



FAMILY CENTERED DEVELOPMENTAL CARE AS EARLY INTERVENTION FOR CHILDREN WITH SPECIAL NEEDS

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ABSTRACT

Disabilities have a lasting effect on child's development and in turn have psychosocial impact on the child's family. Family Centered Care (FCC) is defined as a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child, and in which all the family members are recognized as care recipients. The family centered framework for early intervention is a synthesis of concepts from the Model of Human Occupation (MOHO by Kielhofner) and from the developmental literature on play. The similarities and distinctions between family-centered care and the earlier practices are discussed in this review. The barriers to this practice and the evolving trends are discussed. Providing FCC to families of infants and toddlers with disabilities is an essential component of high-quality early intervention services. Thus, this article may throw light on this vital practice to facilitate better early intervention services.

KEY WORDS: Family centered care, Early intervention, Disability.

INTRODUCTION:

Children with disabilities require special attention from care givers for enabling them to lead a meaningful life. An infant or toddler with a disability is a young child experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more areas viz. cognitive, physical (including vision and hearing), communication, social or emotional and adaptive development¹. Disabilities have a lasting effect on a child's development and in turn have psychosocial impact on the child's family. Children with severe and multiple disabilities often have a total dependence on parental assistance for everyday tasks like feeding, bathing and grooming². Some research suggests that parents, siblings, and other family members of person with a disability are at an increased risk for depression and reduced quality of life³. Disabilities have a lasting effect on a child's development and, in turn, may have a psychosocial impact on the child's family.

The limitations of a child with a disability are often related to family members' stress, depression, and feelings of helplessness⁴. Accordingly, not only do children with disabilities have special needs, but family members have unique needs as well. Families often require financial, social, psychological, and other family support services⁵.

In medical settings, the practice of family centered care is becoming more accepted, especially in Neonatal Intensive Care Units. However, in early intervention services the practice of child-centered care was widely used. As the number of children with disabilities increases, the influence of the family and the use of family centered care in early intervention become more essential. The purpose of this article is to expound on family centered care within early intervention.

BACKGROUND:

The Family-Centered Framework for Early Intervention is a synthesis of concepts from the Model of human occupation by Kielhofner and from the various developmental literature on play. The Model of human occupation provides therapists with a systematic approach to understanding and working with the values, needs, habits, and skills of the family and child within their environments. This model views the person as an open system that is influenced by and acts on its respective environments. According to this model, the open system comprises three major subsystems: volition, habituation, and performance⁶.

In the Model of human occupation play is seen as the primary occupational behavior of the child and the role of player as a primary role of childhood. Play is viewed as an arena for the practice of new skills and a method by which the child can obtain sensory input, enhance competence, and learn new skills. Play is an intrinsically enjoyable, self-motivating behavior that is not imposed or directed by adults. Play can give us clues about volition (the child's and family's values, needs, and interests), habituation (the child's and family's organization of behaviors into patterns and routines), performance (the child's skills and abilities), and environmental strengths and weaknesses as well as help us to facilitate the child's development of skills, habits, roles, interests, and motivation. Many of the other human and nonhuman environmental factors considered in the family-centered framework are listed below:-

1. *Human Environmental Factors:* Parent and child interactions, siblings, peers, early intervention program staff and the health care team.

2. *Non-human Environmental Factors:* Type of toy, toy placement and organization, positioning of child, play space and freedom⁷.

DEFINITIONS:

The Institute for family-centered care defines family as two or more persons who are related in any way — biologically, emotionally, or legally⁸. Each unique family may include individuals possessing guardianship, kinship and possibly shared domicile. More than kinship, however, it is the opportunity and ability of individuals to provide significant support and care that defines family in family centered practice. FCC is defined as a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child, and in which all the family members are recognized as care recipients⁹. Family-centered care in NICU is an approach to planning, implementing, and evaluating healthcare which is formed on the basis of participation of different health and family professions. Its four basic principles are dignity and respect, information exchange, family participation in care, and family cooperation¹⁰. Early Intervention (EI) is a federal program that allows states to provide services to infants and toddlers with developmental disabilities¹¹. Such services include special education; physical, occupational, and speech therapy; parent training; vision, nursing, and health services; and assistive technology. Children are to be evaluated and provided services in the most natural and least restrictive environment, usually at home, daycare, or in an early childhood center¹². *Family-centered practice (FCP) refers to the attitudes and behaviors of a therapist that facilitate and esteem the family's role as lead negotiator in assessment, treatment and discharge. For many reasons one might say that FCP is an idea whose time has come. It is the natural extension of occupational therapy's focus on client-centered care. However, it is the recent focus on evidence-based practice that lends an urgency to the integration of FCP principles into daily practice*¹³.

Thus, in Family-centered developmental care (FCDC), families are integrated into decision-making processes and are collaborators in their baby's care. Through standardized use of FCDC principles in the NICU, a foundation is constructed to enhance the family's lifelong relationship with their child and optimal development of the baby¹⁴.

Table 1: Elements of family-centered care (FCC) as proposed by the Institute for Family-Centered Care (2005)¹⁵.

• Recognizing the family as a constant in the child's life;
• Facilitating parent-professional collaboration at all levels of health care;
• Honoring the racial, ethnic, cultural, and socio-economic diversity of families;
• Recognizing family strengths and individuality and respecting different methods of coping;
• Sharing complete and unbiased information with families on a continuous basis;
• Encouraging and facilitating family-to-family support and networking;
• Responding to child and family developmental needs as part of health care practices;

- Adopting policies and practices that provide families with emotional and financial support; and
- Designing health care that is flexible, culturally competent, and responsive to family needs.

Family centered care terminology:

Family-centered, person-centered, patient-centered, people-centered, person-focused, client-focused, and client-driven are all terms, which have, at times, been used interchangeably. However, despite perceived similarities, these concepts may actually have different meanings^{16,17}. This section will explore the similarities and distinctions between family-centered care and other models of care.

Medical model and professionalism:

The traditional medical model is characterized largely by its orientation to disease and disability, rather than an orientation to people. Although traditionally associated with physicians, the assumptions underlying the medical model are shared by many health-care providers. There are strong socially defined roles implicit in the medical model for both healthcare professionals and families. It is a professional expert model, where the professional is assumed to have the knowledge to diagnose and treat the medically defined problem with no input from the child and family.¹⁸ Authoritative relationships are inherent in Western models of professionalism, with authority being granted on the basis of claims to special knowledge and skills. Professionalism, with its basis in the ownership of a certain body of knowledge, is an obstacle to developing services that envision a collaborative relationship between health-care providers and families.¹⁹

Patient-centered/ Client-centered care:

Patient-centered care and client-centered care appear to be used almost interchangeably in the literature, with both terms focusing on the provision of care that focuses on the needs of the individual. The term patient is used most commonly in the hospital (acute) care setting¹⁷ and in the medical literature¹⁸. The term "client" is considered by some to be preferable to "patient" due to the perception that "patient" is illness-centered and placing the focus on a person's illness, rather than on the person themselves, who is a client of the service¹⁹. Client centered care involves advocacy, empowerment, and respecting the client's autonomy, voice, self-determination, and participation in decision-making.

Person-centered care:

Person-centered care essentially seeks to preserve the 'personhood' of the individual. The concepts surrounding person-centeredness are generally reflective of a client or patient-centered approach to care, incorporating similar key principles and a shared understanding of the importance of developing an understanding of the individual, their environment, values, relationships and social world.^{20,21} In terms of terminology, Edvardsson et al. suggest that 'person' is preferable to the term 'patient,' as the former respects the 'holistic humanness' of the person, whereas 'patient' implies that there are 'imperfections or undesired differences' to a person²⁰. However, the concept of person-centered care has been challenged in the gerontological literature as being too focused on the person and failing to fully capture the interdependencies and reciprocities that underpin caring relationships²².

Relationship-centered care:

An argument is made for the need to go beyond an approach which is centered on the person, to one which focuses more specifically on the relationships that the person holds. This approach is known as relationship-centered care. It is defined by Beach and Inui as care in which all participants appreciate the importance of their relationships with one another. The authors outlined four principles upon which relationship-centered care is built i.e. (i) relationships in healthcare ought to include the personhood of the participants; (ii) affect and emotion are important components of these relationships; (iii) all healthcare relationships occur in the context of reciprocal influence and (iv) the formation and maintenance of genuine relationships in healthcare is morally valuable.²³ The relational process empowers patients as partners. The focus is on the relationship between the client and clinician, and the relationships of clinicians with themselves, their team, family members and the community are also emphasized^{24,25}.

Family centered care:

The family centered care has evolved from the concepts of client centered and relationship centered care. The family-centered approach seems to be a promising method for accurately monitoring psychosocial development, and the context in which infants grow up, in a way that enhances psychosocial development and early intervention if needed.²⁶ FCC was found to be an ultimate solution to appropriately follow these children by involving their families to work with health professionals as partners collaborating in well-designed early intervention program to meet all medical, social, financial, and psychological needs of both children and their families.²⁷ With proper conduction of FCC, engaged families are more likely to be satisfied with the care they receive from their health care professional and, in turn, are more likely to follow instructions and suggestions from their physicians, including referrals to needed specialties for continued therapy and health services.²⁸ Due to the increasing evidences of the efficiency of family centered care, it is widely accepted in clinical practice as the current standard of quality care. It has been suggested that to practice in a family-centered manner requires a shift in the orientation of health services from a pro-

fessionally centered model to a collaborative model which recognizes family involvement as central to their child's care. Within this view, the healthcare provider is an equal partner and facilitator of care, and families are invited to participate actively in the decision making, planning and provision of their child's care to the extent they choose.^{18,20}

Challenges in implementing family-centered care in children with special needs:

(a) **Diversity:** Families of children with multiple and severe disabilities may have different concerns, opinions, and needs depending on their cultural backgrounds. It is critical to take a family's values, customs, and beliefs into consideration when seeking to engage parents in the goal-setting process. Additionally, professionals may suggest changes in daily routines or schedules or ask parents to implement daily programs that alter family habits. However, families develop their own routines and schedules. Family systems are complex, and many factors contribute to the family's adherence to or involvement in a particular treatment. In true family-centered assessment and treatment, providers do not expect families to follow a schedule that is either unrealistic or interferes with customs and rituals²⁹. Goldbart and Mukherjee suggested that family-centered care is a westernized model of parental participation, which may be inappropriate in non-western societies where cultural norms, family contexts and the organization of family roles are different. For example, the extended nature of many families in non-western societies means that a grandparent or relative may be the child's main carer, rather than the parents.³⁰ A study conducted by Shields and Nixon in two developing countries (Indonesia and Thailand) and two developed countries (Australia and Great Britain) investigated attitudes and practices regarding hospitalization of children. They suggested that, while the concept of family centered care and parental participation is well accepted in westernized countries, it is less so in developing countries and that culture plays a major role in determining how care is given by health-care workers and perceived by parents.³¹ Although research carried out in Brazil found that parental participation in care can be facilitated within a health-care setting in the nonwestern world, more research in the developing countries and in varied cultural backgrounds would enlighten us more on this issue.³²

(b) **Barriers related to information sharing:** Barriers often exist in health care and other systems that interfere with the assessment and treatment of families. A qualitative analysis of barriers to family-centered services found that some family participants also feel that professionals kept information from families because they did not want to encourage families to request all possible services.³³ Without discussing this information with families, it is impossible for professionals to truly provide family-centered services. Moreover, the hospitalization of a child, whether planned or unplanned, is stressful for even the most well-organized and functional family.³⁴ Potential disadvantages of family-centered care may be that families feel that they are expected to provide input into the care of their child beyond their expectations or capabilities, or are given more information than either the child or the family is ready to hear. This may cause additional stress or anxiety for both the parents and child.³⁵

(c) **Barriers embedded in health care settings:** Two major barriers observed are a lack of primary care provider's knowledge of the developmental delays the child was experiencing and a lack of referral information from the primary care provider for families. However, children who received FCC were more likely to receive developmental assessments at the pediatrician's office, referred for early intervention services, and also receive preventive services including immunizations.³⁶

The role of Occupational therapists in providing family-centered early intervention services:

It is critical that occupational therapists develop skills in building collaborative partnerships with parents. In practice, the development of these partnerships is not always straightforward. Increasingly, pediatric occupational therapists are being challenged to demonstrate that their intervention has assisted children and families to reach meaningful, functional goals. Collaboration with parents is essential if this is to occur. Therapists therefore need to 'step down from the pedestal' of professionalism to learn from and share the perspectives and expertise that parents bring to the collaborative process.²⁸ In occupational therapy(OT) in Australia, Hanna and Rodger not only suggested that OTs take a family-centered approach by focusing on parent-therapist collaboration, but also suggested for this to be genuinely collaborative and effective, OTs need to recognize the unique perspectives of parents, even when these may conflict with their own.³⁷ Each parent is unique in their parenting style, family structure, ability to share their emotions and needs with health-care workers and the level of involvement they wish to have in their child's care. Hanna and Rodger also reiterated the need for further research investigating whether involving the family in care improves outcomes for the child.

CONCLUSION:

Providing FCC to families of infants and toddlers with disabilities is an essential component of high-quality early intervention services. It allows families to make informed decisions about their child's evaluation and treatment intervention for disabilities. Thus implementing a family centered approach in early intervention

practice would pave for enhanced quality of services. More research on this area would throw light on its efficacy in treatment practice.

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