Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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12th April 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 questions, which were submitted to this department for response.

PQ: 14472/23

To ask the Minister for Children; Equality; Disability; Integration and Youth if consultation took place with therapy professionals representative organisations (details supplied) before or during the process of introducing the progressing disability services model; if he will detail the contents of this consultation; and if he will make a statement on the matter.

Details supplied: The Psychological Society of Ireland, The Irish Association of Speech and Language Therapists, The Association of Occupational Therapists of Ireland.

PQ: 14477/23

To ask the Minister for Children; Equality; Disability; Integration and Youth if consultation took place with therapy professionals representative organisations (details supplied) with regard to the interim clinical guidance for assessors involved in the assessment of need process; if not, the reason therefor; and if he will make a statement on the matter.

Details Supplied: The Psychological Society of Ireland, The Irish Association of Speech and Language Therapists, The Association of Occupational Therapists of Ireland.

HSE Response

Progressing Disability Services

Historically services for people with a disability in Ireland were provided by religious orders and later by voluntary parent and friends associations. Some organisations provided services for people with a specific type of disability or in a specific age group. This resulted in a wide variation in the availability of services and in access criteria to services depending on where a child lived or what diagnosis they had. For example, in one area a child with a physical disability may have had a very good service and a child with ASD may have had no service; equally, children with a particular diagnosis living in one part of the country may have had access to a local disability service but not children with the same diagnosis in another area.

The Progressing Disability Services for Children and Young People Programme (PDS) was developed to address this significant variance and risk. It 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) and supported by the NDA reports of 2011 and 2015, 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.

The PDS programme is agreed Government and HSE policy and 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.

Please see the attached report reference above. The Reference Group was representative of a wide range of health and social care professions including Occupational Therapy, Speech and Language Therapy, Physiotherapy, Psychology, Social Work, Medical, Nursing and management personnel involved in delivering multi-disciplinary services to children.

The Reference Group acknowledged that in the implementation of an integrated model of working for school aged children that there would be need for changes to certain work practices and terms and conditions of employment. It was recognised by the group that this could be achieved through appropriate consultation, engagement and agreement in the partnership process.

At the launch of the PDS Programme, a multistakeholder National PDS Coordinating Group was established to drive this change programme. The group included representatives from National and Regional HSE, Department of Health, Disability Federation Ireland, National Federation of Voluntary Bodies (now National Federation of Voluntary Service Providers), Not for Profit Business Association (now National Disability Services Association), Inclusion Ireland, National Council for Special Education, Department of Education and parent voices. The National PDS Co-ordinating Group and its successors established several working groups on specific aspects of the programme e.g. Team Composition, Training and Development, National Access Policy, Prioritisation of Referrals. In all cases, these working groups included a number of health and social care professionals.

Twenty four Local Implementation Groups (LIGs) were established in the Local Health Forum structures of the health service at that time. These groups were multistakeholder, including representatives from each of the HSE and HSE funded voluntary organisations involved in the reform programme and all health and social care professionals transferring to the new teams. LIGs were mostly led by a Disability Manager or Head of Discipline. The role of the LIG was to develop and implement their local PDS Implementation Plan in line with national guidance and template. They reported monthly into the National PDS Coordinating Group via their Regional HSE Reps.

in due course, the National PDS Coordinating Group was replaced by the National PDS Working Group, subgroup 3 of Working Group 2 under *Transforming Lives*, and finally to the National CDNT Steering Group, as all teams are now in place, and the focus is on developing a child and family centred service model across all teams.

The National CDNT Steering Group developed the *CHO Governance of Children's Disability Networks Policy 2021* to standardise governance structures and processes across all 91 teams and

Lead Agencies nationally. This structure includes the Clinical Advisory Group led by a Children's Disability Network Manager which comprises of all relevant health and social care professionals with child disability competencies and experience. The review of this policy and its implementation currently in train has included a number of consultations including with Disability Advisory Groups reps under the HSE's National Clinical Programme for People with Disabilities.

The National CDNT Steering Group has established a National Children's Disability Network Managers (CDNM) Forum, comprising 30% rotating members of the 91 CDNMs nationally, tasked with driving a standardised approach to service development and provision across all teams and lead agencies. All CDNMs are clinicians registered with CORU, of if a psychologist, eligible for membership of Psychology Society Ireland.

The HSE is satisfied that the PDS consultation process was robust and included representation from relevant stakeholders including clinicians.

Assessment of Need

The Disability Act (2005) provides for an Assessment of Need (AON) that outlines the health and education needs for people born on or after 1st June 2002 who are suspected of having a disability.

The HSE has endeavoured to meet its legislative obligations under the Act. However, as a consequence of a High Court ruling of December 2009, the effect of which was to open eligibility to all children born after 1st June 2002, the number of children aged five and over, and in addition of school-going age, has risen steadily as a percentage of all applications received. At the end of 2011, the figure stood at 26%, while throughout 2022, this figure averaged 55%. This is a reflection that the AON process is an accumulative process in terms of numbers of children seeking access.

The Act does not define 'assessment' and it was apparent that the process was not standardised across the country. It has been widely acknowledged that compliance with the statutory timelines for AON is a significant challenge for HSE and HSE funded services. There were legitimate concerns arising regarding equity of intervention additional to assessment of need.

In 2017 the HSE in response to the need to have a standardised approach to undertaking an AON and having proper regard to "assessment" and "equity of intervention", developed an outline of a Standard Operating Procedure [SOP] for AON. In September 2017 a consultation workshop was held with key stakeholders. Each Community Healthcare Organisation was invited to nominate six representatives to participate in the workshop. Attendance included:

- Assessment Officers
- Liaison Officers
- Community Health Doctors / Community Paediatricians
- Consultant Psychiatrist
- Occupational Therapists
- Physiotherapists
- Psychologists (14% of attendees)
- Speech & Language Therapists
- Service Managers

Following the workshop, a wide range of e-mail submissions were received representing a range of individuals and groups. The feedback coupled with legal advice informed the development of the SOP that was also reviewed by the HSE Leadership Team and circulated widely in December 2017. Further consultation with stakeholders and staff representatives groups continued and the SOP was implemented for all new applications for AON from 15th January 2020. This SOP included a standardised approach to assessment which was described as a Preliminary Team Assessment.

The HSE is satisfied that the consultation process was robust and included representation from relevant stakeholders including members of the professional associations referenced in the PQs. The HSE has also consulted with the Department of Health and the Disability Appeals Officer.
The judgement of Ms Justice S Phelan in the case of CTM & JA v the HSE on 11th March 2022 found that the Preliminary Team Assessment approach described in the HSE's Standard Operating Procedure for Assessment of Need does not meet the requirements of the Disability Act. This judgement in effect requires the HSE to deliver diagnostic assessments where necessary and appropriate as part of the Assessment of Need process. This ruling has a significant impact operationally and has resulted in a growth in the numbers of overdue Assessments of Need. The requirement for services to prioritise the statutory Assessment of Need process will also impact significantly on their capacity to provide necessary intervention / treatment for children with disabilities.

The HSE is continuing to review the files of all children who received a preliminary team assessment and engaging directly with families to establish what additional assessments will be required to meet the requirements of the Act.

Approximately €11m has been allocated to address waiting lists for clinical assessments identified through the Assessment of Need process. This funding will be utilised to procure diagnostic ASD assessments from the private sector. A successful procurement process will facilitate the Children's Disability Network Teams to focus on the provision of intervention for children on their caseloads.

The HSE's National Clinical Programme for People with Disability (NCPPD) has led the process of developing Interim Clinical Guidance to replace the Preliminary Team Assessment.

This new Interim Clinical Guidance has now been clinically approved. There has been engagement with staff representative bodies and will be implemented following approval by the Department of Health.

The HSE is committed to the delivery of appropriate services for children with disabilities and working with families and staff to develop services that meet their needs.

Yours sincerely,

Bernard O' Regan

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