



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Oifig an Cheannaire Oibríochtaí,  
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
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13<sup>th</sup> November 2020

Deputy Carol Nolan,  
Dail Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.  
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Dear Deputy Nolan,

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: 32980/20**

*To ask the Minister for Health the reason there is only one dedicated nurse, focused on 0 to 18 only that specialises in Down's syndrome; if he will provide investment for a dedicated specialist nurse in each of the nine CHO areas; and if he will make a statement on the matter.*

**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 and adults with a disability who have support needs can be effectively supported within mainstream child and adult health services.

Therapy Services are provided through Primary Care Teams in Community Healthcare Organisations to children and young people requiring assessment, diagnosis and treatment. Most children with developmental delay including Down's syndrome will access therapy services via Primary Care. A proportion, representing those with assessed need for specialist services are referred to disability services.

With regard to improvements in access for children with special needs and Down's Syndrome to specialised therapies, 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). It is important to note that access to therapy services under PDS for children, is based on their assessed needs not on diagnosis.

**Progressing Disability Services for Children and Young People (PDS)**

The HSE is rolling out the Progressing Disability Services for Children and Young People (PDS) Programme, which requires a reconfiguration of all current HSE and HSE funded children's disability services into geographically-based Children's Disability Network Teams (Early-Intervention and School-aged or 0-18 Teams). This Programme aims to achieve a national equitable approach in service provision for all children based on their individual need and regardless of their disability, where they live or where they go to school. Based on the recommendations of the Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years (2009), its objectives are:

- ✓ One clear pathway to services providing equity of access for all children with disabilities, according to their need.
- ✓ Effective teams working with partnership with parents and Education to support children in achieving their potential.
- ✓ Available resources used to the optimum benefit for children and their families

Under PDS, the HSE continues to establish Children's Disability Networks across each of the nine CHOs comprised of Specialist Multi-Disciplinary Teams to work with children with complex disability needs. Each Network will have a Children's Disability Network Manager with specialist expertise in providing children's disability clinical services.

Each Community Healthcare Organisation has well established Local Implementation Group(s) to progress the implementation of this project in their local area. These groups have developed Project Initiation Documents and Implementation Plans specific to their area. The National Community Operations – Disability Team through the National Children's Programme Oversight Group provides support to the Community Healthcare Organisations in this regard.

Please note that all HSE Areas planning reconfiguration continue to have significant Early Intervention and School Age Services in place, provided either directly by the HSE, or by voluntary service providers funded by the HSE, such as Enable Ireland, Kare, Muriosa Foundation, St. John of God Services, Brothers of Charity Services, St. Michael's House, Cope Foundation, CRC, Daughters of Charity Services etc.

### **Down Syndrome Ireland.**

One of the many organisations providing services on behalf of the HSE 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.

### **Funding**

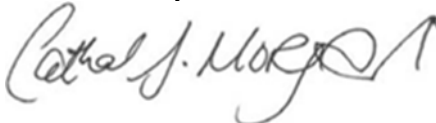
The HSE recognises the value of Down Syndrome Ireland's services to people with Down Syndrome and provides funding to Down Syndrome Ireland under Section 39 of the Health Act, 2004. The bulk of this funding is provided through CHO Area 7. In 2020, Down Syndrome Ireland is scheduled to receive funding of €106,396. Funding has also been given to Down Syndrome Ireland through the HSE National Lottery Grant scheme and this organisation also raises additional finance through fundraising activities.

With regard to nurses who specialise in Down's syndrome; 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 recognises the value of Down Syndrome Ireland's services to people with Down Syndrome, however, further increases in funding, for example, to fund additional nurse specialists, can only be considered within the parameters and scope of funding available to the HSE.

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**