



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
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22nd May 2019

Deputy Clare Daly
Dail Eireann,
Leinster House, Kildare Street,
Dublin 2.
e-mail: clare.daly@oireachtas.ie

Dear Deputy Daly

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 20330/19

To ask the Minister for Health if the healthcare assessment and needs of children suspected of having foetal valproate syndrome will be prioritized; and if there will be no delay in diagnosis and service provision.

HSE Response

The National Valproate Response Project Team

The National Valproate Response Project Team is currently considering a proposal submitted by a subgroup on community support services for those persons (and their families), who have a Foetal Valproate Syndrome (FVS) diagnosis also referred to as a Foetal Anticonvulsant Syndrome (FACS) diagnosis specific to past exposure to Valproate during pregnancy.

The HSE has agreed to establish a dedicated genetics service in the National Children's Hospital Group, based in Crumlin Hospital. This includes a dedicated Consultant Paediatrician, a dedicated Consultant Geneticist, Administrative Support and Laboratory Technician.

A Consultant Paediatrician has been appointed and is in post. She has seen 23 patients to date who have been referred with suspected FVS. There is no waiting list.

A recruitment campaign is on-going to fill the consultant geneticist post. Patients with suspected FVS are currently referred to the General Geneticist Department in Crumlin Hospital.

A care pathway to provide support to patients who have been diagnosed with FVS is currently being finalised as part of the HSE Valproate Response Project. The pathway will be included as a recommendation in the final report to HSE Leadership and the Department of Health for consideration.

Progressing Disability Services

The HSE is rolling out the Progressing Disability Services for Children and Young People (PDS) Programme, which requires a reconfiguration of all current HSE and HSE funded children's disability services into geographically-based Children's Disability Network Teams (Early-Intervention and School-aged or 0-18 Teams). This Programme aims to achieve a national equitable approach in service provision for all children based on their individual need and regardless of their disability, where they live or where they go to school.

Based on the recommendations of the Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years (2009), its objectives are:

- One clear pathway to services providing equity of access for all children with disabilities, according to their need.
- Effective teams working with partnership with parents and Education to support children in achieving their potential.
- Available resources used to the optimum benefit for children and their families.

Current Status:

Fifty six Children's Disability Teams have already been established with a further eighty two Children's Disability Network Teams to be reconfigured from existing services in 2019. However, and in light of Health reform which seeks to have "Networks" in place, HSE is well underway in terms of establishing a total of 96 Children's Disability Networks across each of the nine CHOs. A key enabler to establishment of the remaining Children's Disability Network Teams is the recruitment of the Children's Disability Network Managers. These posts were advertised on 19th November 2018. It is envisaged that the Children's Disability Network Managers will be in place in Q2 2019.

National Policy on Access to Services for Children with a Disability or Developmental Delay

HSE Disability and Primary Care services are working together to support the implementation of the HSE's National Policy on Access to Services for Children with a Disability or Developmental Delay. This policy will provide 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).

It is expected that the re-configuration of services under Progressing Disability Services (www.hse.ie/childdisability) for Children and Young People (0-18s) Programme will have a significant impact on our ability to meet the needs of children and young people in a more efficient, effective and equitable manner and, in particular, on our ability to comply with the statutory time-frames set out in the Disability Act.

Other additional resources

New Therapy Posts

The Budget 2019 provided an allocation of funding for 100 therapy posts to address Assessment of Need waiting lists. This will enable the HSE to reduce the waiting list for Assessment of Need under the Disability Act and to drive implementation of the Progressing Disability Services for Children and Young People Programme through new staff appointments to reconfigured multi-disciplinary, geographic-based teams.

Table 1 below outlines the allocation of posts per CHO area. The posts are allocated and recruited on a phased basis with the target for all posts to be in place by the end of Quarter 4 2019.

Table 1: The phased allocation of posts is outlined per CHO in the table below.

CHO	Phase 1 1/4/19	Phase 2 1/6/19	Phase 3 1/9/19	Phase 4 1/11/19	Total
CHO1	0	3	4	5	12
CHO2	0	1	1	1.5	3.5
CHO3	0	2	5	5	12
CHO4	3	0	0	3	6
CHO5	5	5	0	5	15
CHO6	0	1	1	1.5	3.5
CHO7	6	4	0	3	13
CHO8	0	10	9	0	19
CHO9	6	4	0	6	16
Total	20	30	20	30	100

The 100 therapy posts provided in Budget 2019 have been allocated to each of the Community Healthcare Organisations to recruit on a phased basis. Each CHO area is currently finalising their decisions regarding the allocation of these posts across their network areas.

Yours sincerely,



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



Seirbhís Sláinte
Níos Fearr
á Forbairt

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Service