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How Does Family-Centred Service Make a Difference?

FCS Sheet #3

This FCS Sheet is #3 of an 18 part series on family-centred service.

If you are interested in this FCS Sheet, you may also want to read:

- FCS Sheet #1: What is family-centred service?
- FCS Sheet #4: Becoming more family-centred

Key definitions and a list of the topics in this series can be found at the end of this FCS Sheet.

Maybe you have heard someone say, "*Family-centred service is a wonderful philosophy and it seems like a good idea.*" Within that statement, there is an implied "*but. . .*" How do you respond?

You might say, "*A family-centred approach is better - it's just common sense.*"

But what if they ask you, "*Does it really make a difference? Where's the proof?*"

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Relevance

Family-centred service makes sense to many people and its benefits are often described in real-life stories. Studies have shown that parents and service providers highly value a family-centred approach to service provision (King et al., 2000). Although these pieces of information may work fine in a casual conversation, people who are in the service delivery system (including parents, service providers, managers and policy-makers) may need something more. Thus, before we can advocate for a family-centred approach (and invest money and resources to implement the necessary changes) we should first look closely at the research evidence supporting its effectiveness.

The use of **evidence-based** practice has become more common and necessary in health care. Organizations and individuals are required to use their scarce resources appropriately and to be accountable for the services they provide. Evidence from research studies on family-centred service can help to clarify what the benefits are to using family-centred service. Such information will give support to recommendations for a more family-centred way of providing service to children and families.

Facts & Concepts

What types of outcomes are important in a family-centred approach?

The purpose of working with families who have a child with special needs is to enhance the quality of life for all members (Fewell & Vadasy, 1987). Consequently, the outcomes of interest for a family-centred approach should focus on more than just the child. In fact, much of the research on quality care has focused on the key outcomes of satisfaction with services, reduced stress and worry, and follow-through with therapy programs (King, G. et al., 1996). In addition, outcomes about siblings, the family, health care providers, the community, and the service organization should be considered in showing the benefits of family-centred service (Allen, 1987; Bennett & Guralnick, 1991; Epstein et al., 1989).

What is the nature of the evidence?

The way in which research studies are designed and carried out gives a certain "weight" to the kind of evidence they produce. At one end of the spectrum are studies that have few participants and are descriptive in nature. Although these studies are small, they give us very useful information and help us understand a topic.

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At the other end of the continuum are larger studies, with experimental and control groups, where participants are randomly assigned to a group. The strict methods that these studies use give us considerable confidence in their results. Much of the research on family-centred service comes from studies in between these two extremes. The studies are designed to show associations or relationships but they **do not demonstrate cause and effect** (that is, they do not show that one thing causes another). We need to be aware of this and cautious when interpreting such evidence.

The research evidence gathered for this review comes from the literature that deals with children's rehabilitation or health care that is community-based. This review does not include studies of in-hospital services. While that narrows the focus, this review still does not include every related study. This is because there are many different elements that make up family-centred service (see FCS Sheet #1 – What is family-centred service?) and there are a variety of terms used to describe this approach to service delivery.

There are only a few studies that have **specifically** addressed the effectiveness of family-centred service. Some of these studies have focused on only one element of family-centred service, while other studies have evaluated a complete family-centred service program. There are limitations to both of these approaches. Studying only one element does not help us to view family-centred service as an integrated approach to service delivery. Conversely, examining a comprehensive family-centred service program may not allow us to identify the "active ingredients" that make the most difference.

What is the research supporting family-centred service?

In the following section, the evidence supporting a family-centred way of delivering service is organized by type of outcome: child, parent/family and system outcomes. The specific outcome areas that have been impacted by a family-centred approach are presented in bold. These bolded phrases are quick and easy to remember when you are asked, **"What is the evidence?"** Each outcome area is then followed by a short explanation about one or more studies and their findings. This gives you information about the specific parts of family-centred service that were addressed in the research. Not surprisingly, some studies have had an impact on more than one outcome. Such studies have been identified with an asterisk (*) placed in front of the authors' names. This review includes studies that focus on children of all ages who have a variety of disabilities, as well as children who have chronic medical illnesses or disorders. It is not possible in the space of this document to provide specific details about the studies mentioned here (for example, the kind of study, the measures and statistical methods used). It is also not possible to discuss the limitations and the comparative "weights" given to each study's evidence. However, all studies have been referenced at the end of this document if you are interested in learning more about them.

Child Outcomes

There is limited information about the benefits of family-centred service for children.

The studies mentioned here focus on only two major kinds of outcomes for children. These are developmental gains/skill development and psychosocial adjustment.

Developmental gains and/or skill development

- In a study of an individualized family-focused intervention, children achieved targeted goals, acquired functional skills, and showed accelerated rates of developmental progress. This kind of intervention placed an emphasis on parents and professionals working together, as well as parent education (*Caro & Deverensky, 1991).
- An evaluation of an education program showed improvements in children's skill development and motor development gains. This education program focused on providing general and specific information to the parents, building on parents' skills, and individualizing services (*Moxley-Haegert & Serbin, 1983).
- Children who received family-centred functional therapy showed changes in their individualized motor goals over a 3-month period. This intervention involved parents in identifying goals, fit the therapy to the family's needs and priorities, and had an educational component (Law et al., 1998).

Better psychological adjustment

- Children who participated in a comprehensive program of services that focused on the whole family and its needs showed better psychological adjustment. This improvement was still evident in a 4-5 year follow-up study. Families were encouraged to become more actively involved in taking responsibility for managing their child's care and for making informed decisions in partnership with service providers. The program also offered coordination of services, health education, and support (*Stein & Jessop, 1984, 1991).
- A study of a specialized nursing intervention showed higher scores on measures of children's function, role performance, and self-worth - all indicating better psychological adjustment. This 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 get the services they needed (Pless et al., 1994).

Parent / Family Outcomes

There is more evidence for a family-centred approach in the area of parental outcomes than there is for child outcomes.

The most common outcome is better psychological well-being for mothers (mothers were generally the focus of most studies). There was little research about the family unit as a whole.

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Increased knowledge about development

Parents were found to have gained knowledge about their child's development through a specific education program. This program focused on giving parents general and specific information, building on parents' skills, and individualizing services (*Moxley-Haegert & Serbin, 1983).

Increased participation in therapy home program

Parents in the education program (described in the above paragraph) increased their participation in the home therapy program and continued this involvement at 1-year follow-up (*Moxley-Haegert & Serbin, 1983).

Better psychological well-being

Studies show that parents, mostly mothers, have experienced reduced anxiety, less depression, and better well-being when services are provided in a family-centred way.

- Mothers of children with chronic illnesses showed reduced levels of anxiety when they were linked with mothers of older children with similar conditions. This community-based family support program provided informational, emotional, and affirmational support (Ireys et al., 2001).

- Parents who reported receiving more family-centred care experienced better emotional well-being, with less depression and distress. These associations highlight the importance of providing services that meet parents' needs for information, partnership, support and understanding - all key elements of family-centred service (*King et al., 1999).
- Mothers perceived higher levels of individual and family well-being when relationships with service providers were positive and family-centred (*Van Riper, 1999).
- Mothers of children with chronic illnesses, who participated in a comprehensive pediatric service, experienced a lessening of psychiatric symptoms. These changes in psychiatric symptoms, however, were not statistically significant (*Stein & Jessop, 1984).

Findings show parents experienced less stress/ distress and increased life satisfaction with family-centred services.

- Parents were found to experience less stress when they regularly attended a comprehensive early intervention program that focused on the child and family (Brinker et al., 1994).
- Mothers who received high levels of information about their child's disability and future experienced less psychological distress (Miller et al., 1992).

- Mothers showed increased life satisfaction when they received services that used a family-centred case management model. This service delivery model emphasized parent-service provider collaboration, responsiveness to family needs, interdisciplinary teams, and services that were accessible and coordinated (Marcenko & Smith, 1992).

Feeling competent as a parent

Parents' sense of their own competency as caregivers was shown to be related to service providers' rapport and communication (Washington & Schwartz, 1996).

Enhanced self-efficacy and sense of control

- Parents felt a high sense of control when the behaviours of service providers were positive and productive, competency producing, participatory and accepting (Dunst et al., 1988).
- A relationship was shown between parent-service provider interactions and parents' enhanced feelings of self-efficacy and personal control. Interactions that were empowering included those where the parent was actively involved, acquired knowledge, learned new skills, and made decisions. These findings were shown consistently in three studies. (Dunst et al., 1994).

Individualized family outcomes

Families who reported positive individualized outcomes attributed these to case manager practices that were consistent with family-centred principles. These principles included sharing responsibility and working together, promoting capabilities and competencies, being responsive to family needs, decision-making by the family, and sharing of information. This is an example where the types of outcomes are not detailed because each family specifically identified them. (Dunst et al., 1993).

Service System Outcomes

Satisfaction with care is the service system outcome for which there is considerable evidence to support family-centred service delivery.

Satisfaction has emerged as a powerful indicator of the quality of care and of an organization's success. It is important to understand how services are actually perceived by those who receive them (Cohen, 1999). Satisfaction provides such a report on the service delivery system.

Satisfaction with care

Some of the studies reported on the specific parts of a family-centred approach that "made a difference".

- Parents attributed their satisfaction with services to the way information was provided to them and to the interpersonal qualities of the service providers (Carrigan et al., 2001).
- Parents' satisfaction ratings were highly related to service providers' behaviours that were collaborative, especially supportive understanding and sharing information (DeChillo et al., 1994).
- Mothers were more satisfied with care when they reported experiencing positive relationships with service providers who used a family-centred approach (*Van Riper, 1991).
- Satisfaction with service delivery was enhanced by changes to a more family-centred approach. Parents reported changes that included feeling more involved in decision making, having their views understood, and receiving coordinated services (Stallard & Hutchinson, 1995).
- Parents who participated in an individualized family-focused intervention reported high levels of satisfaction (*Caro & Deverensky, 1991).

For some studies, it was not possible to identify which family-centred features were influencing satisfaction. These were generally studies where a comprehensive program of services was examined.

- Parents who experienced services that were more family-centred had higher levels of satisfaction with care. This relationship was consistently found in various studies by the same authors examining service delivery in Ontario (King et al., 1999; King, S. et al., 1996, 2000).
- Parents' satisfaction with services is strongly influenced by their perception that services are family-centred, by the presence of a more family-centred culture at the organization where services are provided, and by having fewer sources of service (Law et al., 2001).
- Parents experienced greater satisfaction with care when they were involved in a program that provided integrated medical and psychosocial services. This program encouraged family involvement and partnership with service providers in making decisions, and offered coordination of services, health education and support (*Stein & Jessop, 1984).

Summary of Research Evidence

There is considerable research evidence that supports the effectiveness of family-centred service, as seen in outcomes for children, parents, and the service delivery system. However, most of this evidence is focused on a few outcomes, mainly child psychological adjustment, parent psychosocial well-being, and satisfaction with services. It seems important to continue to conduct research, especially on those Elements of family-centred service that have received little attention (for example, cultural diversity). Future research should measure a wider range of outcomes (such as family functioning, interagency collaboration, and cost-benefit analysis). It would also be helpful to understand the effectiveness of family-centred service from multiple perspectives (such as family members, service providers and policy makers).

Strategies for Learning About and Using Family-Centred Service Evidence

To respond to the question - *what is the evidence that family-centred service makes a difference?* - you can use any of the bolded phrases or their supporting statements as outlined in the previous section. Is there more that you could do to promote the findings about family-centred service? The answer to this question for most of us is "Yes!" The following strategies should be useful no matter what your setting or perspective.

Read and understand the existing evidence about how family-centred service makes a difference.
Use the research and program evaluation evidence to support your requests for a family-centred approach.
Get involved in advocating for family-centred service, armed with the facts about the effectiveness of family-centred service.

Encourage more studies to be carried out on those areas where evidence is lacking and needed.
Participate in studies that examine the specific elements that make up family-centred service, and use multiple outcomes and perspectives.
Put these family-centred service ideas into practice yourself and be a role model for others.

All those involved in the service delivery system - parents, service providers, managers, policy-makers and researchers - can work toward achieving a more family-centred approach.

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Key Definitions

Family-Centred Service – Family-centred service is made up of a set of values, attitudes and approaches to services for children with special needs and their families.

Family-centred 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 with service providers to make informed decisions about the services and supports the child and family receive.

In family-centred service, the strengths and needs of all family members are considered.

Service Provider – The term service provider refers to those individuals who work directly with the child and family. These individuals **may** include educational assistants, respite workers, teachers, occupational therapists, physiotherapists, speech-language pathologists, service coordinators, recreation therapists, etc.

Organization – The term organization refers to the places or groups from which the child and family receive services. Organizations **may** include community programs, hospitals, rehabilitation centres, schools, etc.

Intervention – Interventions refer to the services and supports provided by the person who works with the child and family. Interventions **may** include direct therapy, meetings to problem solve issues that are important to you, phone calls to advocate for your child, actions to link you with other parents, etc.

Want to know more about family-centred service?

Visit the CanChild website:
www.canchild.ca

or call us at 905-525-9140 ext. 27850

FCS Sheet Topics

The following is a list of the FCS Sheets. If you are interested in receiving any of these topics, please contact CanChild or visit our website.

General Topics Related to Family-Centred Service

- FCS Sheet #1 – What is family-centred service?
- FCS Sheet #2 – Myths about family-centred service
- FCS Sheet #3 – How does family-centred service make a difference?
- FCS Sheet #4 – Becoming more family-centred
- FCS Sheet #5 – 10 things you can do to be family-centred

Specific Topics Related to Family-Centred Service

- FCS Sheet #6 – Identifying & building on parent and family strengths & resources
- FCS Sheet #7 – Parent-to-parent support
- FCS Sheet #8 – Effective communication in family-centred service
- FCS Sheet #9 – Using respectful behaviours and language
- FCS Sheet #10 – Working together: From providing information to working in partnership
- FCS Sheet #11 – Negotiating: Dealing effectively with differences
- FCS Sheet #12 – Making decisions together: How to decide what is best
- FCS Sheet #13 – Setting goals together
- FCS Sheet #14 – Advocacy: How to get the best for your child
- FCS Sheet #15 – Getting the most from appointments and meetings
- FCS Sheet #16 – Fostering family-centred service in the school
- FCS Sheet #17 – Family-centred strategies for waitlists
- FCS Sheet #18 – Are we really family-centred? Checklists for families, service providers and organizations