



# What is Family-Centred Service?

FCS Sheet #1

This FCS Sheet is #1 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 #3: How does family-centred service make a difference?
- FCS Sheet #5: 10 things you can do to be family-centred.

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

"Copernicus came along and made a startling reversal – he put the sun in the center of the universe rather than the Earth. His declaration caused profound shock."

Let's pause to consider what would happen if we had a Copernican Revolution in the field of disability...the family is the center of the universe and the service delivery system is one of the many planets revolving around it. Now visualize the service delivery system at the center and the family in orbit around it. Do you see the difference? Do you recognize the revolutionary change in perspective? This is not a semantic exercise – such a revolution leads us to a new set of assumptions and a new vista of options for service." (Turnbull & Summers, 1985, as cited in Edelman et al., 1992)

### Relevance

Family-centred service is an approach to providing services to children with special needs. As suggested by the name of this approach, the family is considered to be at the centre of the services. This makes family-centred approaches different than traditional approaches where the focus is on the child, and where service providers are the ones who make decisions about the services a child receives.

For family-centred service to be effective, it is important that everyone who is involved understands what family-centred service means. This includes families, service providers, and directors of programs and organizations.

The 18 FCS Sheets in this series have been developed to help increase people's understanding of family-centred service. Each FCS Sheet contains information about the topic and specific strategies to encourage family-centred behaviours. This first FCS Sheet provides general information about family-centred service. It is the basis for the other FCS Sheets in this series.

### **Facts and Concepts**

# What is the history of family-centred service?

Carl Rogers, a psychologist, was one of the first individuals to discuss ideas related to family-centred service (see Rogers, 1951). His approach was referred to as "client-centered". It focused on giving control to the client. rather than the service provider. In the 1960s, the Association for the Care of Children in Hospital began to relate these ideas to children and their families through discussion of "familycentred care". Since this time, the concepts behind family-centred care and family-centred service have been written about and researched by many individuals and organizations.

CanChild's definition of family-centred service is based on **concepts from the literature** on family-centred service (for example, Dunst et al., 1988; Johns & Harvey, 1993; National Center for Family-Centered Care, 1990; Shelton & Stepanek, 1994; Tunali & Power, 1993), and on **research** in the fields of early intervention and pediatric rehabilitation (for example, King et al., 1998; King et al., 2000; Stein & Jessop, 1984).

### CanChild's Definition of 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.

# What does family-centred service mean for children's services?

The chart on page 4 provides more detail about the ideas in CanChild's definition of family-centred service. The chart is a framework for family-centred service that was developed to show the practical implications of the ideas that are discussed in the literature (see Rosenbaum et al., 1998 for detailed information about the development of the framework).

The framework includes three premises (or basic assumptions) that form the foundation of family-centred service. Each of the premises is then followed by guiding principles and key elements. The guiding principles describe what families should expect in family-centred relationships with service providers. The key elements outline behaviours that are expected of service providers, and the rights and responsibilities of families. This is a useful tool for learning about family-centred service because it brings concepts from the literature together with things that parents and service providers can see and do.

## Strategies for Learning More About Family-Centred Service

Take a moment to think about the information provided in this FCS Sheet. Does it affect you in your relationships with others? If so, how? Are there things that you would like to know more about or would like to be able to do better? If so, here are some things you can do:

# Learn more about family-centred service.

- Read articles and books.
- Check out the websites listed in the Resources section.
- Ask other people about their beliefs about family-centred service.
- Ask your organization to provide an education session for families and service providers on family-centred service.

### **Summary**

This FCS Sheet provides an overview of family-centred service. The ideas behind family-centred service are broad and can be applied to all the services a child receives, including rehabilitation, school, and community programs. Continue to explore these ideas and think about what they mean to you. By doing so, you will be better able to support and participate in family-centred relationships.

### Resources

Dunst, C., Trivette, C., & Deal, A. (1988). Enabling and empowering families. Cambridge, MA: Brookline Books.

Edelman, L., Greenland, B., & Mills, B.L. (1992). *Building parent/professional collaboration: Facilitator's guide*. St. Paul, MN: Kennedy Kreiger Institute.

Johns, N. & Harvey, C. (1993). Training for work with parents: Strategies for engaging practitioners who are uninterested or resistant. *Infants and Young Children*, 5(4), 52-57.

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. (2000). Children with disabilities in Ontario: A Profile of children's services. Part 2: Perceptions about familycentred service delivery for children with disabilities. Hamilton, ON: McMaster University, CanChild Centre for Childhood Disability Research.

Law, M. (1998). Family-centred assessment and intervention in pediatric rehabilitation. New York: The Haworth Press, Inc.

National Center for Family-Centered Care. (1990). What is family-centered care? (brochure) Bethesda, MD: Association for the Care of Children's Health.

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Bethesda, MD: Association for the Care of Children's Health.

Tunali, B., & Power, T.G. (1993). Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. Journal of Child Psychology and Psychiatry, 34, 945-957.

### **Organizations**

Beach Center on Families and Disability www.beachcenter.lsi.ku.edu 785-864-7600

CanChild Centre for Childhood Disability Research <a href="https://www.canchild.ca">www.canchild.ca</a> 905-525-9140 ext. 27850

Frank Porter Graham Child Development Center <u>www.fpg.unc.edu</u>

919-966-2622

Kennedy Krieger Institute www.kennedykrieger.org 443-923-9200

# Premises, Principles, and Elements of Family-Centred Service

#### 1st Premise (basic assumption)

### 2nd Premise (basic assumption)

#### 3rd Premise (basic assumption)

Parents know their children best and want the best for their children.

Families are different and unique.

Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.

#### Guiding Principles ("should" statements)

Each family should have the opportunity to decide the level of involvement they wish in decision making for their child. Parents should have ultimate responsibility for the care of their children.

Each family and family member should be treated with respect (as individuals).

The needs of all family members should be considered. The involvement of all family members should be supported and encouraged.

#### Key Elements (rights and responsibilities)

## Expectations and Rights of Families

- Be the ultimate decision makers.
- Utilize their own resources.
- Receive information which will enable them to make decisions about the care that will most effectively meet their needs.
- Define the priorities of intervention.
- Choose their level and type of involvement and the level of support they require.
- Receive services with a minimum of hassle and in a timely manner.
- Have access to information regarding their child and family.

# Service Provider Behaviours

- Encourage parent decision-making in partnership with other team members (to utilize family empowerment strategies.)
- Assist families to identify their strengths and build their own resources.
- Inform, answer, and advise parents (to encourage informed choices).
- Work in partnership with parents and children and help them identify and prioritize their needs from their own perspective.
- Collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation).
- Provide accessible services that will not overwhelm families with paperwork and bureaucratic red tape.
- Share complete information about the child's care on an ongoing basis.

# Expectations and Rights of Families

- Maintain their dignity and integrity throughout the care-giving process
- Be supported in the decisions that they make.
- Have their opinions sought and to be listened to.
- Receive individualized services.

#### Service Provider Behaviours

- Respect the values, wishes and priorities of families.
- Accept and support decisions made by families.
- Listen.
- Provide flexible and individualized services (and to respond to the changing needs of the family).
- Be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socioeconomic).
- Believe and trust parents.
- Communicate in a language understandable by parents.

# Expectations and Rights of Families

- Have their needs and concerns taken into account.
- Feel welcome and supported in the level of participation they choose.

## Service Provider Behaviours

- Consider and be sensitive to the psychosocial needs of all family members.
- Provide an environment that encourages the participation of all family members.
- Respect the family's own style of coping without judging what is right and what is wrong.
- Encourage familyto-family support and the use of natural community supports and resources.
- Recognize and build on family and child strengths.

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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 familycentred
- 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 familycentred? Checklists for families, service providers and organizations