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16th December 2020

Deputy Alan Farrell,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: alan.farrell@oireachtas.ie

Dear Deputy Farrell,

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 59956/21

To ask the Minister for Health if the HSE has a plan to extend the role of the clinical nurse specialist for down syndrome patients to regions outside of Leinster; 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 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 including therapy services for children with disabilities and developmental delays.

The implementation of the Progressing Disability Services for Children & Young People (PDS) programme is agreed Government and HSE policy. This policy supports the reconfiguration of children's disability services across all statutory and non-statutory organisations into Children's Disability Network Teams (CDNT) to provide equitable, child and family centred services based on need rather than diagnosis, where the child lives or goes to school.



The PDS model addresses the previous inequity in service provision whereby there may have been an excellent service for some children and little or no service for others. This variance may have been linked to diagnosis, age group or geography. Under the PDS programme children's disability services are changing from diagnosis based to needs based, so that all children with a disability or developmental delay have access to the right service based on their needs no matter where they live.

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The HSE is committed to the full implementation of the PDS programme. PDS is a significant change 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 (CDNTs)

In line with the PDS model, resources assigned to children's disability services are allocated to the birth – 18 CDNTs, 91 Children's Disability Networks (CDN) have aligned to 96 Community Healthcare Networks (CHNs) across the country and each Children's Disability Network has one CDNT providing services and supports for children aged from birth to 18 years of age. Every child across the country with complex needs arising from their disability will have access to a CDNT

CDNTs are teams of health and social care professionals, including nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work and others. The team works closely together in a family centred model, focusing on the child's and family's own priorities.

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.

The range of posts recruited / in recruitment in 2021 include; dietitians, occupational therapists, physiotherapists, psychologists, speech & language therapists, nurses and some administrative support. These posts have been assigned based on a number of factors, including the existing ratio of staff to the number of children with disabilities in each area.

The special school posts were approved by the Minister of State for Disabilities to facilitate the provision of in-reach services to those special schools that have heretofore provided a school based service. These staff members will be employed as part of the new CDNTs and will report to the Children's Disability Network Manager. CHOs will ensure that the allocation of any posts to CDNTs are targeted towards providing appropriate interventions.

Services in most parts of the country have now reconfigured to CDNTs. The remaining teams in Mayo will be established before the end of 2021 thereby all 91 CDNTs will be in place and delivering services at that time. The newly established CDNTs are currently providing services for children in prioritised groups while also validating their new caseloads.



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.

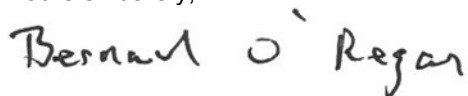
Down Syndrome Ireland has specialists in the areas of health, speech and language, early development, education and adult education and independence that enhance the lives of thousands of children and adults with Down syndrome across the country.

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 and provides nationwide support for children and families from birth to 18 years.

The HSE provided €139,394 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 2021.

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,



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

