

"Experts by Experience are people who have personal experience of using, or caring for someone who uses health, mental health and/or social care services".

Family participation in the Children's Disability Network Teams (CDNT) is promoted through Family Forums at Children's Disability Network (CDN) level. The **Family Forum** provides an opportunity for families to discuss general issues and ideas about the children's disability services in the Network. Family members and carers of children and young people attending a CDNT in the Network are invited to join the Family Forum. The Family Forum will meet a minimum of twice per year. Confidentiality, Data Protection and GDPR are to be upheld at all times.

The purpose of the Family Forum is:

1. To involve families in the development of children's disability services in their local Network through:
 - a. The expression of ideas for future service development and improve existing services
 - b. Identification of issues and ideas for service development and/or enhancement.
2. To share information on:
 - a. Service provision, governance and access
 - b. Community Supports
 - c. Rights of the child and the family
 - d. Other relevant topics of interest
3. To facilitate networking and sharing knowledge and experiences amongst families.
4. To elect two **Family Representatives** to represent the forum, who will meet the CDNM regarding Network issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level.

The role of the Family Representatives is to:

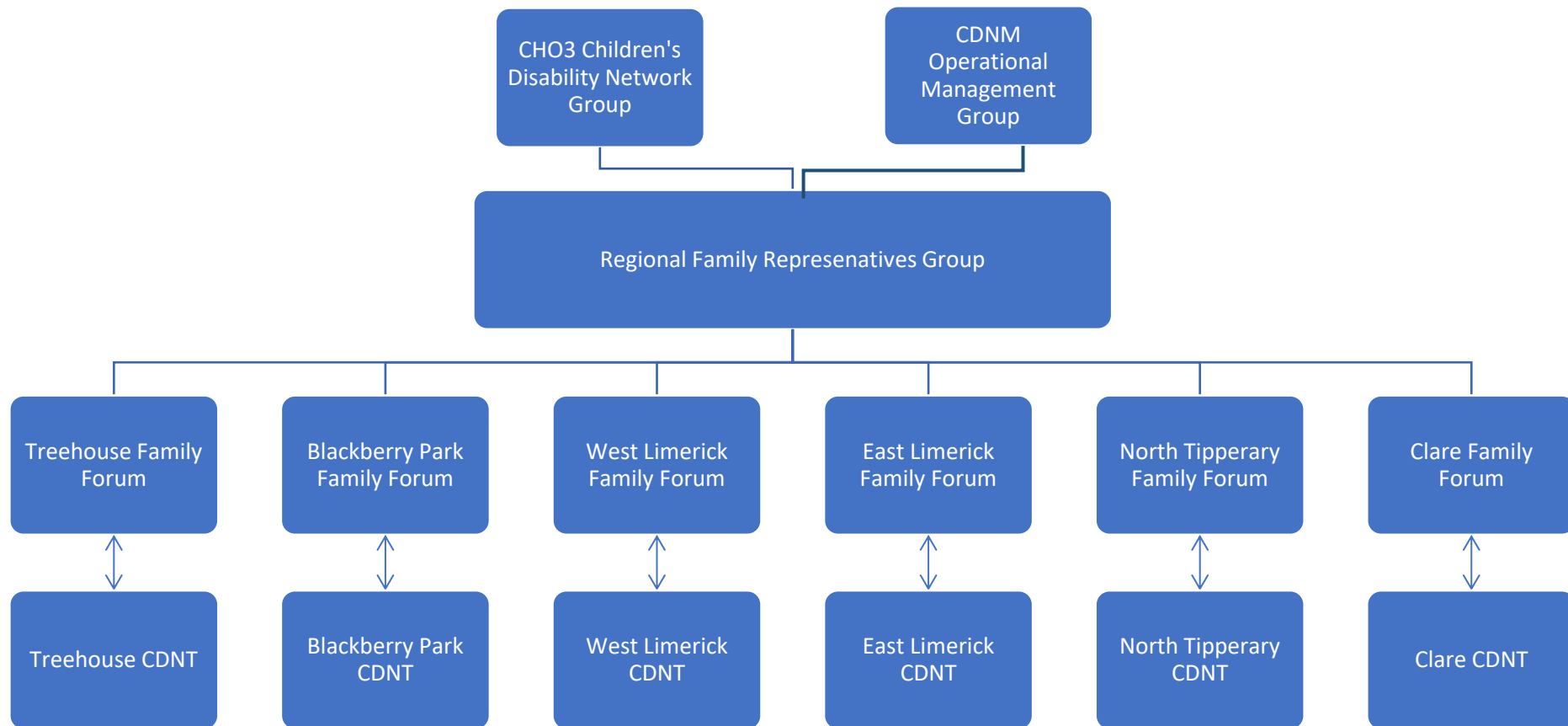
- a. Meet with the CDNM to relay issues and ideas raised at the Forum
- b. Attend meetings of the CHO Family Representative Group (see details below)
- c. Represent their Family Forum at CHO level by expressing their views, concerns and suggestions for improvements based on collation of general areas and themes from their Family Forum.
- d. Represent all issues and ideas raised by families.
- e. Ensure there is feedback to the Forum about issues and ideas raised and resulting actions.

(If a family has an issue or complaint about their own child's service, they should raise this with the team or with the CDNM. If a family issue cannot be resolved by the team and CDNM, then the family can log a formal complaint using the local complaints procedure, or HSE's Your Service Your Say).

Mid-West Children's Disability Network Team

Family Forum

Two Family Representatives from each Family Forum will form a **Family Representative Group** at CHO/regional Level. The purpose of the Family Representative Group is to learn and share feedback from the various Network Family Forums, and to raise issues for discussion and resolution at appropriate levels of the governance structure. To facilitate this, two members of the Family Representative Group will be members of the CHO3 **Children's Disability Network Governance Group**, and so the Family Representative Group will meet prior to each Children's Disability Networks' Governance Group meeting.



Mid-West Children's Disability Network Team

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In addition to this, two representatives of the Family Representatives Group will also meet with the **CDNM Operational Management Group** no less than four times per year. The Family Representative Group will also develop a feedback template for feedback to the Network Family Forums.

The inclusion of family representatives on the CHO3 Children's Disability Networks Governance Group adds significant value by:

- Ensuring there is always a focus on the needs of children and their families.
- Bringing the view from the family perspective on all issues discussed.
- Bringing a wide range of competencies and experience.
- Bringing lived experience and themes expressed via Family Forums.

We are currently seeking Family Representative Nominations for our Network Family Forum, with voting to elect Family Representatives taking place at our next Family Forums. If you are interested in nominating yourself, please contact Clinical Manager / Administrator for your child's team. If you would like additional information on this topic, please contact your team or CDNM.