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22nd March 2023

Deputy Pauline Tully,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: pauline.tully@oireachtas.ie

Dear Deputy Tully,

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: 11586/23

To ask the Minister for Health if the condition 16p12.2 microdeletion is accepted as being on the autism spectrum; and if he will make a statement on the matter.

HSE Response

A 16p12.2 microdeletion is a rare genetic condition caused by a tiny missing part of one of the body's 46 chromosomes – chromosome 16. For healthy development, chromosomes should contain just the right amount of material – not too much and not too little. Even a tiny piece of missing material can disrupt development, although it doesn't always do so.

It has been estimated that the incidence of 16p12.2 microdeletion is about 1/15,000. There seems to be a large variability in the clinical features of people with a 16p12.2 deletion. Additionally, every person with a 16p12.2 microdeletion is unique and so each person will have different medical and developmental concerns.

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.

Children who may present with an Autistic Spectrum Disorder can present either through; Primary Care Services, through Children's Disability Network Teams (CDNTs), through Child and Adolescent Mental Health Services (CAMHS), or through the Assessment of Need process under the Disability Act, 2005.

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.

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 with ASD may access supports from a Children's Disability Network Team or from Primary Care depending on the complexity of their needs.

Children's Disability Network Teams (CDNTs)

There are ninety one Children's Disability Network Teams (CDNTs) providing services for children with complex disability needs aged 0 – 18 years.

Regardless of the nature of their disability, where they live, or the school they attend, every child with complex needs including autism and their families have access to the full range of family centred services and supports of their 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 are provided as is feasible in the child's natural environments - their home, school and community.

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

Autism Service Improvement Programme

In addition, there are ongoing improvements in the provisions of services for children and adults with autism.

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.

This work takes two specific forms. First, there has been a Task Group established under the National Clinical Programme for People with Disability to design improvements in disability services generally. This group is a multi-stakeholder group with lived experience representation. Secondly, and more specifically related to autism, a Service Improvement Programme for the Autistic Community has been commenced.

National Autism Programme Board

This programme was subsequently renamed to The Service Improvement Programme (SIP) for the Autistic Community, due to use of language and that we should refer to autistic people.

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. The programme aims to respond to the need for



greater awareness amongst clinicians and the general public regarding both autism and the support for Service Providers working with autistic people.

In tandem with the above, the HSE agreed to fund AsIAm to provide a phone line for the autistic community for a three-year period.

AsIAm Phone Line for the Autistic Community

Supported by the HSE, the Information Line operates for 4 hours per day, five days a week. The calls are responded to by either a clinician or an appropriately qualified autistic advisor to ensure appropriate responses and supports to meet the needs and concerns of the range of callers and to inform follow-on activity.

The aim of the service over the next three years will be to develop the range of information resources, seminars and programmatic activity so that callers will receive the information and support they need. The service will operate within the partnership for change model, building on the capacity of individuals and families to manage the challenges of everyday life. All callers will receive a follow-on email summarising their call and where required, will be provided with follow-on information and supporting methods/tools.

The service will be widely promoted nationally through a co-branded information campaign and will operate on both a phone line and instant messaging basis.

Annual insight reports, in addition to interval data reports, on calls received and topics explored, will be provided to inform HSE and Government policy in the area of autism.

Yours sincerely,



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

