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1st March 2022

Deputy Jackie Cahill
Dail Eireann,
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Kildare Street,
Dublin 2.
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Dear Deputy Cahill

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 7883/22

To ask the Minister for Health his plans to improve autism services in County Tipperary; and if he will make a statement on the matter.

HSE Response

Disability services are provided based on the presenting needs of the individual rather than by their diagnosis or the actual type of disability or service required. Services are provided according to the individual requirements and support needs.

With regard to improvements in autism services, following the commissioning and publication of the *Review of the Irish Health Services for Individuals with Autism Spectrum Disorder* (the Review) the HSE commenced implementation of a Service Improvement Programme for the Autistic Community based on the recommendations of the Review. €2m funding was secured in the 2020 budget for this project.

National Autism Programme Board

A National Autism Programme Board was established with the responsibility for leading the implementation of the Review report recommendations. The Board consists of senior operational and clinical decision makers as well as independent professional / academic support.

Importantly, the Programme Board has representation of persons with lived experience of Autism participating as equal members of this collaborative team effort.

Implementation Priorities and Health Service Developments

In implementing the recommendations of the Review Report, the Programme Board has been tasked with leading out on an agreed set of priorities that will have greatest impact in terms of shaping how services can be delivered to people with Autism and in respect of creating greater awareness of Autism in terms of supporting communities in promoting inclusion and fostering positive attitudes.



The agreed set of priorities are summarised as follows;

- i.* Implement a Programme of Awareness Raising / Engagement with the Public;
- ii.* Build professional capacity and competence amongst key professionals working with Autistic people, including the implementation of a tiered model of assessment as recommended in the ASD Review Report.

Awareness Working Group:

Information available to the autistic community, family members, carers and service providers was limited and inconsistent from region to region and did not always reflect current understanding and approaches.

The HSE, through the work of the Awareness Working Group has taken a comprehensive approach to addressing this and is reviewing existing content, seeking the views of the Autistic Community, Family Members, Carers and Service Providers on this content and working to ensure it can be produced and made accessible to people all over the country, online and in print.

This quality process has been progressing and will continue into next year.

The Awareness Stream of the programme is designed to respond to the call for greater clarity amongst clinicians and service providers regarding both autism and the supports available to people with autism.

There are a number of individuals with the lived experience participating in this group.

- The availability of comprehensive accessible information relating to autistic people, their families, and healthcare workers working in the field
- The development of an online knowledge hub combined with a helpline aimed at providing contemporary information in relation to:
 - Location and types of services,
 - Tools and resources for service users, their families and clinicians and
 - Signposting to other essential community, voluntary and statutory based supports and services.

The outputs from this work will have wider application and benefits across all disability services.

Assessment and Pathway Working Group:

The Assessment and Pathways working group aims to develop a Standardised Assessment approach for use in all services dealing with the assessment of those with autism to ensure that every assessment is of an acceptable and agreed standard, regardless of which service is being accessed. In addition, it seeks to agree a standardised service user journey and the implementation of a consistent core service offering across those providing services to people with autism.

The Working Group, including people with lived experience of autism, has consulted widely with key stakeholders in the design and formulation stage of the project; this is particularly important in the context of the implementation of a tiered approach to assessment. The draft protocol is being piloted initially in four Community Healthcare Organisations. It will then be evaluated to inform the further iteration and development.

Overall Reform of Children's Disability Services

With regard to children with autism, 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. This aligns with the UN Convention on the Rights of People with Disabilities.



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.

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.

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 who have support needs can be effectively supported within mainstream 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).

Children's Disability Network Teams (CDNTs)

91 Children's Disability Networks (CDN) are 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. Early Intervention Teams and School Age Teams previously in place have reconfigured into 0-18 CDNTs. Every child across the country with complex needs arising from their disability now has access to a Children's Disability Network Team.

There are 8 CHN's in the Mid West with 7 CDN's aligned to these networks. North Tipperary CDNT is aligned with Networks 3 and 5 in HSE Mid West. In Tipperary South in Community Healthcare Area South East, there are two CDNTs; one based in Clonmel which covers children aged from birth to 18 years with complex needs who live in the areas of Cahir, Clerihan, Clogheen, Ardfinnin, Clonmel and Carrick On Suir; and one based in Cashel, which children aged from birth to 18 years with complex needs who live in the areas of Cashel, Tipperary Town and Slieveardagh. These teams of health and social care professionals include nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work and others. The teams work closely together in a family centred model, focusing on the child's and family's own priorities. Every child with complex needs has access to a team, regardless of the nature of their disability, where they live in Tipperary, or the school they attend.

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. Every child with complex needs has access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Children and their families 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 profile of children accessing the services of CDNT's has changed considerably over the years with a significant increase in Autistic Spectrum Disorder (ASD). It is estimated that an ASD assessment takes approx. 30 hours of clinical time to complete which impacts greatly on the CDNT ability to provide effective and timely supports to families and meaningfully address the waiting list for supports.

HSE Mid-West is currently implementing an ASD Waiting List Initiative to address the waiting times across all CDNTs. This will allow the CDNT to free up their clinician's time to engage in ASD family-centred practice across the Mid West, including North Tipperary.

This will involve a three-pronged approach to ASD Assessments:

A. Outsourcing ASD assessments - where the CDNT's feel it appropriate, full ASD assessments will be outsourced to private providers to complete ASD assessment.

B. The development of a Regional ASD Assessment Team for a defined period who would support the CDNT's in completion of ASD assessments being directly linked to the CDNT staff and families.

C. ASD assessments continue to be completed by the CDNT's.

It is envisaged that both strand A and B above would free up the CDNT's to provide ASD assessments for more complex cases, or when family situations do not support outsourcing of assessments.

Phase 2 PDS - Development of the Family Centred Practice Model across all CDNTs

Commencement of services in all 91 CDNTs by December 2021 marked the end of Phase 1 PDS.

Meanwhile, in parallel, phase 2, development of the interdisciplinary family centred practice (FCP) model of PDS, is now in train. This involves a significant mindset change for all stakeholders, including clinicians, families and referrers. Health and social care professionals (HSCP) are trained at undergraduate level to 'provide care and treatment' for children and their families typically in 'blocks of therapy' and this is what parents and referrers have come to expect.

However, there is growing evidence that this model of service provides limited skills retention and transfer into the child's everyday life. On the other hand, supporting and empowering families to work with their child in their natural everyday environment is 3 times more effective, 'the child or young person is not reliant on intense 1:1 input from 'specialists' but rather those who surround him/her day to day are empowered to maximise opportunities for growth and development in their everyday environments...effective in producing better outcomes' (Moore 2011).

The HSE has run 2 National Conferences in recent years, themed "Partnership" and "Family Centred Practice" respectively for staff and families to commence the move from unidisciplinary service provision to authentic child and family centred model of service. This was attended by 750 and 1500 participants respectively.

Subsequent to this, the HSE with its partner non statutory agencies developed and implemented a substantial **National Team Development Programme** to support Children's Disability Network Managers and their teams' development of FCP.

Tier 1: for all 91 CDNTs run online, capturing collective experience of those teams in place for a number of years was completed in Dec 2021. This is based on survey of CDNT development needs and includes plenaries, Q &A sessions and breakout rooms to maximise shared learning.

Tier 2 run online at CHO level by CDNTs with their staff on PDS and FCP.

Tier 3: is now being delivered by each CDNT with their team on PDS and FCP.



As the National Team Development Programme concludes, the HSE will launch the National CDNM Forum to ensure a continued drive towards consistent implementation of policy and model of service across all CDNTs so that all children with complex needs as a result of their disability have access to a similar type of service based on their individual need and regardless of where they live in the country.

In addition, following a 2-year pilot on implementing FCP in the 6 Midwest CDNTs, implementation of OCFE (***Outcomes for Children and their Families, a Performance Management and Accountability Framework for CDNTs***) will commence with a phased roll out of FCP model across all remaining teams in Q1 2022.

Yours sincerely

A handwritten signature in black ink that reads "Bernard O'Regan". The signature is written in a cursive style with a clear, legible font.

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