Statement by Dr Noreen O'Leary and Assistant Professor Geraldine Moran to Meeting of the Oireachtas Committee on Disability Matters on Wednesday, 22 May 2024

Key Message: The HSE'S Progressing Disability Services (PDS) for Children and Young People is not Evidence-Based

We thank Deputy Moynihan and the committee members for the opportunity to present our review and recommendations.

Our background is that we are both CORU registered speech and language therapists who have worked in Children's Disability Services, both before and after reconfiguration. My experience has been over a ten-year period in early intervention and community services for school aged children, while my colleague Geraldine has worked across a number of Special Schools over 15 years. We are both involved in academic research roles at present. Our impetus for undertaking this review came from our frontline experiences and deep concerns about the current and future state of Children's Disability Services.

We analysed twenty-eight HSE key policy and procedure documents to determine the evidence base for PDS. Evidence-based practice means that we question what we do, we make decisions based on the best data available and consider its possible limits. Therefore, the aim of our review was to analyse the key policy and procedure documents to determine the evidence-base for PDS.

Within these key documents was a 72-page "Report of Reference Group on Multi-disciplinary Services for Children aged 5 to 18 Years" that was described as "*the foundation for the PDS programme's planned changes.*" We found that the report is not clear on how evidence from existing models of service delivery for disability services informed the development of PDS. There seemed to be an assumption that equality (giving everyone the same service) would lead to equity (giving everyone what they need based on individual needs). There is evidence that this practice has not succeeded and may have created a situation where many children now have less access to services. Children are waiting on lists for services instead of the integrated system that was promised. Access can be a postcode lottery. In creating the final model underpinning PDS it is stated in the report that the group "*used fictitious scenarios to test out the proposed structure of services and determine service pathways for children.*" That process is confirmed in the minutes of the Reference Group meeting of 6 November 2008.

An unchallenged assumption of PDS within the documents reviewed was that reconfiguration in of itself was equivalent to improving service quality and access. While service reconfiguration can contribute to overall healthcare improvement, it must be combined with measures to strengthen how care is delivered, cultivate a culture of improvement and be grounded in the best available evidence. When reconfiguration lacks a robust evidence base against which to plan and evaluate the reconfiguration process, it creates a significant risk for clinical services, including for those who deliver and access them. This can be seen in the current PDS situation regarding staff retention and wait times for services. The absence of evidence-based implementation strategies for PDS likely further contributed to challenges.

A key recommendation of the Global Report on Children with Developmental Disabilities (WHO and UNICEF Sept 2023) was the need to strengthen the capacity of disability services to provide inclusive and people-centred evidence-based care which can be responsive to evolving healthcare needs. It is not suggested that there is one specific model would be a panacea for disability services. The multi-factorial nature of these services requires flexible and evolving models, but this does not preclude applying and adapting evidence-based models. PDS was an aspirational vision to achieve equity across children's disability services. However, aspiration needs to be matched with evidence, especially when dealing with complex health services like children's disability services. Minister Anne Rabbitte has stated that *"I can see the policy is not working and I am trying to fix it".* As the HSE seeks to address some of the visible challenges relating to the level of service being provided and to staffing, it is imperative that it tackles the problem of developing a fit for purpose and evidence-based delivery model for the complex area of children's disability services.

Recommendations

We recommend the following:

- Review and revise the service-delivery model underpinning PDS so that it is based on:
    - Systematic and comprehensive research to identify current disability models of service delivery internationally
    - Critical analysis of service delivery models with a view to determining applicability to the Irish context and understanding the need for differentiation across this large and complex population
    - Meaningful engagement with key stakeholders including clinicians, parents/carers and children and young people with disabilities, incorporating their perspectives on what features are required for an effective service
    - Engage with multi-sectoral stakeholders to integrate evidence from relevant bodies beyond health care, e.g. education, transport and housing bodies.

- In any future reconfiguration of services, it is imperative to ensure that features of existing services that are delivering successfully for clients are maintained and integrated into any new model, or if ceased that this is a decision well supported by practice and research evidence.

- Programmes of reconfiguration need to be rolled out in conjunction with quality improvement and change management strategies.

- In the complex area of disability, new developments in delivery models and frameworks are happening at the international level, hence, there is an ongoing need to monitor and evaluate these developments and be able to adapt service delivery methods in order to achieve improvements and greater effectiveness for children and families in the Irish context.