Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Social Care Division,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369
Suíomh Gréasáin/Website: http://www.hse.ie

11th October 2021

Deputy Gino Kenny,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: gino.kenny@oireachtas.ie

Dear Deputy Kenny,

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 46124/21

To ask the Minister for Health the estimated full year cost in 2022 of clearing waiting lists for autism assessment.

HSE Response

Children who require a diagnostic assessment for ASD usually access these assessments through children's disability services (Children's Disability Network Teams – CDNTs or equivalent). However, some children will access these assessments through Child & Adolescent Mental Health Services (CAMHS) or through Primary Care. Children do not need to apply for an Assessment of Need under the Disability Act (2005) to access an ASD assessment.

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.

Diagnostic ASD assessments are in the main lengthy multidisciplinary assessments that include a number of components such as parent interviews, school observations and standardised assessments. The numbers of children requiring ASD assessment is very high and the impact of COVID-19 has also had an effect on waiting lists.

The HSE and disability service providers recognise the critical need and importance of disability supports for children with complex needs including autism and are very much aware of the importance of service provision for the families of children with disabilities. The impact of COVID-19 on people's lives has and continues to be very significant. Our collective aim is to continue the provision of services and supports based on prioritised needs of service users and their families in a safe way and in line with the very significant investment made by the State and funded agencies.

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 their diagnosis. Many children with a disability 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).

Progressing Disability Services

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 to provide equitable, child and family centred services based on need rather than diagnosis. The PDS programme will ensure that services are provided for children with complex needs regardless of where they live or where they go to school. Each Community Healthcare Organisation will work with key stakeholders in their area including parents and education services to ensure that appropriate arrangements are put in place to facilitate in-reach services to special school settings as appropriate.

The Progressing Disability Services for Children and Young People (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.

The HSE is committed to the full implementation of the Progressing Disability Services for Children and Young People Programme (PDS). 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 (CDNTs)

In line with the PDS model, resources assigned to children's disability services are allocated to the 0 – 18 Children's Disability Network Teams (CDNTs) rather than to a dedicated early intervention team or dedicated school age team.

91 Children's Disability Networks (CDN) are aligning 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. Early Intervention Teams and School Age Teams already in place are reconfiguring into 0-18 CDNTs. 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.

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. 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.

The first step for all areas is the reconfiguration of existing staff resources into CDNTs. The staffing mix available in each area will be influenced by the historical development of services. For example, some areas may have a significant number of nurses available for reconfiguration, others may have family support workers or early educators.

Since 2019, 285 development posts have been allocated to children's disability services across the country. This includes 100 posts allocated under the HSE National Service Plan 2021. 185 development posts were allocated to children's disability services across the country in 2021. 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.

In June 2021, the Minister of State for Disabilities confirmed that the HSE should progress the recruitment of 85 whole time equivalent (wte) posts 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 must 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 Community Healthcare Organisation 8 will be established before the end of November 2021 thereby all 91 CDNTs will be in place and delivering services at that time.

Assessment of Need under the Disability and Standard Operating Procedure

An internal HSE review of the practice of implementation of Part 2 of the Act in 2016 confirmed anecdotal evidence that the approach to AON was not consistent across the country. It was apparent that practice varied widely across the 9 Community Health Organisation (CHO) areas as well as within CHO areas. While a large number of "Guidance Notes" regarding AON processes had been issued since 2007, there had been no nationally standardised or agreed definition of an Assessment of Need. This led to an inconsistent approach to assessment as well as inequity in terms of time afforded to 'assessment' versus 'support or treatment' interventions with children and their families.

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, Stage 2 of the Assessment of Need process comprises 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 CDNT. The Standard Operating Procedure provides an indicative timeframe for this assessment, however, the format for each assessment is a matter for the assessing clinicians and will be based on the information provided through the stage 1 desktop assessment. 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 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.

In parallel with the development of CDNTs, the implementation of the Standard Operating Procedure for AON will facilitate the HSE to meet its statutory obligations under the Disability Act. It should be noted that a 2011 report by the National Disability Authority highlighted the fact that where services have reconfigured to geographically based CDNTs there is less reliance on the AON process. This eliminates the requirement for a legal determination to be made at a young age that the child / young person has a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment." It is the preference of the HSE that equitable, child and family centred services should be provided for all children and young people with complex needs regardless of their diagnosis and based on their level of need. Implementation of the PDS model of service will facilitate same.

Yours sincerely,

Bernard O'Regan

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