Family-Centered Service for Children With Cerebral Palsy and Their Families: A Review of the Literature

Susanne King, Rachel Teplicky, Gillian King, and Peter Rosenbaum

Pediatric neurologists and other specialists working with children with cerebral palsy or other disabilities play important roles in providing services in ways that make a difference in the lives of these children and their families. This article defines family-centered service and outlines a conceptual framework of the premises and principles underlying this approach to service delivery. Research evidence supporting family-centered service is presented for child, parent/family and service system outcomes, with a focus on community-based rehabilitation or health care services. The research evidence shows strong support for family-centered service in promoting the psychosocial well-being of children and their parents and in leading to increased satisfaction with services. There is less evidence for other outcomes. It is recommended that all service providers assess their beliefs and behaviors about family-centered service.

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Family-Centered service is both a philosophy and an approach to service delivery that is considered to be a best practice in early intervention and pediatric rehabilitation.1-3 Over the past 10 to 15 years, a family-centered approach in hospitals, clinics, and community-based service organizations has been increasingly adopted across North America. Children with cerebral palsy (CP) or other neurodevelopmental disabilities are seen in these settings by various health care professionals, including such specialists as pediatric neurologists. These children often have complex long-term needs that are best addressed by a family-centered service delivery model. This article outlines what family-centered service is, provides research evidence that illustrates how family-centered service makes a difference, and discusses the outcomes that should be examined.

Consider the following example of a child and family’s first contact with special health care services, which we revisit at the end of the discussion. Pam Green is an 18-month old first child referred for assessment because of her parents’ concerns that she has delayed development. On history and examination it is clear that she has four-limb CP, probably visual impairment, and a general delay in social and cognitive development. The Greens are upset by the news and have a host of questions about the prognosis, where to obtain the best services for Pam, and what they can do to help her achieve optimal progress. They also want to know what to tell their families, and whether Pam’s grandparents can have a role in Pam’s therapy.

WHAT IS MEANT BY FAMILY-CENTERED SERVICE?

The notion of client-centered or family-centered practice derived from Carl Roger’s work in the 1940s with families of “problem” children.4 In the mid-1960s, the Association for the Care of Children in Hospitals was founded in the United States to promote a more holistic approach to care for hospitalized children, particularly in terms of psychosocial issues and family involvement. Much of the literature on family-centered service has come from the family support and early intervention fields.5 More recently, family-centered service has been applied to the field of pediatric rehabilitation.6-10 There has been a growing understanding of the role of the family in the child’s life and the importance of the insights of parents into their child’s abilities and needs.

The literature on professional caregiving, which encompasses the medical field, repeatedly notes three important aspects of caregiving: information exchange, respectful and supportive care, and partnership or enabling.11 These three aspects of inter-

From the CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada.
Supported in part by the Ontario Ministry of Health’s research program for health-system linked research units.
Address reprint requests to Susanne King, CanChild Centre for Childhood Disability Research, IAHS, Room 408, McMaster University, 1400 Main St. West, Hamilton, ON, Canada L8S 1C7.
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personal caregiving are foundational to family-centered service.

Many definitions of family-centered service have been developed by professional and service organizations, as well as by researchers and authors in the fields of health care, early intervention, family support, and social science.\cite{5,12,20} The evolution and expansion of ideas about family-centered service has helped service providers and families better understand its concepts. Our research unit (CanChild Centre for Childhood Disability Research) has developed a conceptual framework of family-centered service\cite{21} that distills the ideas found in the literature and provides the basis for our measurement development work and research with children’s rehabilitation centers in Ontario. Our definition is as follows:

Family-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In family-centered service, the strengths and needs of all family members are considered.\cite{22}

This definition reflects the three basic premises of our framework: (1) that parents know their children best and want the best for their children, (2) that families are unique and different, and (3) that optimal child functioning occurs within a supportive family and community context. From these premises flow several guiding principles that, along with definitions and explanations proposed by others in the field, reflect the common features and core concepts of family-centered service. These include parental involvement in decision making, collaboration and partnership, mutual respect, acceptance of the family’s choices, support, a focus on strengths, individualized and flexible service delivery, information sharing, and empowerment. It is clear that family-centered service moves away from the professional-centered model of service delivery. This framework is based on family systems theory, which recognizes the importance of the family’s well-being to the child’s well-being.\cite{23} It focuses on the strengths and resources of the child and family, within an ecological context. The family-centered service framework is strengths-based\cite{24} and enablement-oriented.

A framework and definition of family-centered service provide important guidelines for how pediatric neurologists and other health care professionals should approach the delivery of services and their interactions with families. It is also important, however, that health care professionals understand the specific behaviors that are encompassed in a family-centered approach. Our CanChild framework takes the core family-centered service premises and principles one step further by describing the specific behaviors of health care providers that put them into action. In addition, we have developed several measures to assess the family-centeredness of services as viewed from the perspectives of parents\cite{25,26} and service providers.\cite{27} Several other research groups have also operationalized family-centered care in specific behavioral terms.\cite{18,28,30} This focus on the behavioral elements is a needed adjunct to the conceptualization of family-centered service and has helped promote its adoption and implementation. Health care professionals often assume that they are taking a family-centered approach; completing a behavioral inventory may provide them with important insights into their own practices.

**WHAT TYPES OF OUTCOMES ARE IMPORTANT IN AN FAMILY-CENTERED APPROACH?**

The goal of working with a family with a child with special needs is to enhance the quality of life for all family members.\cite{31} Engagement in meaningful activity and community participation of the child are also primary goals of pediatric rehabilitation services.\cite{32,34} Consequently, the impact of a family-centered approach should be seen in a broad spectrum of outcomes. Although each discipline may have a specific area of expertise and thus particular outcomes of interest, it is important to consider the development of the child as a whole. Outcomes should include, but need to go beyond, those of the child’s physical, emotional, social, and cognitive functioning. Much of the research on quality care has focused on the key outcomes of parental satisfaction, reduced stress and worry, and adherence to therapy programs,\cite{31} and these parental outcomes certainly should be considered. In addition, outcomes related to siblings, the family
as a whole, health care providers and teams, the service organization and community also are relevant in demonstrating the benefits of family-centered service.14,35,36

WHAT’S THE NATURE OF THE EVIDENCE?

The research evidence gathered for this review comes primarily from literature that deals with community-based children’s rehabilitation or health care services (rather than acute and inpatient care). The focus of these services is generally on children with various neurodevelopmental disabilities, of which CP is but one. We believe that the “noncategorical” approach to service delivery for childhood disorders makes it appropriate to generalize the findings of this research to children with CP and their families. The children and families in the studies cited here are similar to those seen by pediatric neurologists, making the research findings relevant to these professionals.

Even with this particular focus, conducting a comprehensive review of family-centered service is challenging, because of the many elements of family-centered service and the wide variety of terms used within the literature databases for this approach to service delivery (eg, patient-centered care, family involvement, professional-family relations). Few studies have explicitly addressed the effectiveness of family-centered service. At the same time, studies that focus on a single family-centered element or on a comprehensive program have limitations. Studying a single element does not fully address the fact that being family-centered involves an integrated approach to service delivery. Conversely, examining a comprehensive program often does not identify the “active ingredients” of family-centered service that make a difference.37 Several randomized clinical trials have been conducted, but much of the research on family-centered service comes from cross-sectional studies. Thus most of the evidence highlights associations but does not demonstrate cause-and-effect relationships.

The evidence outlined here supporting a family-centered approach is organized by type of outcomes, those concerning the child, the parent/family, and the service delivery system. This review includes studies focusing on children of varying ages with a variety of disabilities, as well as children with chronic medical illnesses or disorders. It is not possible in this article to provide details about all of the studies cited; however, the studies’ descriptions do provide information about which elements of family-centered service were addressed. Not surprisingly, some studies have examined more than one child, parent, and/or system outcome.

Evidence for Child Outcomes

The scope of information on the benefits of family-centered service for children is limited. Studies have generally focused on two major kinds of outcomes for children, developmental gains/skill development and psychosocial adjustment.

Several studies have demonstrated developmental gains and/or skill development in children, and the ones cited here examined comprehensive family-centred programs. A randomized controlled trial (RCT) demonstrated that an education program that focused on providing general and specific information, building on parents’ skills, and individualizing services resulted in the development of skills that were the goals of home programs and in motor developmental gains for infants in the experimental group.38 In a pre-post study of an individualized family-focused intervention, infants and young children with moderate or severe disabilities achieved targeted goals, acquired functional skills, and demonstrated accelerated rates of developmental progress.39 This intervention emphasized parents and professionals working together, along with parent education. Family-centered functional therapy was evaluated in a pilot study of young children with CP.40 Children receiving this approach to therapy demonstrated changes in individualized motor goals over a 3-month period. This intervention involved parents in identifying goals, fit the therapy to the families’ needs and priorities, and had an educational component.

Two other studies, both of which used RCTs, focused on children’s psychological adjustment. Children with a chronic illness who received a comprehensive program focusing on the whole family and its needs demonstrated better psychological adjustment compared with children who received standard care.41 These results were still evident in a 4- to 5-year follow-up study.42 However, no differences were found in the children’s functional status. This integrated program encour-
aged families to become more actively involved in taking responsibility for managing their child’s care and in making informed decisions in partnership with service providers, and offered coordination of services, health education, and support. Another study assessed a specialized nursing intervention for 4- to 16-year-old children with chronic physical disabilities. The intervention focused on the overall concerns of the child and family and provided support and individualized services. The nurses collaborated with families to identify their needs, build on their strengths, and obtain the services that they needed. Results demonstrated higher scores on function and role performance and on a child’s measure of self-worth, all indicating better psychological adjustment.

Another RCT examined a child- and family-focused intervention for school-age children with epilepsy. Retest data obtained at 5 months demonstrated that the children in the experimental group had better knowledge about their disorder, improved perception of competency, and better behavior. This program focused on the children’s informational and psychosocial needs and involved them as “equal partners” in acquiring skills and knowledge. This study is an example of greater breadth of child outcomes, because it examined more than developmental progress or skill development.

Evidence for Parent/Family Outcomes?

Although there is much evidence supporting a family-centered approach in the area of parental outcomes, there has been little work reported on the family unit as a whole. The most common outcome is better psychological well-being for mothers (because they generally were the participants in most of the studies). Other outcomes are related to changes in paternal/maternal knowledge and participation and in feelings of competency, self-efficacy, and sense of control.

Several RCTs have demonstrated that parents, mostly mothers, have experienced better psychological health, as demonstrated by reduced anxiety, less depression, and higher levels of well-being, when programs or services are provided in a family-centered way. In a 15-month family support intervention, mothers of children with chronic illnesses who were linked with mothers of older children with similar conditions showed reduced levels of anxiety. This community-based program provided informational, emotional, and affirmational support. In another study (described earlier in the section on child outcomes), mothers of children with chronic illnesses who participated in this interdisciplinary comprehensive pediatric home care service experienced decreased psychiatric symptoms, although the findings were not statistically significant. In another study, parents in an experimental group that offered knowledge and skill development, support, opportunities to voice concerns, and recognition of their strengths demonstrated more greatly reduced anxiety.

Two cross-sectional studies also examined parental well-being. Parents of children with neurodevelopmental disabilities who reported receiving more family-centered caregiving had improved emotional well-being, as indicated by less depression and distress. These associations, shown through structural equation modeling, highlight the importance of providing services that meet parents’ needs for information, partnership, and support and understanding. In another study, mothers of children and youth with Down syndrome perceived higher levels of individual and family well-being when relationships with service providers were positive and family-centered.

Other investigations have shown that parents experience less stress or distress and increased life satisfaction when they receive services that are family-centered. In a pre-post study of a 10-month early intervention program involving mothers of infants with developmental delays, frequent attendance was associated with less stress on the part of mothers. This transdisciplinary program included therapy for children and information and emotional support in response to parents’ needs. Stress and coping also were examined in a case-control study of mothers of children with and without physical disabilities. Findings demonstrated that providing high levels of information about their child’s disability and future was related to mothers’ lower psychological distress. A cross-sectional study of mothers of children with both a developmental disability and a chronic illness examined a family-centered case management model. Mothers demonstrated increased life satisfaction between baseline and follow-up. This service delivery model emphasized parent–professional collaboration, re-
sponsiveness to family needs, interdisciplinary teams, and accessible and coordinated services.

A randomized controlled study (cited earlier in the section on child outcomes) examined other kinds of outcomes for parents.\textsuperscript{38} This education program focused on individualizing services, sharing information, and emphasizing parents’ strengths. Parents gained developmental knowledge, increased their participation in the home treatment program, and continued this involvement at a 1-year follow-up.

Several studies have examined outcomes related to parents’ competencies. A multiple case study of two families with children with special health care needs demonstrated that a high sense of control was associated with help-giver behaviors that were positive and productive, competency-producing, participatory, and accepting.\textsuperscript{12} A series of cross-sectional studies examined the appraisals of self-efficacy by parents of preschool children in relation to the help-giving practices provided through programs of early intervention, family support, public health, and social services.\textsuperscript{51} The largest of these studies involved 1110 parents of children with disabilities or developmental delays enrolled in family-focused early intervention programs. Collectively, the three studies by Dunst and colleagues\textsuperscript{51} demonstrated a consistent pattern: Parent-professional interactions considered to be empowering (ie, ensuring active involvement, acquiring knowledge, learning new skills, making decisions) were associated with parents’ enhanced feelings of self-efficacy and personal control. This work was extended in another cross-sectional study of mothers of young children involved in an early intervention family support program. Using structural equation modeling, the findings showed that professionals’ empowering behaviors were associated with parents’ greater sense of control over life events.\textsuperscript{52} A qualitative study of mothers of children with disabilities reported that the mothers’ sense of their own caregiving competency was related to their rapport with service providers and the service providers’ communication.\textsuperscript{53}

A case study methodology of case manager practices was used to examine individualized family outcomes.\textsuperscript{54} Families who reported positive individualized outcomes attributed these to case manager help-giving practices that were consistent with family support principles. These principles included sharing responsibility and collaborating, promoting capabilities and competencies, being responsive to family needs, supporting family decision making, and sharing information. The authors of this study did not provide details on the effects on the families because the outcomes were specifically identified by each family.

Evidence for Service System Outcomes

Satisfaction with care or services is an outcome for which considerable research evidence exists. Satisfaction has emerged as a powerful indicator of the quality of care at the level of an organization or service delivery system, as well as for individual providers. It is essential to understand how services are actually perceived and judged by those who receive them.\textsuperscript{55} and satisfaction provides such a report. Satisfaction is an outcome that can be measured more easily across disorders and settings than can outcomes linked to the effectiveness of specific services or procedures.\textsuperscript{56}

Some studies have reported the specific elements of a family-centered approach that are related to parents’ satisfaction with care. In a pre-post intervention study described earlier,\textsuperscript{39} parents reported high levels of satisfaction with an individualized family-focused program. Three cross-sectional studies also used satisfaction as an outcome. Mothers of children with Down syndrome were more satisfied with care when they reported experiencing positive relationships with service providers who used a family-centered approach.\textsuperscript{47} A prospective study, following introduction of individual program planning (IPP), was conducted to examine overall satisfaction of parents of preschool children with disabilities.\textsuperscript{57} This IPP process was developed to address shortcomings identified by an earlier parent survey. Satisfaction with service delivery was enhanced by changes to a more family-centered approach. The changes that parents reported included feeling more involved in decision making, having their views understood, and receiving coordinated services. The satisfaction of parents of children with primarily severe emotional disorders was assessed in a cross-sectional survey.\textsuperscript{58} These children were described as receiving multiple services over a period of time on a regular basis. Ratings of parental satisfaction were closely related to professionals’ behaviors that were collaborative, especially support, under-
standing, and sharing information. In a qualitative study of an occupational therapy service, parents attributed their satisfaction with services to the way in which information was provided to them and to the interpersonal qualities of the service providers. For some studies, it was not possible to identify which family-centered features were influencing satisfaction. These generally were studies in which a comprehensive program of service was examined. Three cross-sectional studies evaluating service delivery for children with disabilities and their families found that parents’ reports of services being more family-centered were strongly associated with higher levels of satisfaction with care. This relationship was consistently found across these studies by the same research group. In addition, one of these studies showed, using structural equation modeling, that parents’ satisfaction with services was most strongly predicted by their perception that the services were family-centered and by the presence of a more family-centered culture at the organization providing the services.

In an RCT, a comprehensive and integrated program of medical and psychosocial services produced greater parental satisfaction with care. This program encouraged family involvement and partnership with service providers in making decisions and offered coordination of services, health education, and support.

WHAT DOES THIS RESEARCH EVIDENCE TELL US?

Studies have shown that family-centered service is highly valued by both parents and service providers. The accumulation of evidence presented here from RCTs, pre-post investigations, cross-sectional studies, and qualitative or case study methodologies demonstrates considerable support for the contention that family-centered service is effective, as seen in outcomes for children, parents, families, and the service delivery system. It is important to note that no studies were found that presented negative outcomes for family-centered service.

The studies cited in this review incorporated many of the key elements of a family-centered service framework. Information sharing provides the basis for parents and professionals working together in collaboration and was a common feature examined. In these studies parents felt understood and listened to, respected, and supported while they sought/received services that they felt met their specific needs, priorities, and goals. The findings demonstrate the importance of behaviors that promote capabilities and competencies by building on families’ strengths and empowering them to make informed decisions and direct the care for their children. Family-centered service appears to work best in the context of interdisciplinary teams who strive to provide coordinated and comprehensive care, even if members are not physically located together.

Much of this evidence is focused on a few specific outcomes—mainly the child’s psychological adjustment, the parents’ psychosocial well-being, and satisfaction with the service delivery system. It is important to continue to conduct research especially on elements of family-centered service that have received little attention, such as accepting diversity (including cultural, social, economic, and educational diversity). It is equally important to use multiple perspectives and to increase the breadth of outcomes examined. Other child outcomes could include improved peer relationships, social participation, recreation and leisure, health and fitness, and satisfaction with care. Additional suggestions include evaluating whether the child develops a positive self-image, becomes knowledgeable about his or her disability, and develops ways to manage the impact of the disability. Family outcomes related to coping and family functioning and system-related outcomes, such as cost-benefit analysis and interagency collaboration, are examples of other outcomes that await systematic exploration.

HOW DO YOU KNOW IF YOU ARE BEING FAMILY-CENTERED?

The various definitions of family-centered service, our conceptual framework, and the descriptions of family-centered interventions and of key features that relate to improved outcomes all provide guidance for health care professionals in determining how family-centered they are. It is particularly useful to consider the specific behaviors that derive from these concepts. We recommend that professionals examine their own behaviors and beliefs by completing self-rating measures that capture the perspectives of those providing services. For a full
picture of service delivery, it is of course also important to obtain the perceptions of the recipients of care. Several measures are available for this purpose.\textsuperscript{18,25,26,61} Other resources in various fields provide practical suggestions on how to become more family-centered.\textsuperscript{22,65-69}

CONCLUSION

A pediatric neurologist or other health care specialist for children with disabilities can make a difference in the lives of these children and their families beyond the contribution of his or her own technical expertise. The findings reviewed in this article highlight that what is also important and effective is the “how” of service delivery—the processes of caregiving. Specialists can help create an environment of teamwork by serving as role models for family-centered behavior. They can communicate “bad news” in ways that alleviate parents’ stress and are supportive, and they should not assume that all parents will be devastated by information about their child’s difficulties. Thus all service providers, regardless of the frequency of their interactions with the child and family or what role they play, need to be aware of the key elements of family-centered service and understand their own beliefs about it, especially beliefs about their own ability to implement family-centered service. Assessing one’s beliefs about confidence and competence in family-centered skills and examining one’s own behaviors can help identify how family-centered one is and where one could improve. Many diverse and positive outcomes can occur through a family-centered approach to service delivery.

Returning to the child in the opening case study, Pam Green, how can a pediatric neurologist or developmental pediatrician provide a family-centered approach to her care and service? The brief answer is that the health care professional should provide services in interpersonal ways that involve, respect, and empower the family. He or she should begin by taking the time needed by the Greens (and probably the grandparents as well) to explain “cerebral palsy,” covering the ground in more than one interview, as needed. Rather than simply having a discussion about a “typical” case of CP, counselling would address the unique strengths and needs of Pam and her family. Next, using the best available information, the health care professional would answer the family’s questions about prognosis honestly, leaving room for hope, especially when a child is as young as Pam. Referrals need to be made to the relevant assessment and treatment programs for the evaluation of Pam’s visual, motor, and cognitive development. Plans should be made at the outset for a postassessment case conference with structured feedback to the Greens (involving the grandparents, if they wish). In planning the therapy services, special attention should be paid to coordinating what was being done by whom and at what sites, to integrate services and avoid the fragmentation of care that Pam’s family might easily experience. Ongoing follow-up of Pam and her family will provide an opportunity for the development of a collaborative relationship between the Greens and their consultant developmental specialist, and also will ensure continuity of thought and action as Pam’s abilities and needs, and her family’s perspectives and goals, change and develop over time.

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