HSE Briefing Note

For

Joint Committee on Disability Matters

On

Family Centred Practice

January 2023

Family Centred Practice

Family Centred Practice is a model of care which prioritises and promotes the strengths and abilities of the family; it recognises the family as unique and central in the delivery of services. The adoption of a child and family centred approach is a fundamental principle of the Progressing Disability Services for Children & Young People Programme (PDS). Importantly, Family Centred Practice is a philosophy of care rather than a set of standardised interventions and practices.

There is a strong body of evidence that supports the use of Family Centred Practice for children with disabilities. It first emerged in the 1950s in the UK and US as an alternative to the paternalistic and expert-led paediatric disability and hospital care of the time. Over a number of decades there has been a very clear move to a social model of disability care. Children's disability services in Ireland, like other countries have developed to incorporate both medical and social perspectives through an interdisciplinary biopsychosocial model.

The bio-psychosocial model is a broad view that attributes outcome to the interaction of biological factors (genetic, biochemical, etc), psychological factors (mood, personality, behaviour, etc.), and social factors (cultural, familial, socioeconomic, medical, etc.). Services are delivered holistically, focusing on all aspects of a child and young person's and family's life, particularly in the context of the community and society. The model promotes the idea that society and the environment must recognise and accommodate individual needs, based on dignity and respect, supporting and facilitating children and families to access and be included in their community and society. This involves working in partnership with families and the wider community.

The United Nations Convention on the Rights of People 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 also with the agreed Progressing Disability Services policy.

Expert or medical model	**Family Centred Model**
Focus on child's deficits and how to fix them	Focus on strengths as well as difficulties
Professionals have the answers	Fits in with everyday life for this family
Blocks of 1:1 therapy in a clinic	What are their choices and priorities?
Limited retention of skills in everyday life	Team brings their expertise to work 'with' the child and family rather than 'to' or 'for'
Competence lies with professional not parent	Builds family's competence

Children's Disability Network Teams

In line with the Progressing Disability Services model of service, 91 Children's Disability Network Teams have been established to provide interdisciplinary supports for children with complex disability needs and their families. The staff on these teams will work together to deliver Family Centred Practice.

Unfortunately, some stakeholders perceive this as a poorer quality model of support and believe that interventions like parent training are provided because of a lack of suitably qualified clinical staff. While resourcing and recruitment challenges are acknowledged, this model of care has been implemented because it is acknowledged as the most appropriate way to support children with disabilities to become active members of our society.

All children develop and learn by taking part in daily life and activities. The child's family and those who are with them every day are the most important people in their lives. Life happens at home, in pre-school or school and with friends, not in a clinical setting. Therefore, services must support the significant people in the child's day to day life in order to support the child's development. Children's Disability Network Teams support families to develop the additional skills required to meet the demands of parenting a child with a disability.

Example of working with the child's natural environment and daily routines

Chloe aged 2 has low muscle tone and uses a Kaye walker. Her family want her to develop her independent walking.

During a video call 'home visit' the physio sees Chloe with the family's cat. The physio and parents work out together how Chloe could help to feed the cat. With her father's help and brothers' encouragement, Chloe collects food in a bucket and happily walks to put it in the cat's bowl.

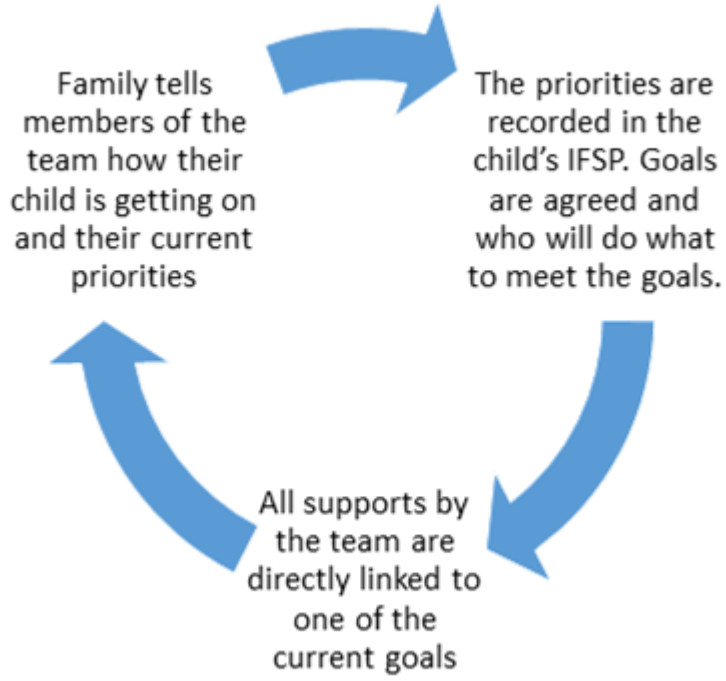
This is more effective in encouraging Chloe's walking than attending physio sessions in a clinic. She is doing something she is interested in, at home and every day.

Family centred services require the team and the family to work collaboratively. To facilitate this collaborative approach the team and the family need to agree and share a plan; an **Individual Family Support Plan** (IFSP). Developing these plans should not be a lengthy or complex process. The team works with the family to establish the important issues from the perspective of the family. Examples of family goals and priorities are provided below.

- develop verbal communication skills
- develop an alternative communication system as they are non-verbal
- be able to transfer from their wheelchair to the toilet
- take a few steps within the family home to increase their independence
- participate in social activities with their siblings

Together the family and the team share their knowledge and expertise to agree how they are going to achieve the identified goals. The Individual Family Support Plan is the cornerstone of the service model; it is the essential framework to enable joint priority setting and collaborative working between families and staff.

However, in the context of limited staff availability and competing priorities, it is important that the Individual Family Support Plan process is conducted in a manner that is supportive of families, timely and focussed. The HSE has provided guidance and tools for staff to assist in this.



Example of a goal agreed by family and team

Conor will expand his diet to include one more food item, which is pasta for his dinner at least once a week.

What is happening now?

Conor currently eats mashed potato, chicken, yoghurt and rice. He struggles when other foods are introduced and refuses them or gags.

What will the family and others do to help achieve this goal?

They will complete a food diary for one month, to include notes of dinnertime each day, the food Conor was offered, any strategies used to encourage Conor to eat pasta and what he ate. The diary will help to identify the strategies which work and track progress.

What will the team do to help achieve this goal?

The OT will give Conor's family written guidance on strategies and food play ideas. She will phone the family once a week to check in and offer any advice and support needed.

The team will offer Conor's parents a place on the Fun with Food programme in November in the centre.

Children's Disability Network Teams provide three types of support, each determined by the needs of the child and family as set out in the Individual Family Support Plan.

- Universal Supports
- Targeted Supports
- Individual Supports

Each level of evidence-based support has an important part to play in meeting the assessed needs of a child and their family. It is a core component of the model that these types of support are used in a manner appropriate to the needs of each child and their family.

<table>
<tr><th colspan="3">CDNT Model of Service</th></tr>
<tr><th>Universal Supports</th><th>Targeted Supports</th><th>Individual Supports</th></tr>
<tr><td>For needs which many children with disabilities and their families share.</td><td>For needs which some children with disabilities and their families share</td><td rowspan="3">For a child or family's individual needs, for example

►Movement difficulties - Family and therapist agree a plan. It may include 1:1 intervention or equipment. Some children may need a specialised service such as a review of an orthopaedic consultant

►Feeding, eating, drinking, swallowing difficulties

►Communication difficulties</td></tr>
<tr><td rowspan="2">Delivered through information sessions, talks and workshops for families such as,

►How to help your child sleep through the night
►Toilet training for children with extra needs
►Supporting your child with language development and communication
►Helping your child play with other children and develop friendships</td><td>Bringing families together with common and shared challenges can be powerful</td></tr>
<tr><td>Evidenced based group work with good outcomes such as

►'It Takes Two to Talk' for children with language delay
►'More than Words' and 'Talkability', for children with autism or social communication disorder
►'Triple P' and 'Triple P Stepping Stones' for families of children with additional need to learn skills to help with everyday family life</td></tr>
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Ends
HSE Disability Operations Socialcare
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