



Family-Centred Service in Ontario: A “Best Practice” Approach for Children with Disabilities and Their Families

What is family-centred service?

Family-centred service is a **philosophy and method of service delivery** that:

- recognizes parents as the experts on their child’s needs
- promotes partnerships between parents and service providers, and
- supports the family’s role in decision making about services for their child (Rosenbaum, King, Law, King, & Evans, 1998; Shelton & Stepanek, 1995).

Family-centred service involves the following types of **service provider behaviors**:

- respectful and supportive care
- coordinated and comprehensive care
- enabling and partnership
- providing general information, and
- providing specific information about the child (King, Rosenbaum, & King, 1996).

What are the benefits of family-centred service?

A family-centred approach to service delivery is considered to be a **best practice** in early intervention services (Bailey, Buysse, Edmondson, & Smith, 1992; Baird & Peterson, 1997). In pediatric rehabilitation, there is evidence that a family-centred approach results in greater parental satisfaction with services, better parental psychosocial well-being, and better psychological adjustment of children (King, King, & Rosenbaum, 1996; King, King, Rosenbaum, & Goffin, 1999; King, Law, King, & Rosenbaum, 1998).

Over the past 10 to 15 years, there has been **increasing adoption** of a family-centred approach in hospitals and community-based service organizations across North America. These organizations include children’s rehabilitation centres and Community Care Access Centres in Ontario. The majority of the 19 children’s rehabilitation

centres that comprise the Ontario Association of Children’s Rehabilitation Services (OACRS) have formally adopted a family-centred approach.

CanChild’s 1999 Ontario-wide survey of family-centred service delivery

CanChild Centre for Childhood Disability Research is a health system-linked research unit funded by the Ontario Ministry of Health, with a formal partnership with OACRS. In the early 1990s, *CanChild* conducted surveys of families and service providers to examine the implementation of family-centred service in Ontario. Due to changes in children’s rehabilitation services over the past few years, *CanChild* believed it would be useful to conduct another Ontario-wide survey of family-centred service for children with disabilities and their families.

A total of 494 parents, 324 service providers, and 15 chief executive officers (or their designates) from **10 OACRS centres** and **6 Community Care Access Centres** participated in the 1999 survey. Details about the survey, including information about the characteristics of participants, the measures, and specific findings, are provided in three reports published by *CanChild*:

- **Report #1** provides information about families, service providers, and service provision in Ontario (King et al., 2000a).
- **Report #2** describes parents’ perceptions of the family-centredness of service delivery, their beliefs about participation in family-centred service, and their satisfaction with service (King et al., 2000b). This report also contains information about service providers’ perceptions and beliefs about family-centred service.

- **Report #3** outlines the factors found to be most important in determining parents' perceptions of care and their satisfaction (Law et al., 2001).

What did the survey find and how is this information useful?

The most important conclusions drawn from the survey findings are discussed below. These conclusions are relevant to parents, service providers, managers, and legislative policy makers.

1. Children's rehabilitation services in Ontario are highly family-centred.

- Parents see children's rehabilitation services in Ontario as **highly family-centred**. This was also the case in *CanChild's* 1992 Ontario-wide survey, which did not include Community Care Access Centres.
- Service organizations in Ontario are doing well in informing parents about their child's **therapy progress**, involving parents in **making decisions** about services for their child, and treating parents **respectfully and supportively**. There have been improvements at OACRS centres since 1992 in the first two of these areas. Ontario organizations therefore are making a difference in areas that matter to parents.
- Parents report that the provision of general information is the aspect of family-centred service that is least well done. This has been found in previous *CanChild* studies. The findings therefore confirm parents' often-mentioned concern about the **lack of appropriate and needed general information** about the causes and implications of various disabilities and about existing services and eligibility criteria.
- Service providers and parents strongly believe in the importance and utility of family-centred service. Their beliefs are therefore not a barrier. The **major barriers to implementing family-centred service** concern time, human, and financial resources.

2. Family-centred services increase parent satisfaction

- When parents view services as more family-centred, their satisfaction with services is higher. This association between family-centredness and satisfaction has been found in previous *CanChild* studies.

3. Children have complex needs and require individualized, expert services

- It is important for service organizations to continue to provide **comprehensive and individualized services** for children with disabilities because many children have complex needs. Therapists and clinicians require **specialized expertise and experience** to deliver effective services to these children and their families.
- The survey found that services are provided by **highly experienced service providers** who have training in a variety of disciplines. Parents should feel encouraged by this expertise and by the fact that service providers feel confident in their ability to deliver family-centred services. It is important that organizations continue to employ service providers who have expertise in working with children with complex developmental issues.

4. Interagency coordination of services is required to increase parents' satisfaction

- Children who have greater numbers of health or development conditions are very likely to receive services from multiple sources. Going to multiple locations for services is a concern often mentioned by parents. The findings show that receiving services from multiple sources is associated with lower satisfaction with services and perceptions of services as less family-centred. Therefore, **interagency service coordination** is of utmost importance for families whose children have complex and continuing needs, and who receive services from multiple sources or at a number of different locations. Although **coordination of services between agencies** is the ideal, providing family-centred services can buffer the effects of receiving services from several different organizations. **Decreasing the number of sources of service** within a community is also an important policy goal.

5. Organizations with family-centred cultures create satisfaction with services

- Organizations with **family-centred cultures** have explicit organizational values and shared behavioral expectations that reflect a family-centred approach. The presence of a family-centred culture strongly influences parents' satisfaction with service, independent of parents' perceptions of the quality of the individual services they receive. The support and active involvement of the chief executive officer is very important to the development of a family-centred organizational culture.

6. Family-centred service should be considered a “best practice” approach

- The findings strongly suggest that family-centred service should be considered a **“best practice” approach in pediatric rehabilitation** because it outlines the principles and specific behaviors of service providers that are important to parents and is supported by research evidence.
 - The survey findings show that parents and service providers strongly believe in the **importance and utility of family-centred service**. They strongly believe in the principles of family-centred service and believe that family-centred services lead to positive outcomes for families.
 - Furthermore, research indicates that family-centred service has **actual benefits** for children and families, including better psychological adjustment for parents and children, and greater parental satisfaction with services (Rosenbaum et al., 1998).
- Adopting family-centred service as a “best practice” will support the **development of policies** to encourage family-centred care. Policies endorsing a family-centred approach will have important payoffs for children with disabilities and their families because family-centredness is linked to satisfaction and well-being (Rosenbaum et al., 1998).

Where can I get more information about family-centred service?

To obtain the 3 reports from this survey (marked with an * in the **References** list), please visit *CanChild*'s website www.fhs.mcmaster.ca/canchild/

Useful information also can be obtained from:

- the **Beach Center** website www.beachcenter.org.
- Publications available from the **Frank Graham Porter** website <http://www.fpg.unc.edu/pubs>
- the **Institute for Family-Centred Care** <http://www.familycenteredcare.org/>

What does an “ideal” family-centred service organization look like?

Family-centred service specifies how services should be delivered to meet the needs of children and families rather than what types of services should be provided. Based on the survey findings, we conclude that “ideal” family-centred health and social service organizations:

- **Formally adopt a family-centred approach to service delivery.**
- **Provide information to families about family-centred service.**

This includes information about what family-centred service means and involves, evidence for the utility of this approach, and concrete information about what families should expect in their association with the organization. It is important to explicitly consider beliefs because the survey showed that parents' beliefs about family-centred service influence their perceptions of family-centred service within an organization.
- **Implement strategies consistent with a family-centred approach.**

Some strategies are: implementing family-friendly intake procedures and hours of operation, involving parents in goal setting for their child, providing parents with information brochures about services and user-friendly reports about their child's progress, and providing a parent resource centre.
- **Train and support staff members in family-centred service delivery.**

Organizations that provided training in family-centred service to staff members (and had a more family-centred culture overall) were found to provide better family-centred service in the eyes of both parents and staff members. These organizations also received higher satisfaction ratings from parents. Service providers who feel that they can carry out family-centred service effectively have a positive influence on parents' perceptions of and satisfaction with service.
- **Work to improve interagency coordination of services across their community.**

“To strengthen families and improve the health and well-being of children, a community-based ‘system’ which is comprehensive, coordinated and family-focused is required” (Human Resources Development Canada, 1998, p. 111).

References

- Bailey, D. B., Jr., Buysse, V., Edmondson, R., & Smith, T. M. (1992). Creating family-centered services in early intervention: Perceptions of professionals in four states. *Exceptional Children, 58*(4), 298-309.
- Baird, S., & Peterson, J. (1997). Seeking a comfortable fit between family-centered philosophy and infant-parent interaction in early intervention: Time for a paradigm shift. *Topics in Early Childhood Special Education, 17*, 139-164.
- Human Resources Development Canada. (1998). *Investing in children: Ideas for action*. Report from the National Research Conference held in Ottawa. Author.
- King, G., King, S., & Rosenbaum, P. (1996). Interpersonal aspects of care-giving and client outcomes: A review of the literature. *Ambulatory Child Health, 2*, 151-160.
- King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology, 24*, 41-53.
- King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers' perceptions of the family-centredness of children's rehabilitation services. *Physical & Occupational Therapy in Pediatrics, 18*(1), 21-40.
- *King, S., Kertoy, M., King, G., Rosenbaum, P., Hurley, P., & Law, M. (2000b). *Children with disabilities in Ontario: A profile of children's services. Part 2: Perceptions about family-centred service delivery for children with disabilities*. Hamilton, ON: McMaster University, *CanChild* Centre for Childhood Disability Research.
- King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of caregiving: Development and validation of a measure of processes. *Developmental Medicine and Child Neurology, 38*, 757-772.
- *King, S., Law, M., King, G., Kertoy, M., Hurley, P., & Rosenbaum, P. (2000a). *Children with disabilities in Ontario: A profile of children's services. Part 1: Children, families and services*. Hamilton, ON: McMaster University, *CanChild* Centre for Childhood Disability Research.
- *Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2001). *Children with disabilities in Ontario: A profile of children's services. Part 3: Factors affecting family-centred service delivery for children with disabilities*. Hamilton, ON: McMaster University, *CanChild* Centre for Childhood Disability Research.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics, 18*(1), 1-20.
- Shelton, T. L., & Stepanek, J. S. (1995). Excerpts from family-centered care for children needing specialized health and developmental services. *Pediatric Nursing, 21*(4), 362-364.

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