

# **Joint Committee on Disability Matters**

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## **OPENING STATEMENT**

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**Mr Bernard O'Regan**

**HSE Head of Operations – Disability Services**

**26<sup>th</sup> January 2023**



Good morning Chairman and members of the Joint Committee. Thank you for the invitation to attend the Committee meeting to give “Consideration of Family Centred Practice and Parent Training Interventions”, including a Family Centred Practice approach in CDNT’s, Individual Family Service Plan, Governance and aligning with the UNCRPD.

I am joined today by my colleagues:

- Professor Malcolm MacLachlan, Clinical Lead for National Clinical Programme for People with Disability
- Angela O’Neill, National Disability Specialist, Children’s Services
- Caroline Cantan, National Programme Co-Ordinator, Progressing Disability Services for Children and Young People

The United Nations Convention on the Rights of Persons with Disabilities requires us to provide a social model of support that facilitates disabled people to achieve maximum independence. The traditional, expert led model of service provision is no longer fit for purpose. A family centred model of support aligns with current international best practice and policy direction.

Family-centred Practice (FCP) recognises that families know their child best and professionals bring knowledge, skills and experience in disability. Together family and team can work towards best possible outcomes for the child to live the life of their own choosing.

The family and the CDNT focus on what is uniquely important to the child and their family in their everyday life, and work to achieve the goals they have chosen. FCP is therefore a vehicle for services to better support child and family outcomes.

From the first contact, service professionals, researchers, planners, and policy makers must recognise and strengthen the primacy of the family. Services are based on a partnership between families and team members.

The team works with the child and family to explore what everyday life is like, to identify the family's choices, their priorities and how to achieve them and how the team can support them.

Family centred practice and interdisciplinary team working are recognised worldwide as optimal to support children with disabilities and their families to reach their best possible outcomes. There is extensive literature supporting the model.

Each family's Individual Family Support Plan enables joint priority setting and collaborative working between families and staff. The HSE has developed and issued guidance and tools for staff to assist in this work.

There are broadly three types of support provided to children and families. The support required is determined by the needs of the child and family and set out in the Individual Family Support Plan. Each level of evidence based support has an important part to play in meeting the needs of a child.

- **Universal Supports**

Universal supports are used when a child has needs which many children with disabilities and their families share. Universal supports are usually delivered through information sessions, talks and workshops for families on topics such as sleep, toilet training and communications.

- **Targeted Supports**

Targeted supports are helpful for needs which some children but not all children with disabilities and their families share. They include well-recognised and evidenced programmes for children and 'or for parents. Bringing children together is more enjoyable for them and they learn from each other. Bringing families together with common and shared challenges can be powerful.

- **Individual Supports**

Individual supports address a child or family's specific individual needs. This can be the child's movement difficulties, feeding and communication difficulties.

As well as delivering a Family Centred Practice approach, our CDNTs must also incorporate the requirement to provide existing assessment and intervention services as necessary.

The following principles are fundamental:

1. Families and services listen to the child and strive to achieve the best possible outcomes for that child.
2. Families are fully capable of making informed choices and acting on their choices. Parent/carers have the ultimate responsibility for the care of their children and for all decisions made about them.
3. Services exist to support children and families to attain the best possible outcomes.
4. Interventions are appropriate to the needs of the child and family, and emphasise capacity-building, strengthening existing skill sets, promoting the acquisition of new skills, medical care, and other supports; and
5. Children, families, and service providers all benefit most when services are based on true collaborative partnerships between families and professionals.

We are happy to answer any questions Committee members may have.

**Thank you.**