



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
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13th April 2021

Deputy Holly Cairns,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: holly.cairns@oireachtas.ie

Dear Deputy Cairns,

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 16952/21

To ask the Minister for Health the support being offered to parents of infants and young children with Down syndrome born during the Covid-19 pandemic who have not been able to access the same range of support due to restrictions; and if he will make a statement on the matter.

“Clarification received from Deputy’s Office : Deputy Cairns was referring to specialist disability services, we were informed that parents would have access to support groups and be facilitated in meeting parents in similar situations ordinarily.”

HSE Response

In line with public health guidance, at the outset of the pandemic, Children’s Disability Services, along with many other services, were significantly reduced to limit exposure to COVID-19. Through the pandemic, services continued to be provided on the phone/online and also, face to face for some children and families with high prioritised needs, taking all of the required infection prevention and control (IPC) precautions and in line with HSE’s Alternative Models of Support (Non-Residential)(March 31st). Some services continued with staff working with service users and their families remotely and using technology in new and effective ways.

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. The impact of COVID-19 on people’s lives has and continues to be very significant. Our collective aim is to restore services in a safe way and in line with the very significant investment made by the State and funded agencies and we will continue to work with service users and their families/carers to ensure that we achieve this aim.

The HSE provides Guidance and Resources for Disability Services for COVID-19 to services, service users, carers, families, healthcare staff and service provider organisations. These are available under the tab HSE Approved Guidance for Disability Services at <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources>

This Guidance Documentation clearly maps the pathway of access to services and supports, commencing with on phone/online supports, and where that does not meet the needs of the child and/or their family, moving to face to face interventions and what is required to do so safely.

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

In addition to the information and resources provided by the HSE during this current difficult time, Down Syndrome Ireland also provides support and resources available at: <https://downsyndrome.ie/whats-happening/covid-19/>

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.

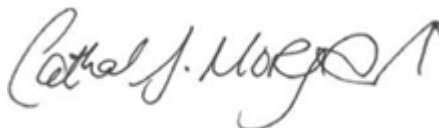
Children and their families will have access to the full range of services and supports of the CDNT according to their individual needs. This includes universal, targeted and specialist supports, such as individual therapeutic intervention and access to specialist consultation and assessment when needed. 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

Yours sincerely,



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