Family-centred care in practice
Evidence summary

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About this resource
This resource aims to appraise available evidence in relation to family-centred care approaches to working with children, young people and their families. This evidence can then be considered by occupational therapists in relation to how it might apply to their own practice.

This evidence summary is aimed at occupational therapists working with children, young people and families. It is accompanied by an infographic to help explain the topic to others if needed. As family-centred care is a concept used across many professions, the literature search included reviews from a range of contexts, particularly nursing and hospital-based family-centred care.[1]

Key terms defined
There are various terms in use which relate to family-centred care including 'family-integrated care' and 'family-oriented care'. The literature does not differentiate clearly between these. Therefore, in this summary we have used the term 'family-centred care' to mean those terms too.

Family-centred care differs from person-centred care, which is about focusing care on the needs of the individual.[2]

Several studies have attempted to define the concept of family-centred care, identifying a number of attributes which make it up:

- Healthcare professionals work in partnership with families.[3,1,4]
- Parents are active participants in their child's care, including in hospital settings.[3,1,5,4]
- Interprofessional collaboration includes the family and focuses on achieving mutual goals.[5,3,1,4]
- Respect and dignity are prioritised through building trusting and respectful relationships.[3,1]
- Family members' support needs are considered and addressed.[3,5,1]
- Information and technical resources are shared with the family.[3,1,6,7,4]

The term "parent" has been used throughout to refer to the primary carer of the child.

What is the purpose of this intervention?
The purpose of family-centred care is to ensure that service provision includes the family in every aspect of planning and intervention to optimise the outcomes for children and families. It focuses on the needs and aspirations identified by the family and considers the needs of the broader family as well as the child or young person with an identified health condition.

Elements of family-centred care require working together as a multi-professional team, but several elements can be implemented as part of uni-professional care.

Is this intervention effective?

There is a large body of research on family-centred care dating from the 1990s to the current day. Several systematic reviews have found evidence of positive outcomes across the various definitions and provisions described.[6,7,8,3] The quality of the evidence varies from weak to moderate. The definition of family-centred care varies across studies and includes a range of different elements, making direct comparison more difficult.

Evidence for the effectiveness of family-centred care has been demonstrated with children and young people with ADHD, autism, behavioural disorders, brain injury, cerebral palsy, developmental delay, intellectual disability, obesity and children with special health care needs including chronic physical, developmental, behavioural or emotional conditions that require health and related services,[7,8,6,] neonates in intensive care[3] and children in hospital.[1]

Benefits that have been found include:

- Improved outcomes related to wellbeing,[5] goal-based outcome measures[9] and function.[7,3]
- Enhanced parental knowledge and understanding of goals for care.[8,6,3,10]
- Enhanced parent empowerment and adjustment.[6,8,7,3,1,5,10]
- Enhanced parenting competencies and parent-delivered interventions.[8,3]
- Improved health status and reduced use of healthcare services including hospitalisation.[8,6,3,11,10]
- Stronger provider-client relationships and improved satisfaction with services.[8,6,9,3,10,1]
- Improved connection of neonate with parents.[3]
- Enhanced understanding by professionals of care plans and interprofessional collaboration.[10]
- Professional satisfaction for staff.[3,5,10]

Services have been shown to be effective when they include:

- Family-centred goal setting and intervention planning: partnership working with the child and family to identify needs, set goals and develop treatment plans.[9,7,4]
- Information: providing general information on the family-centred care approach,[10] conditions and resources, for example, websites, leaflets, social media.[7,8,4]
- Education: targeted information on conditions and best practice aimed at families through group sessions, for example, family education days, transition groups, e-learning.[7,8]
- Training/instruction: training family members to take a therapeutic role and perform interventions in the child's environment, for example, Constraint Induced Movement Therapy (CIMT), positive parenting programmes.[9,8,7]
- Support groups: emotional, practical and cognitive support through sharing experiences, acting as mentors, practising new behaviours in a supportive environment with other families/children for example, parent support groups (provider or parent), sibling support groups.[8]
- Psychosocial support: focusing on parent empowerment and meeting the parents' own needs, for example coaching, counselling focused on family adaptation, short breaks.[7,8]
- Care coordination: support to navigate the healthcare system, including care, equipment and adaptations, for example, key worker/lead professional roles.[8]

What equipment is required?

It is important to ensure that equipment suited to the delivery of the relevant interventions described in the previous section is available for the family where necessary.

What processes support the success of this intervention?

Successful family-centred care requires:

- A well-integrated management structure that promotes family-centred care.[12,11]
- Sufficient time for more involved work with families.[12,11]
- Training and evaluation for individuals and teams.[12,3,11]
- Matched expectations between the families and professionals, including understanding the roles in family-centred care.[7]
- Clearly agreed roles and responsibilities between the family and professionals.[3]
- Consideration of the parents' desired level of involvement and monitoring their desire for involvement over time.[4]
- Information sharing that is honest and transparent, avoiding the use of euphemisms, jargon and complex language and resisting the urge to 'protect' families from difficult news.[1,10,4]

What qualifications, skills and training are required?

No specific qualifications are required to adopt most elements of family-centred care, though common training for teams on family-centred practice has been found to support success.[12,3,11]

What is the time commitment for the service?

There isn't clear guidance on time commitments. There is some evidence that family-centred care will decrease reliance on health services over time, which may justify time investment to develop strong relationships and partnership working at the outset of care.[12,11]

What is the time commitment for the family and child?

Parent-delivered interventions have implications for the family and children. Family-centred care is focused on ensuring the family context and capacity are central to intervention planning, including consideration of their time.

What is the dose (quantity of time, frequency and duration) required for effectiveness?

No specific information relating to dose was included in the studies.

Cautions and contraindications

When implementing family-centred care it is important to consider the following:

- Parents may be reluctant to raise concerns or views for fear of disrupting their relationship with their child's care team.[4]
- Clinician bias may restrict partnership working with minority ethnic and racial and socioeconomic backgrounds.[4]
- Where families rely on interpreter support to be fully informed and involved, ensure interpreting is robust and given sufficient time.[10]
- Family members may wish to opt out of certain conversations, especially around challenging areas or where there aren't clear answers.[4]
- Family stress can impact on the level of engagement or satisfaction with family-centred practices.[10]
- Constant presence at the child's hospital bedside and participating in care may lead to financial and emotional stress for a family.[1,5]
- The child's voice should be heard as well as the parent voice, and any conflicts should be acknowledged to avoid marginalising the child.[13]

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