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3rd August 2022

Deputy Éamon Ó Cuív,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: eamon.ocuiv@oireachtas.ie

Dear Deputy Ó Cuív,

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: 41804/22

To ask the Minister for Health when comprehensive services will be available to autistic children from their local children's disability network team nationally; the shortfall in staff in each CDNT at present and the grades and specialities involved; the steps that are being taken to rectify this issue; the reason that full early intervention is not being provided given that it is recognised to be vital in terms of long-term outcomes for children; and if he will make a statement on the matter.

HSE Response

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.

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

The principle and importance of early intervention is recognised by the HSE across its services and in particular in the context of the services and supports it provides to children with disabilities, and their families. Additionally, in developing the national policy for the provision of children's disability services, the focus of the HSE is to ensure that services are:

- Reflective of best national and international practice
- Responsive to the requirements of the UN Convention on the Rights of Persons with Disabilities
- Family and child centred
- Provided as close as possible to the community where children and their families live in line with Sláintecare.

Progressing Disability Services for Children & Young People (PDS)

The implementation of the 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 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, access to children’s disability services has changed 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 or where they go to school.

PDS is a significant change programme for the provision of services and supports for children from birth to 18 years of age, 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 Access Policy

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 i.e. Primary Care for non-complex functional difficulties and Children’s Disability Network Teams for complex functional difficulties.

Children’s Disability Network Teams (CDNTs)

In line with the Progressing Disability Services 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.

In 2021, the remainder of ninety-one multidisciplinary CDNTs were established in 96 Network areas to provide services and supports for all children with complex needs within a defined geographic area.

Since 2019, more than 475 development posts have been allocated to children’s disability services across the country. 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.

Work is ongoing on mapping specialised services and supports, and paediatric supports available and gap analysis for children with highly complex needs including autism, in order to develop standardised approaches to integrated pathways of support for CDNTs and Primary Care staff.

A Children's Disability Network Team (CDNT) Staff Census and Workforce Review was undertaken in October 2021 and a final report has been issued to the Department of Health and relevant stakeholders. This report has provided valuable information on the number of staff working in the CDNTs by discipline and grade and staff vacancies at a point in time. Vacancies continue to be tracked monthly.

Please see copy of the attached report for your information. This gives the information that you are requesting and also gives the number of CDNTs in each Community Healthcare Area and their local area.

The vacancy rate at the time of this staff census was 28%.

The information from the Census Report is supporting targeted workforce planning by the HSE in consultation with the CDNT Lead Agencies to reinforce the skill mix of their teams to accommodate local population need.

Most of the disciplines working in CDNTs are similar to those working in other areas of the health services including Primary Care Services, Mental Health Services, Older Person Services and Acute Hospitals. The HSE experiences ongoing challenges recruiting staff across a range of disciplines and grades.

The HSE continues to explore a range of options to enhance the recruitment and retention of essential staff across all aspects of the health services. In addition, the HSE is working collaboratively with the CDNT Lead Agencies at CHO level to market CDNTs as an employer of choice in a competitive employment market. Each lead agency is responsible for recruitment of staff on their CDNTs and is using a variety of approaches to fill funded vacancies.

Options regarding the recruitment of staff, including psychologists, for the CDNTs being explored in the first instance include:

- Targeted National Recruitment for CDNTs
- Targeted International Recruitment for CDNTs with the possibility of a relocation allowance
- Sponsorship Programme
- Apprentice Programme for therapy grades
- Employment of graduates as therapy assistants as they await CORU registration
- Expansion of therapy assistants in the system with HSE supporting individuals to return to education to quality as therapists.

The Community Operations, Disability Services is actively developing business propositions for approval by HSE National Human Resource Services

A comprehensive PDS national team development programme has been provided for CDNMs and cascaded to all team members. This programme, which was designed to support the establishment of the new CDNTs and to support the implementation of the new model of service, will also support staff retention.

Ongoing Developments and Improvements in Childrens' Disability Services

With all 91 teams in place, the primary focus now is development of the interdisciplinary family centred practice (FCP) model consistently across all teams. Moving from the traditional deficits focused 'Expert/Medical' model to a strengths based, child and family outcome focused model involves a significant mind-set change for all stakeholders, including health professionals, families and referrers.

All children develop and learn by taking part in daily life and activities with their family, in their home, in pre-school, in school and their community. The child's family and those who are with them every day are the most important people in their lives. Family centred practice focuses on the child and family's strengths, capacity and skills. The family and team work in equal partnership to explore the child and family's daily routine and to identify the child and family's priorities and goals and how the team will support them to achieve their goals.

Following on from the National Team Development Programme, HSE Disabilities is commencing a National Support Programme for CDNTs in Family Centred Practice, including service planning and delivery with families.

National Autism Programme Board

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.

The Service Improvement Programme (SIP) 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 important 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;

- Implement a Programme of Awareness Raising / Engagement with the Public;
- 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

The Awareness Stream of the programme aims to build Awareness of Autism, and the services and supports available to autistic people, both within the Service User, Family Member and Carer communities and within the Service Providers themselves.

It is designed to respond to the call for greater clarity amongst clinicians and Service Providers regarding both Autism and the supports available to autistic people by firstly developing a programme of better information for autistic people and their families, helping them to find services, access support and understand their condition better and secondly providing guidance to clinicians and service providers.

These objectives will be achieved by:

- Mapping and gathering information and resources relating to Autism by reviewing both national and international practices – 25% complete and work ongoing
- Review material available to provide information on services and supports. – 30% complete and work ongoing
- To explore gaps within resources available To engage with key stakeholders on the final set of information products and communication means. This will align with the standardised pathways which the Assessment and Pathways are working group to see section 2 hereunder
- To generate content for an online and print resource emerging from the above –
- To launch and promote the new information products

Unfortunately, the Awareness stream of the project was vastly impacted and paused due to the Covid-19 Pandemic and the responses required of the Health Service. The project has recommenced and work will continue to be progressed in Q3 and Q4 2022.

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 offered across those providing services to people with Autism.

An interdisciplinary working group with lived experience representation was established and over 12 months period they developed a protocol to streamline autism assessment and intervention and match these to the complexity of presentation. The piloting of this protocol has now commenced. The tender for the independent evaluation of the Autism Assessments & Interventions Pathway Protocol was awarded to the Centre for Effective Services in December 2021, the service contract began in January 2022.

To assist the pilot phase an Expert Advisory Group (EAG) has been formed to provide oversight and advisory to the external independent evaluators Centre for Effective Services. The EAG comprises of one member with a clinical background, one member with lived experience and one member providing advisory relating to research, academic and ethical matters.

The participating pilot sites are within CHO 2, CHO 7 and CHO 9. The fourth pilot site envisaged to participate at tender stage (CHO 4) were unable to proceed due to a number of changes and challenges within their CHO at the time of commencement.

The pilot commenced over the three sites in February 2022, this involved engagement on the co-design and development of a tracker tool to track and assess the data throughout the pilot. The tracking and evaluation of the protocol is currently in progress and will run for a three month period. Fieldwork and interviews with service users and service providers will take place throughout July and August as part of the overall evaluation.

To date, there has been 22 service users assessed or have assessments scheduled in the coming weeks, this figure is expected to increase monthly.

The first stage of the pilot and evaluation will run up to September 2022 with an initial report due in October 2022. The second stage of evaluation will run to the end of March 2023, with the final report due by 24th May, 2023. The budget for stage two of the evaluation has been approved and we are currently engaging with HSE Procurement for re-tendering of the second stage of evaluation.

Yours Sincerely,

Bernard O' Regan

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