



Advocacy: How to Get the Best for Your Child

FCS
Sheet
#14

This FCS Sheet is #14 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 #6: Identifying and building on parent and family strengths and resources
- FCS Sheet #11: Negotiating: Dealing effectively with differences

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

You have applied for home nursing assistance for your child, who will soon be leaving the hospital. Your request for nursing care has been denied at this time and your child's name has been put on a waiting list. You feel that the people making the decision were not aware of all the issues in your family's life, or of the complexity of your child's situation. How will you advocate to be sure your child receives this care?

Relevance

One of the basic assumptions of family-centred service is that parents know their child best and want the best for their child (Rosenbaum et al., 1998). Consequently, parents carry the responsibility to be the “advocates” for their children. This is a challenging and often difficult role for which many people have no formal training or experience.

The purpose of this FCS Sheet is to explore what advocacy means and how it can be done effectively. The information presented here has been prepared as a guide for families of children who come into contact with systems, such as the health, education, or social services systems. The ideas have been written with parents in mind. It is acknowledged that parents need to interact successfully with these systems, whose resources and supports make a difference in their lives, as well as the lives of their children. The ideas should also be of use to service providers. Often, if service providers refer only to their own perspective and understanding about the child and family issues, there can be unwanted tension with the family. Acknowledging the family’s need to advocate their own perspective can help service providers diffuse this tension, as well as be more family-centred in their approach to service delivery.

Facts & Concepts

Advocacy involves speaking out in support of a cause, as well as actively promoting that cause (Law, Stewart et al., 2001, Patterson, 1996). People can be advocates either on their own or as part of larger advocacy groups (Alper et al., 1996; Law, King et al., 2001). For parents, being an advocate has a dual purpose – parents can speak on behalf of their child, as well as on their own behalf, about the values and issues that are important to them (Cunconan-Lahr & Brotherson, 1996). Of course, service providers also have personal and professional points of view. Some may have their own ideas about what is best for a particular child and family with whom they are working. This situation can form the basis for differences of opinion. Sometimes in these situations, tensions can develop among well-intentioned people and make the need for “advocacy” especially important.

When should you advocate?

- If there is a conflict of views or other possible ways of doing something.
- If there is no agreed course of action, or if the process is stalled and there is a need to create movement.
- If your perspectives can offer a view that is not already being considered in the discussion.
- If you need to create a consensus, or build an agreement, so that action can happen.
- If you want to encourage the team to try something different in order to solve a problem.

What makes advocacy seem difficult?

- Advocates may try to show people sides of an issue that are different from the popular point of view. Doing this is often challenging, requiring persistence and hard work.
- Because advocates may offer views that are not already being considered, they may be perceived as being “pushy”.

Although these points address the difficulties advocates may face, it is important to remember the positive outcomes of advocacy. Advocates present another point of view. Depending on how (and how well) this is done, everyone can benefit.

How might you think about advocacy as a positive experience?

- Think of advocacy as “educating people”. As an advocate, view your role as that of a “teacher” or “informer”.
- Be aware that your listeners may not have the same facts or understanding of the situation as you, the advocate.
- Presents facts and ideas to those people who you assume to be interested in learning more about the specific issues.
- By approaching advocacy from the viewpoint that it can be a positive experience, you may help your listeners be more comfortable with the process. Also, by avoiding the use of a confrontational approach (where all interactions are expected to be a big battle!),

you can allow your listeners to view this interaction as an opportunity to develop a shared understanding of the issues on which to build a mutually agreeable solution.

How do you know when advocacy is done well?

- There is good communication in both directions. The advocate is able to reach the listeners, and the listeners are responsive as indicated by their questions and comments.
- There is evidence of a clear, mutual understanding of the issues and perspectives. The discussion appears to include, and be sensitive to, the points of view that have been presented by the advocate. The base for further action has been laid.
- There is evidence of mutual respect among the people in the discussion. This implies that people have listened to and heard each other’s ideas. People leave the meeting with the feeling that something worthwhile has transpired, and that future meetings (if necessary) will be carried on in a spirit of collaboration.
- People take the opportunities available to expand the discussion and learn from each others’ perspectives. In the best of all worlds this will lead to better solutions for everyone concerned, based on a broader awareness of the issues.

Strategies for Effective Advocacy

Strategies for Parents

As an advocate, you may be presenting a point of view to people who may not have the same perspectives as you do. You are “selling” your ideas. Several points are important when preparing and “performing”:

Prepare well:

- Set priorities to make sure that you are dealing with the critical needs first.
- Find out who is attending the meeting. Be sure that the people who are attending are the “right” people (with the appropriate authority) to address and resolve your priority issues.
- Link up with a parent, parent group, or network that may have experience with similar issues, or may have experience with the people or agencies with whom you are now advocating. Their insight into the processes and the approach to decision-making can be very helpful to you.
- Have your facts and arguments ready ahead of time, arranged in a logical manner.
- Practice and rehearse! Before the meeting, ask people you trust to listen to your points of view and give you feedback about whether you talk too fast or too slowly; whether you use jargon (technical) words and phrases that others might not understand;

whether you become emotional when a cool head would help; whether your voice is too soft or too loud; whether you seem to have a “chip on your shoulder” (by manner or tone of voice). These practice sessions can prove invaluable when the real meeting happens.

Provide clear and relevant information:

- It is helpful to start by stating your assumptions (whatever you consider to be the issues behind the perspective you are advocating). For example, people may not be aware that your child has a particular need. Filling in the background briefly can be very important.
- Be clear about your priorities, and about your “bottom line” position. Don’t try to tell the whole story, especially aspects of the story that are not the responsibility of the present listeners, or are not relevant to the current dilemma.
- Try to remain calm. Speak or write clearly. Take your time. Although we may be passionate about our arguments, our emotions may interfere with others’ ability to listen and consider the “facts” we are putting forward.

Listen and be respectful:

- Believe that the people you are talking to want good (but perhaps different) things for your child and that they are basically well-intentioned. This will make you less likely to start out being angry and confrontational, and more likely to encourage a discussion that is informed by ideas, rather than by anger.

- Try to understand the positions and perspectives of the people you are meeting with. If you practice before the meeting, have your friends act as “devil’s advocate” and challenge your ideas. Practice responding to different opinions so that you are prepared to address them if the need arises.
- Always be respectful about others with whom you have worked in the past. Being disrespectful about one person in front of another may make the current listener wary about how you will speak about them at the next meeting.

Follow up after meetings:

- At the end of the meeting, try to summarize what has been said and agreed to. Review the “action plan” with everyone, so that everyone hears what you believe to be the conclusions and decisions from the discussion.
- Keep notes with people’s names and telephone numbers, as well as the key issues and decisions discussed.
- Write a thank-you note to people who have been helpful, even if all they did was to listen to your point of view. In the future, they may be more interested in helping you if you have been polite and respectful.
- Plan a follow-up meeting or conference if it looks like it would be useful or necessary. It may be a good idea to have a brief meeting, even if only to recognize that the advocacy has “worked” and to thank the people who have seen your ideas put into action.

- Keep a list of the things that you thought went well (and not so well!) in order to build on your successes as an advocate for the next time advocacy is needed.
- Seek feedback from the people you have met with – what did they find most helpful about whatever you have done? Do they have any suggestions for you about the way the session went?

Strategies for Service Providers

Assisting Parents to Become Successful Advocates

- Help parents identify and sort through the systems they must work with.
- Open doors for parents by identifying other sources of help. Link parents with other parents, parent networks or support groups.
- Give parents the information that will help them make decisions. Conversely, don’t be afraid to tell a parent if you don’t have the answer.

Summary

Advocating for your child or yourself can be a challenging but rewarding experience. By establishing your priorities, collecting facts, and developing your arguments, you will be in the best position to present your point of view. Talk to other people (such as other parents or service providers) to figure out the best “advocacy route” to take. With patience and persistence, you will be well on your way to getting the best for your child and family.

Resources

Alper, S., Schloss, P.J., & Schloss, C.N. (1996). Families of children with disabilities in elementary and middle school: Advocacy models and strategies. *Exceptional Children*, 62, 261-270.

Beach Center for Families and Disabilities, University of Kansas – www.beachcenter.org

Cunconan-Lahr, R., & Brotherson, M.J. (1996). Advocacy in disability policy: Parents and consumers as advocates. *Mental Retardation*, 34, 352-358.

Kendrick, M. (2001, February). Advocacy. Presentation to Family Alliance Ontario, Hamilton, ON.

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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.

Leone, J. (1997, Summer). Power, control, confidence, and courage. *The Voice of Low Vision*. Downloaded on October 30, 2002 from <http://www.handinet.org/text/POWER.TXT>

Patterson, L.A. (1996). Conceptualization and measurement of parental advocacy in response to a child with disabilities. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 57 (6-B), 4039.

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.

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