a significant change programme for the provision of services and supports for children from birth to 18 years of age, in line with Sláintecare and the Programme for Government, in order to:

- Provide a clear pathway and fairer access to services for all children with a disability.
- Make the best use of available resources for the benefit of all children and their families
- Ensure effective teams are working in partnership with families and with education staff to support children with a disability to reach their full potential.

PDS aligns with two clear objectives of The Sláintecare Report to:

- Provide the majority of care at or as close to home as possible
- Create an integrated system of care with healthcare professionals working closely together.

Children's Disability Network Teams (CDNT) are being established to provide services and supports for all children with complex needs within a defined geographic area. CDNTs are teams of health and social care professionals, including occupational therapy, psychology, nursing, physiotherapy, speech and language therapy, social work and others. The team will work closely together in a family centred model, focussing on the child's and family's own priorities. Once all teams are in place, every child with complex needs will have access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Children and their families will have access to the full range of services and supports of the CDNT according to their individual needs. This includes universal, targeted and specialist supports, such as individual therapeutic intervention and access to specialist consultation and assessment when needed. Supports will be provided as is feasible in the child's natural environments - their home, school and community.

## **Developments in 2021**

The HSE welcomes the recent announcements from the Government of additional funding for Disability Services:

- An additional €100 million secured for Disability Services in the recent budget. In the National Service Plan for 2021, the HSE commits to:
  - Providing 100 additional multi-disciplinary posts within children's network teams to improve assessment of need and treatment with a particular focus on behavioural, dietetics and paediatric services within the children's disability network teams and move towards the completion of reconfiguration under progressing disability services.
  - The NSP also commits to the development of additional Respite Services and in-home intensive transitional support packages.
- €20 million in one-off grants will be provided to reform disability services, build the capacity of disability organisations and to improve the quality of life of those who rely on these services.

€7.8 million has been allocated by Sláintecare to facilitate the HSE and its funded service providers to address the overdue Assessments of Need for children and young adults with disabilities

## **Down Syndrome Ireland.**

The HSE supports and provides funding to many organisations providing services on behalf of the HSE. These services include guidance, support and advocacy for children with disabilities and their parents/carers. One of these organisations is Down Syndrome Ireland. This organisation has over 3,000 members and 26 branches nationwide and provides a range of services, including: Early Intervention and Development Programmes; Mother & Child Groups; Therapy Services; Employment Opportunities; Counselling and Adult Advocacy Services.

Down Syndrome Ireland has specialists in the areas of health, speech and language, early development, education and adult education and independence that enhance the lives of thousands of children and adults with Down syndrome across the country.

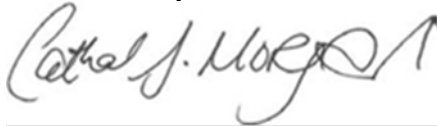
The Family Support Service provides an 'all-through-life' service to families across Ireland. Currently there is a clinical nurse specialist post based at Paediatrics in the National Children's Hospital, Tallaght. The post is supported and managed by Down Syndrome Ireland.

The HSE provided €139,393 in funding to Down Syndrome Ireland via a S39 Service Arrangement and €18,172 in funding to Down Syndrome Limerick via a S39 Grant Aid agreement in 2020.

With regard to the query if there are plans to recruit advanced nurse practitioners dedicated solely to children with Down syndrome in 2021 and or in 2022 ,services are provided based on the complexity of the child's presenting needs rather than based on diagnosis. HSE Disability Services are unaware of plans to recruit advanced nurse practitioners specifically dedicated to children with Down syndrome .

The HSE is fully committed to working in partnership with all service providers to achieve maximum benefits for children with complex needs, and aims to ensure that resources available are used in the most effective manner possible.

Yours sincerely,



**Dr. Cathal Morgan,**  
**Head of Operations - Disability Services,**  
**Community Operations**