



Family-Centred Strategies for Waiting Lists

FCS
Sheet
#17

This FCS Sheet is #17 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 #14: Advocacy: How to get the best for your child

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

My daughter has been having problems eating. I can't seem to get her to put anything in her mouth and I'm getting very scared. Her therapist referred her to a Feeding Clinic and I was relieved until I found out we would have to wait 4 months. What can I do?

Relevance

With increasing demands for health, rehabilitation and recreation services, families must often wait a period of time before services can be received. Waiting lists can cause increased stress and frustration, particularly for families with a child who has recently been identified as needing service. A family-centred approach to dealing with waiting lists suggests that organizations, service providers and families should work together to improve the situations families face during the waiting period.

Facts & Concepts

In one study, parents who were satisfied with their child's rehabilitation services and parents who were dissatisfied were asked to comment on the things they liked and disliked about the services (King et al., 2001). Parents who were dissatisfied frequently identified long waiting lists to be a problem. This suggests that the way in which a family is treated immediately after they have been referred to a program or service can affect their overall satisfaction. As such, these early experiences can set the tone for parents' willingness and ability to work with the service team in the future. The following section provides strategies that are intended to address the issue of waiting lists in a family-centred way.

Strategies for Fostering Family-Centred Service in the School

Families, service providers, and organizations all have a role to play when working toward improving waiting periods. Strategies for each of these groups have been organized according to three goals:

1. Decreasing the waiting period.
2. Improving the initial contact between the family and the organization (or program).
3. Taking active roles during the waiting period.

Strategies for the Waiting Period

Things a family member can do

- Ask for information about the programs and services provided by the organization. This way, you can make an informed decision about what you need.
- If you need only one service, ask to receive it immediately.
- Ask if priorities are given in certain situations.

Things a service provider can do

- Provide families with information about the programs and services that are available. Encourage families to choose those that are a priority for them.

Things the organization can do

- Examine the intake and referral process carefully
- Is it family-centred?
- Are there different ways for a family to enter the service system?
- Is the procedure too lengthy?
- Are all steps necessary?
- Are there methods that could be used to prioritize the waiting list?
- Can families that require only one service enter that service immediately, without a comprehensive team assessment?
- Work with families already involved with the organization. Develop specific strategies for decreasing waiting lists based on their experiences.

Strategies for Improving the Initial Contact between the Family and the Organization (or Program)

Things a family member can do

- Be prepared with a list of your immediate concerns. If you share your concerns, ask how they will be addressed and who you can follow up with.
- Ask the person you are speaking with to use the language that you understand – ask for a translator when necessary.

Things a service provider can do

- Ask families if they have any immediate concerns that can be addressed.
- Ask families if they would like you to arrange the services of a translator when you do not speak their preferred language.

Things the organization can do

- Establish a policy that ensures families are asked what their immediate concerns are. Make sure that steps are taken to address these concerns.
- Provide an orientation package about the organization to the family. Consider having it available in different languages and different formats (for example, print or video).

Strategies for Taking Active Roles During the Waiting Period

Things a family member can do

- Ask how long you should expect to wait for the service. Follow-up with the organization to see how the waiting list is moving.
- Seek out opportunities to speak about your concerns. See if the issues most important to you can be addressed right away.
- Ask who to contact if issues arise and where you can get more information if needed.
- Find out about forms or assessments that need to be completed. Complete the forms as soon as possible.
- Attend information sessions or group programs at the organization.
- Use the parent resource centre to get more information.
- Inquire about parent groups associated with the organization.
- Link up with a family who is already receiving services at the organization. They will be able to share information and tips with you based on their experiences.

Things a service provider can do

- Be realistic when telling families how long they can expect to wait for services.
- Help the family to prepare for the first formal meeting by giving them a list of questions to consider.
- Ensure that families are listened to. Use the intake assessment as an opportunity for families to tell their story and share their concerns, rather than focussing on structured assessments.
- Tell families who they should contact if issues arise.
- Provide group information sessions for new families. Ask families that are already involved with your program to recommend topics that would have been useful for them. These information sessions can be offered before the new family is able to receive individualized services.
- Link the family to parent resource centres, websites and other accessible material.

Things the organization can do

- Provide a service where a new family can be linked with a family who is already receiving services through the organization.
- Schedule regular family coffee days for new families.
- Consider providing centralized booking of appointments for all services. This co-ordinates and speeds up the scheduling of initial appointments.
- Ensure that a service provider meets with the family as soon as possible following the initial referral.
- Consider using a primary service provider, or intake co-ordinator, as the initial contact person for the family.
- Streamline the intake procedures so families are not asked the same questions repeatedly.

Summary

The strategies in this FCS Sheet outline different roles that family members, service providers and organizations can play in working towards improving a family's experience when waiting for services. The strategies suggest the importance of providing families with information, as well as reasonable expectations, about the services that will be provided. Efforts by the organization and service providers are particularly essential when families are accessing services for the first time because the family may not be familiar with what their role can be. Overall, these strategies highlight that waiting does not have to be a passive process – all who are involved can take active steps to make the waiting period as productive as possible.

Resources

Bennett, T., Nelson, D.E., & Lingerfelt, B.V. (1992). *Facilitating family-centred training in early intervention*. Tuscon, AZ: Therapy Skill Builders.

Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T.L. (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. San Francisco: Jossey-Bass Publishers.

King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care*, 30, 111-134.

McWilliam, P.J., & Winton, P. (1991). *Brass Tacks: A self-rating of family-centred practices in early intervention*. Chapel Hill, NC: Frank Porter Graham Child Development Center, University of North Carolina.

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