



Making Decisions Together: How to Decide What is Best

FCS Sheet #12

This FCS Sheet is #12 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 #10: Working together: From providing information to working in partnership
- FCS Sheet #13: Setting goals together

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

Does this sound familiar?

Mike and Mary are concerned that their daughter, Sarah, is slow in learning to crawl and sit. Tomorrow they will attend a meeting with the service providers who have been assessing Sarah's development. A physician has talked about the need for Sarah to be on medication or have surgery. The occupational therapist and speech-language pathologist have suggested that Sarah attend a preschool where she can receive the developmental help she needs. Mike and Mary want to do what is right for Sarah, but too many people are making suggestions. There are so many decisions to be made. How are parents supposed to know what to do? How can parents make decisions that are right for their family?

Relevance

One of the premises of family-centred service is that families should make the decisions about the services, programs, and medical interventions for their children. How should service providers and families work together to make the best decisions? **Well-informed decisions** meet the needs, values, and goals of both children and their families, and have the long-range needs of the child in mind.

Facts & Concepts

What types of service-related decisions need to be made?

The types of decisions that need to be made depend on the child's needs and the family's concerns and priorities. Decisions may need to be made about issues as diverse as: what equipment to buy for school, what summer programs to involve the child in, and whether the child should have surgery.

Decisions involve two steps:

- First, decisions need to be made about **which issues are most important to address**. Clearly identifying the most important issue is crucial in achieving positive outcomes for the child. Doing this ensures that everyone is focussing on the same goal (Tuchman, 1996).
- Second, decisions need to be made about **which strategies will best address these priority issues**. Service providers and the family should work together to develop and use these strategies. All team members, including parents, should be encouraged to offer ideas. Parents will only feel comfortable in providing suggestions when there is an atmosphere of trust and acceptance (Tuchman, 1996).

Who should be involved in the decision-making process?

All relevant people should be involved. The team will include parents or guardians, service providers, and the child or youth (depending on his/her age).

Who makes the final decision?

Families are the ultimate decision-makers. Service providers should assist parents to collect information. This will help them make well-informed decisions that they feel are right for their families (Leviton et al., 1992). More specifically, service providers have a role in providing information about the child's condition, assessment findings, and possible intervention options.

How should decisions be made?

Service providers and parents need access to up-to-date information about the effectiveness of various interventions and strategies, so that together they can decide what is appropriate or useful for a child. Decisions are, however, not just based on information about what works. They must take into account the desires of the child, the priorities of the family, and the needs of other family members.

Decisions should be well informed.

Sarah's legs are scissoring and crossing over each other. The service providers made a series of observations and did some tests. They found that the scissoring is due to spasticity in her legs. They spoke with the family about intervention options for Sarah (including medication and surgery). Each option has important implications for Sarah and her family. The medication has side effects. The surgery would require intensive, long-term rehabilitation. Sarah's family would need to be committed to the long-term therapy that Sarah would require.

Decisions should be based on the **needs, values, and goals** of both the child and family. It does not make sense to involve the child in an intensive program when regular attendance is not practical for families and/or conflicts with other family priorities. It is never in the best interest of the child to create a situation in which the family is overburdened with demands (for example, providing home programs that require more time than the family has available).

It is really important to Sarah's family that she has the opportunity to learn to walk. Being able to walk will help Sarah be a part of family activities because her family is involved in lots of outdoor activities and sports. The parents also believe that being able to walk will allow Sarah to participate more fully at preschool.

Decisions should involve the **child's wishes**. It is important to involve the child as much as possible in the decision. Ask children what they would prefer, and give them options to consider among a range of things that are acceptable to you and their parents. Help children understand that they are in control. Make decisions that help children get what they want. Realize that children's wishes will change over time as the child seeks new experiences and sets new goals.

Decisions should keep the **long-range needs** of the child in mind. The best short-term decision may not be the best decision in the long term. In the long-term, think of the child's participation at school, as well as in community recreation and leisure activities. Be considerate of what gives the child a sense of meaning in life. It is important to realize what is the best today may not be what is best at another time in the child's life. Decisions need to fit the circumstances at the time. Since circumstances change, it makes sense that decisions may change as well.

Sarah's family is willing to work toward a goal that will help with Sarah's long-term participation at school. They recognize that Sarah's intervention will be long-term and that Sarah may require more surgery when she gets older. The service providers assist the family to weigh the intervention options, and provide them with information about what each option will mean for them and for Sarah. Mike and Mary believe that they are making an informed decision that is right for them.

Strategies for Making Well-Informed Decisions

- **Ask questions and talk with others.** Other people can provide you with important links to information and can give you practical strategies. Parent support groups are a useful way for parents to find out how others have dealt with issues (Law, King et al., 2001).
- **Gather information.** Find out as much information as you can. Librarians, resource centre personnel, and researchers can help you find out the information you need. Be familiar with resource centres in your community that have information about disabilities. These may be located in your local children's rehabilitation centre or elsewhere in your community. Use the Internet for information. Your local resource centre can assist you. You can also access links on the websites of the various children's treatment centres throughout the province.
- **Remember that not all information is good information.** Discuss the information with others so that you can weed out good information from bad. The effectiveness of certain types of interventions can be doubtful, so make sure that you have the best information.
- **Keep an open mind.** Consider how open you might be to using information that may not fit with your preconceived ideas about what is useful for your child. Consider the pros and cons of the best available options.

Summary

The key to good decision-making is to be informed. You will be on the right track if you first think about your child's short- and long-term needs, your child's wishes, and your family situation, and then seek out relevant information to clarify your options. Trust your instincts to tell you if something does not feel right. Raise questions if something is bothering you. **In the end, it is important to make sure that a decision feels right to you.**

Leviton, A., Mueller, M., & Kauffman, C. (1992). The family-centered consultation model: Practical applications for professionals. *Infants and Young Children*, 4 (3), 1-8.

Tuchman, L. I. (1996). Team dynamics and communication. In P. Rosin, A. Whitehead, L. Tuchman, G. Jesien, A. Begun, & L. Irwin (Eds.), *Partnerships in family-centered care: A guide to collaborative early intervention* (pp. 145-185). Baltimore: Paul H. Brookes.

Resources

Law, M., King, S., Stewart, D., & King, G. (2001). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 21(2/3), 29-48.

Law, M., Stewart, D., Burke-Gaffney, J., Szkut, T., Missunia, C., Rosenbaum, P., King, G., & King, S. (2001). *Keeping it together: A practical resource for parents of children and youth with special needs (Research version)*. Hamilton, ON: McMaster University, CanChild Centre for Childhood Disability Research.

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