



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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29th April 2021

Deputy Bernard Durkan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: bernard.durkan@oireachtas.ie

Dear Deputy Durkan,

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 19731/21

To ask the Minister for Health the alternative options available to parents who are attempting to secure an autism assessment for their child but who cannot afford to wait the time via the public system or the fees via the private system; and if he will make a statement on the matter.

HSE Response

Children who may require a diagnostic Autistic Spectrum Disorder assessment can present either through children's disability services, through Child and Adolescent Mental Health Services (CAMHS), through Community Services or through the Assessment of Need process under the Disability Act 2005.

The HSE is not aware of alternative options or funding streams to to secure an autism assessment. With regard to private assessment, while in some instances, families source private assessments which may facilitate access to educational supports such as special schools or classes these are mostly unidisciplinary assessments. In general, HSE or HSE funded services, in line with best practice guidelines, use a multidisciplinary approach to assessment, specifically to ASD assessment. While these services will take cognisance of any unidisciplinary reports that may be available, they will undertake a multidisciplinary assessment where appropriate, to confirm a diagnosis and to determine the necessary interventions.

Review of the Irish Health Services for Individuals with Autism Spectrum Disorder

The implementation of the recommendations arising from the *Review of the Irish Health Services for Individuals with Autism Spectrum Disorder (2018)* were temporarily put on hold due to the Covid-19 pandemic.

This programme of capacity building and public awareness has a budget of €2m of new investment specific to the needs of this vulnerable group.

In accordance with the National Service Plan, the additional funding secured will be used in a number of priority areas:

- To implement a programme of awareness raising that can provide a better information resource for children and parents about what supports are available;
- To deliver a campaign to assist in creating awareness of the challenges, needs and experiences of people with autism; and
- To build capacity and competence amongst key professionals working with autism – including a national training programme for clinicians and the implementation of a tiered model of assessment in order to improve access to and responses by services for those with ASD.

The HSE's ASD Programme Board has re-engaged and has, for example, tasked, a multi-stakeholder working group (including individuals with ASD) to agree an Autism Assessment and Pathways Protocol that will realise a more streamlined clinical pathway for service users with ASD; improved collaborative working with parents; tiered or staged assessment; and more structured transition planning.

Working Group on Autism Innovation Strategy

On Friday 2nd April 2021, World Autism Awareness Day, Minister of State with responsibility for Disability, Anne Rabbitte T.D., announced her intention to establish a Working Group to develop a cross departmental Autism Innovation Strategy. Building on the work of the HSE's ASD Programme Board, the focus of the strategy will be to deliver a clear pathway of supports needed.

Assessment of Need

In respect of those children applying for an assessment under the Disability Act 2005, the Act gives an individual with a disability the right to an assessment of their health needs. The intention of the Assessment of Need process is to identify the health needs resulting from the child's disability. It is a matter for clinicians, based on their experience and qualifications, to decide how best to evaluate the needs at the time of the child being assessed. The Act does not give the right to a specific assessment at a particular point in time. Nor does it give a right to access to a diagnosis unless it is required at that time to identify the health needs occasioned by the disability.

The HSE records data, pertaining to the assessment of need process, under the Disability Act, 2005. The Act concentrates on identifying need and does not require diagnosis and the category of disability is only recorded where known. It should also be stressed that the Act currently only applies to those children born after 1st June 2002 and that not all eligible children apply for an assessment under the Act.

The Disability Act requires the HSE to provide a consistent approach to Assessments of Need across the country. The HSE acknowledges that this has not been the case and that approaches to assessment and waiting times have varied.

To help address this situation, the HSE has implemented a Standard Operating Procedure (SOP) for the Assessment of Need process to ensure that;

- children with disabilities and their families access appropriate assessment and intervention as quickly as possible;
- the approach to Assessment of Need is consistent across all areas.

In line with this procedure, an Assessment of Need will include a Preliminary Team Assessment that will identify initial interventions and any further assessments that may be required. This preliminary assessment will usually be undertaken by a children's disability service that are also tasked with delivering intervention. While not required by the Act, diagnostic assessments will continue to be provided, as appropriate, and these will be captured in the child's Service Statement as part of the Assessment of Need process.

These changes are intended to alleviate the current situation where children in some parts of the country may wait a number of years before they can access an assessment. During this waiting period, they often have little or no access to intervention or support. It is intended that the changes in the SOP, particularly the new preliminary assessment, will facilitate children with disabilities to access assessment in a timelier fashion.

The HSE believes that the implementation of this SOP and the planned reorganisation to Children's Disability Network Teams (CDNTs), will have a positive impact on the lives of the children and young people who require our services.

The recent allocation of €7.8 million through Slaintecare to address overdue Assessments of Need will further support the HSE and its funded service providers to meet the legislative timelines for Assessment of Need.

This funding has been allocated to CHO areas based on the numbers of overdue AONs at 30th June 2020. Each CHO area has developed a plan to address this backlog through a combination of:

- Restoration of relevant clinicians to children's disability services
- Waitlist initiative utilising existing clinicians working overtime at weekends or evenings
- Procurement of private assessments
- Commitment to filling maternity leaves
- Recruitment of Additional Clinical Staff for fixed term contracts of 6 months from 1/9/20

The HSE acknowledges the challenges in meeting the demand for children's disability services and is acutely conscious of how this impacts on children and their families.

Overall Reform of Children's Disability 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). This requires the reorganisation of all current HSE and HSE funded children's disability services into geographically-based CDNTs.

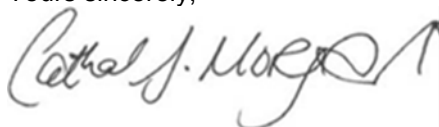
PDS is doing this by forming partnerships between all the disability organisations in an area and pooling their staff with expertise in the different types of disabilities to form the CDNTs. These teams will provide for all children with significant disability, regardless of their diagnosis, where they live or where they go to school.

The HSE is establishing a total of 91 Children's Disability Networks across each of the nine CHOs comprised of specialist inter-disciplinary Children's Disability Network Teams (CDNT) to work with children with complex disability needs and their families in an interdisciplinary, child and family centred approach. This reconfiguration of services under the Progressing Disability Services for Children & Young People (PDS) programme is in line with Health Service Reform and the implementation of Community Healthcare Networks under Slaintecare.

The 91 Children's Disability Networks (CDN) will align to 96 Community Healthcare Networks (CHNs) across the country and each Children's Disability Network will have one CDNT providing services and supports for children aged from birth to 18 years of age. On full reconfiguration of children's disability services into CDNTs, every child across the country with complex needs arising from their disability will have access to a Children's Disability Network Team.

To date, 67 CDNs have been established and it is envisaged that the remaining 24 CDNs will be established by end Q2 2021.

Yours sincerely,



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