



International Alliance
of Academies of
Childhood Disability

Family-Centred Services for Paediatric Populations

An Overview

by

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What can you expect from this resource? ¹

Family-centred service (FCS) is a philosophy, and an approach to service provision, that aims to deliver services to children with special needs while focusing on the priorities of the entire family. It is an evidence-based approach to practice that has been tried and approved by countless families. FCS recognizes that: (i) each family is unique; (ii) the family is a constant presence in the child's life; and (iii) parents are the experts on the child's abilities and needs ¹. This creates an environment where the centre of attention is directed toward the individual strengths and needs of each unique family. Although this process may be thought to take extra time and effort, there is evidence of positive outcomes for the child and the family which makes it worthwhile.

This document provides a brief overview of FCS, the rationale, and the evidence behind it, as well as the truths about some common myths surrounding FCS. At the end of this resource, you will find an example of an FCS practice, specific ways you can apply its principles and behaviours in your services, and recommended resources for further knowledge translation and research. A lot of this information is also available in the CanChild Family Centred Services Fact Sheets

<https://www.canchild.ca/en/research-in-practice/family-centred-service>

We hope that by reading this document, you will see the substantial benefits of FCS and that you will introduce its elements in your programs and services. If you are already practicing FCS, then you can use this document as an additional resource to promote education and knowledge brokering in your community.

What is FCS and how is it different from traditional care models? ¹

Family-centred service (FCS) (earlier referred to as family-centred care (FCC)) is an improvement on previous systems in which the decision-making was done by the healthcare providers with little consideration for the experiences, feelings, values or beliefs of the immediate family. Here's an example of a patient's negative experience in the traditional system, from their point of view:

I got the call on Monday. Another meeting to discuss my child. "When is it?" I asked.

"In a month from today at 3:30," the secretary told me.

"I have to work during that day."

"Sorry, that's the only time we have available."

"Oh. Well, what is the meeting about?" I asked.

"We'll discuss that at the appointment. See you then."

I went to the meeting alone – it made no sense to sacrifice my husband's income as well as my own. I was shown into a meeting room where several people already sat around a large table. Who were they!? There were no introductions. Someone was invited to begin. For the next hour, the people around the table each took their turn to describe how my child could not do this and would not do that. I was asked if I had anything to say, but I just knew if I spoke, I'd end up in tears. I said, "No."

The meeting was over. No one had taken notes, and no action plan was developed. I walked numbly to my car and burst into tears. What had just taken place was our "team" meeting.¹

While the example above describes the very worst-case scenario, there are many elements of traditional care that can leave the parents in distress and without proper support. FCS aims to prevent many of these negative experiences by prioritizing the needs and wishes of the family, in order to reduce the stress and anxiety involved with raising a child with a disability, as well as directly improving the child's outcomes. This is not an entirely novel idea, as it has been considered by the Association for the Care of Children in Hospital (ACCH) as early as the 1960s ¹. It borrows a lot from notions of client-centred medicine pioneered by Carl Rogers ². At its core, these systems aim to enable the client (in this case families) to hold, control and share power on their terms, instead of the healthcare provider being the sole director of the story.

Specifically, FCS is based on three main pillars ³:

1. Parents know their children best, and want the best for them, so each family should have the ultimate responsibility and decision-making for the care of their children. This means that the healthcare provider should:

- Inform and advise parents in their decision-making to help them identify their needs and priorities
 - Collaborate with parents at all levels (care of the individual child, implementation and evaluation of programs, and formation of larger scale policies)
 - Provide accessible services and share complete information on an ongoing basis
2. Each family is different and unique, so they should be treated with respect and understanding as individuals. This means that the healthcare provider should:
- Listen and respect the values and wishes of families and support their decisions
 - Be flexible in providing individualized services when needed
 - Be aware of and accept diversity in families (racial, ethnic, cultural, and socio-economic)
3. A supportive family and community are needed for optimal child functioning, so the wellbeing and involvement of all family members should be considered. This means that the healthcare provider should:
- Provide an environment where participation of all family members is welcomed
 - Encourage family-to-family and community help to create support structures
 - Recognize and build on strengths of the family and children

By following the elements of these pillars, healthcare providers can build a meaningful long-term relationship with families. This allows families to:¹

- Receive appropriate information to be the ultimate decision-maker for their issues
- Have their needs and concerns considered while feeling supported by the system
- Create solutions that use their own resources and most effectively address their issues

This creates a back and forth channel of discussion between the two parties. To ensure that any appointment or encounter with professionals results in a mutual agreement in a pleasant manner, several principles of communication need to be followed:¹

- Keep the long-term relationship with the family in mind
 - Establish the purpose of each meeting, overall service and roles of each party
 - Manage expectations by sharing your program's strengths and limitations
 - Develop mutually agreed-upon long-term goals that you consistently follow up on
- Be flexible
 - Adapt to the parents' language, as well as their ethnic, cultural backgrounds
 - Understand the family dynamics (who are the family members involved)
 - Be willing to compromise during decision-making

- Learn about the family's needs and responsibilities
 - Before appointments help the family to identify their needs
 - As children mature, involve them in the discussions and decision-making
 - Acknowledge and talk about the family's feelings
- Approach conflicts carefully
 - Understand the core reasoning behind families' frustrations
 - Attempt to find common ground and interests between both parties
 - Separate the individual and your relationship from any conflicts

Does FCS make a difference? 1

Not only is FCS great in theory – it is also supported by empirical evidence. FCS has been shown to be associated with better outcomes for both children and parents. While causation has not been established (as most of the data comes from cross-sectional studies that demonstrate relationships (correlations) between FCS and outcomes), there is a considerable amount of research with various methodologies and outcomes that has shown consistently the benefits of FCS. Some examples are listed below:

- Child outcomes
 - Accelerated developmental motor gains and skill development
 - Law et al. (1998)^[4]; Caro & Deverensky (1991)^[5]; Moxley-Haegert & Serbin(1983)^[6]
 - Improved psychosocial adjustment such as children’s function, role performance, and self-worth
 - Pless et al. (1994)^[7]; Stein & Jessop (1991,1984,)^[8,9]
- Parent outcomes
 - Reduced maternal anxiety and depression
 - Ireys et al. (2001)^[10]
 - Increased overall parental emotional well-being
 - King et al. (1999)^[11]; Van Riper (1999)^[12]
 - Decreased stress levels and increased life satisfaction
 - Raina et al. (2005)^[13]; King et al. (1999)^[11]; Brinker et al. (1994)^[14]; Miller et al. (1992)^[15]; Marcenko & Smith (1992)^[16]
 - Greater satisfaction with care
 - Carrigan et al. (2001)^[17]; King et al. (1999)^[11]; DeChillo et al. (1994)^[18]; Van Riper (1991)^[12]; Caro & Deverensky (1991)^[5]; Law et al. (2003)^[19]
 - Enhanced self-efficacy and sense of control
 - Dunst et al. (1993)^[20]; Dunst et al. (1988)^[21]
 - Increased knowledge about child development and participation in therapy
 - Moxley-Haegert & Serbin (1983)^[6]
 - Other individualized outcomes unique to each family
 - Dunst et al. (1993)^[19]

These are just some of the well established and recorded outcomes of FCS. For a more detailed overview of benefits of FCS, including more recent studies and evidence, please refer to the resource section at the end of this paper. There you will be able to find additional links to full papers as well as more articles showing the efficacy of FCS.

What are the common myths surrounding FCS?!

Readers may have some preconceived notions when reading this resource; there is a lot of information available about FCS. However, not all of what is available is reputable and factual. In the next section, we provide some examples of common myths surrounding this topic, and the real truths behind them.

- “FCS is a fad”
 - *Ideas behind FCS have been around for over five decades, and while the approach is new to some people, it is supported by empirical evidence across many years, and is used in many practices.*
- “Our programs and services are already family-centred.”
 - *While in the past two decades there has been more focus on involving families in care, there are still many areas that should be reviewed and improved. The term ‘family-centred’ is widely used, but there are often gaps between words and actions and policies.*
- “There are problems involved with delivering FCS that are too big to be solved.”
 - *Any changes in structures or service can be challenging, however many clinics have successfully integrated FCS in their care.*
- “FCS means families always get what they want. Service providers may have to go against what they believe professionally to satisfy a family’s request.”
 - *While the family does make the ultimate decisions about their child and family, the decision-making process is a collaboration between different parties. Health care providers can/must always refuse requests if they are deemed unsafe or unethical.*
- “FCS means families must be responsible for making decisions or doing things that they would rather have service providers do.”
 - *Families can (and do) ask service providers to help with decision-making. Furthermore, families can decrease or increase their involvement to their comfort level at any time and take on many roles in their child’s care:*
 - *Information provider: family informs care providers about their child’s strengths and needs, and asks for help with specific decisions that they identify*
 - *Consultant: family provides input into intervention methods*
 - *Assistant: family receives education to help them select intervention strategies*
 - *Director: family members are leaders in decision-making process with the service provider acting as a resource and a consultant*

What can we do to become more family-centred?1

Now that you know a lot about FCS and the evidence behind it, you might be thinking of how you can integrate it into your program on different levels (individual, organizational and inter-agency). So far, this resource has provided an overview of some abstract concepts. The question now is, what are specific elements that healthcare providers can introduce into their practice to be more family-centred? A few examples are provided below, but you should consult parents in your program for help and advice on any or all of these ideas

- Organizational changes
 - Recognize what you are doing that is already family-centred, as these elements are a great foundation on which to expand.
 - Verbalize your commitment to FCS in the clinic and online (for example using a vision statement).
 - Consider FCS values when hiring staff or during performance reviews.
 - Collaborate with other family-centred organizations to be updated on current research or effective strategies.
 - Actively seek feedback from families regarding your program via comment boxes or post-appointment questionnaires.
 - Seek opportunities for in-service sessions on FCS for the entire team.
 - Organize multidisciplinary assessments when possible to reduce families' time commitments.
- Prior to appointment
 - Reduce stressor factors on families whenever possible: consider issues with parking (availability and costs), times of appointments, how comfortable the waiting area is, how prompt appointments are to minimize waiting, ease of the referral process, whether families can navigate the telephone system to reach your office/program.
 - Be aware of commonly requested resources such as information pertaining to the condition, local support structures, government initiatives and so on – and have these materials available.
 - Make sure the purpose of the appointment is known and clear to everyone.
 - Ensure all topics or issues can be covered in the set duration of the appointment. This is best done by asking the family how we can be helpful at this visit.
 - Encourage everyone involved in the care of the child to attend the meetings about that child.

- During each appointment
 - Communication
 - Attentively listening to parents to elicit their agenda and full range of concerns.
 - Inquire about the degree to which parents wish to be involved in the decision-making and management processes
 - Be honest and realistic when providing options or general information.
 - Speak in an easily understanding manner and avoid ambiguous or academic phrasing.
 - If there are language barriers, ensure the presence of a translator, as long as the family agrees.
 - Paraphrase the parents' words back to them, to let them know you understand them.
 - Take time to learn the names of the members of the family and don't just refer to people as 'Mom' or 'Dad'.
 - Encourage parents to share their needs, wants and ideals to be true collaborators in the goal setting process.
 - Use person-first language (child with a disability instead of disabled child) or better still, refer to the child by name!
 - Goal setting
 - Set SMART goals (Specific, Measurable, Achievable, Realistic and Timely)
 - Update goals as needed to have goals appropriate to the changing child. Inquire about the family's strengths and available resources.
 - Do not omit possibilities or choices based just on your own discretion.
 - Involve the child in the process wherever possible.
 - Do not devalue parental opinions even if they are not evidence-based
 - Ensure all goals set are evaluated at the agreed time point.
- Follow-up and support outside of the office
 - Provide parents with both tangible (e.g., written) and virtual (e.g., website) resources where they can gather more information.
 - Connect families together to build support structures – as long as the family being recommended as a link has agreed to be available in this way.

- Provide a safety net and a system by which families can easily get their questions answered.

Keep in mind that these are just examples to get your started. There are many ways to integrate family-centred services into your practice depending on your daily routine. As long as you are prioritizing the family and following the pillars of FCS, you are on the right track.

How would a family-centred appointment look?1

In the previous section, we covered several aspects of FCS. It might be quite daunting to see that and try and introduce it as a part of routine care. To help guide the process, below is an example of what a typical appointment could look like.

Two parents, Mike and Arya, are concerned that their daughter, Sarah, is slow in learning to crawl and sit. They have received a lot of different advice and information about Sarah's care and want to consult you about it. How would you approach their appointment?

From what we can see at the moment, the developmental delay is the family's main concern. However, this is not a lot of information, so you will have to begin by asking more about the situation. This might begin by asking the parents to tell you what their daughter CAN do and LIKES to do (learning more about her day-to-day life and the overall functioning unit of the family). This offers parents an opportunity to focus on the positives. After that ground has been covered:

- Is there anything else that Mike and Arya are concerned about? (using parents' names and eliciting a full range of concerns).
- What is Sarah's and her family's routine?
- What sort of information have Mike and Arya already received? Do they have any questions about it? (What do they already know/understand and where did this information come from?)
- What are Mike's and Arya's expectation for the visit? (how should you approach the appointment?)
- What are they most concerned that they might hear from us?

From your introduction, you learn that their pediatrician mentioned that Sarah may need medication or surgery; the occupational therapist talked about selecting a preschool with appropriate accommodations; and Sarah's grandparents want her to get some sort of treatment right away. Mike and Arya want to do the best for Sarah, but they are overwhelmed at all of these suggestions. For them, it is quite important that Sarah has the opportunity to learn to walk, as her family engages in a lot of hiking and sports, in which they want her to be involved as well. They are also concerned about how she will be able to function in preschool if she has difficulty walking. Already, you have learned a lot about Sarah and her family's concerns, needs and priorities, simply by asking questions and letting the family express themselves.

After a physical examination and some tests, you note that Sarah has some spasticity in her legs. You know that there are several treatment options available including medications and surgery. Both methods have their own advantages and challenges. Mike and Arya are unsure of what they should do.

Having reached a tentative impression of what Sarah's issues might be, and having had an open discussion with the parents about your thoughts, there are many things you need to consider while

guiding Mike and Arya in their decision-making toward a goal that can help Sarah. You will need to lay out the all the possible options relevant to Sarah (not to her ‘diagnosis’), including their benefits and risks, without omitting anything. You will need to help them consider the support structures that they have and what they would like to prioritize. As Sarah gets older, she should begin to be involved in the conversation as well. All of this will have to be done while keeping an open mind and ultimately allowing Mike and Arya to make an informed decision that will be right for their specific situation. Of course, afterwards, we will need to point them to useful resources (online or in the community) and develop an action plan for the foreseeable future.

Family-Centred Service Checklist¹

Once you have begun introducing FCS into your practice, it is important to have a feedback system in place to ensure that the practices that you have begun are effective at giving the family the power over their child’s management. This can be accomplished in several ways. One of these methods is a simple quick self-administered check-in that you can go through after each appointment. You need to check in with the family:

- Were each person’s needs met?
- Did everyone feel respected, trusted and understood?
- Was an action plan developed for the future with parental involvement?
- Did everyone feel satisfied with the outcome of the appointment?

Once family-centred service is a consistent aspect of your care, you need to evaluate whether your organizations and their members are routinely engaging in family-centred care. There can be a large gap between asking parents questions during individual appointments and adjusting your entire service to prioritize opinions of families. Below is a quick checklist you can use to evaluate that:

<u>Section 1: Organizational Structures</u>	
Do you understand the research on FCS and use this evidence to advocate for the use of family-centred approaches?	
Do you talk to your colleagues and the families you work with about what FCS means to them?	
Do you describe families in the same respectful way, whether or not they are present?	
Do you promote staff awareness of other community resources?	

<u>Section 2: Preparation for appointments</u>	
Do you offer families a choice of location and time to meet, and schedule appointments that work best for them?	
Do you help families prepare for the first formal appointment, and if so, how?	
Do you communicate openly and frequently with parents about things that are happening at school?	

<u>Section 3: During appointments</u>	
Do you ask parents about their strengths and resources, including their own skills and the people they find supportive?	
Do you listen to what families tell you, believe them and trust in them?	
Do you ask families if they would like to connect with another family and provide resources to do so?	
Do you ask parents how involved they want to be in the planning and delivery of their child's services? Do you respect their decision?	

<u>Section 4: During decision making</u>	
Do you present and explain all options to the family to allow them to make decisions?	
Do you negotiate solutions with families when there is a difference of opinion?	
Do you develop an action plan that outlines what tasks need to be done, who will do them, and timelines?	

However, responding to these questions might be subjective, so a better idea would be to use a tool like the Measure of Process of Care (MPOC), a parent-informed evaluation tool designed to assess parents' experiences of the family-centredness of the services that they receive ^{22,23,24}. This questionnaire has been created and validated with parents of children with neurodevelopmental disabilities and used in many countries to evaluate the efficacy of family-centred policies. A companion measure, MPOC-SP, is comprised of similar questions but targeted at pediatric healthcare service providers (SPs) to allow them to self-evaluate their services. Using both questionnaires allows practices to determine the effectiveness of their family-centred services from the perspectives of both staff and parents. You can find more information on the CanChild website linked in the resources section

Where can I find more information?

Below are some additional helpful resources for each section mentioned. Each resource has a brief description as well as a hyperlink to its website (all resources listed are easily accessible without the need for any journal/article subscriptions).

- Overview
 - **CanChild Family Centred Services Fact Sheets**
 - A large portion of information in this document was taken directly from these fact sheets, please refer to them for more detailed accounts
 - Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review
 - Thorough systematic review of various outcomes in FSC in children with special needs and chronic conditions
 - [Family-Centered Care and the Pediatrician's Role](#)
 - Overview of Family-Centered Care and support for FCS from the American Academy of Pediatrics
 - [Family-Centered Theory: Origins, Development, Barriers, and Supports to Implementation in Rehabilitation Medicine](#)
 - Great overview of FCS, its origin, progression, and current use
 - Family Centered Care of Hospitalized Children: A Hybrid Concept Analysis in Iran
 - Benefits and challenges of introducing FCS into a new environment
 - Family Centered Pediatric Nursing Care: Sate of the Science
 - In depth resource of FSC in a nursing environment
 - Good resource for FSC in nursing
 - Patients as Partners: Engaging Patients and Families: Patient and Family Centred Care
 - Detailed overview of FCS from Patient Safety Education Program Canada
 - Model of Child and Family-centred Care
 - Helpful and concise infographic about FCS from SickKids
- Evidence
 - Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review
 - Thorough systematic review of various outcomes in FSC in children with special needs and chronic conditions

- “We found positive associations of FCC with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost”
- Family-Centered Care and the Pediatrician’s Role
 - Overview of Family-Centered Care and some of its outcomes including but not limited to decreased anxiety, lower emotional distress, better coping and adjustment, faster recover, parental confidence and overall patient satisfaction.
- The Health and Well-Being of Caregivers of Children With Cerebral Palsy
 - The study investigated important predictors of caregivers’ well-being and how caregiving demands, day-to-day child needs, family functioning and stress management all impact the health of caregivers of children with cerebral palsy.
 - “These data support clinical pathways that require biopsychosocial frameworks that are family centered, not simply technical and short-term rehabilitation interventions that are focused primarily on the child.”
- Associations of Family-Centered Care with Health Care Outcomes for Children with Special Health Care Needs
 - Examination of relationship between FCS and specific health care service outcomes in children with special health care needs
 - “FCS was associated with less delayed health care, fewer unmet service needs reduced odds of ≥ 1 h/week coordinating care and reductions in out of pocket costs.”
 - “FCC was associated with more stable health care needs, reduced odds of emergency room visits and increased odds of doctor visits.”
- Maternal Outcomes of a Randomized Controlled Trial of a Community-Based Support Program for Families of Children with Chronic Illnesses
 - Quantitative study of community-based support impact on maternal outcomes in families with children with chronic illnesses
 - “Maternal anxiety scores for participants in the experimental group decreased during the intervention period for all diagnostic groups and for the total group; scores for the control group increased”
- Effects of Family-centered care on the satisfaction of parents of children hospitalized in pediatric wards in a pediatric ward in Chalooos in 2012
 - Quasi-experimental study of effectiveness of FCS on parental satisfaction
 - “Our findings showed that the practice of FCC in caring for the sick children can increase the satisfaction of their parents significantly. The role of the family’s involvement is critical in every component of the intervention efforts, as shown by

the constructs of participatory support, educational support, and psychological support”

- A Quasi-Experimental Trial On Individualized, Developmentally Supportive Family-Centered Care
 - “Preterm infants who received developmentally supportive family-centered care demonstrated fewer behavioral stress cues and comparable short-term outcomes and resource utilization than infants who received routine care”
- Evaluating the effectiveness of a family empowerment program on family function and pulmonary function of children with asthma: A randomized control trial.
 - Randomized control trial of the effect of family empowerment on children with asthma
 - “The family empowerment program decreased parental stress and increased family function (cohesion, expression, conflict solving, and independence). Children in the experimental group had better pulmonary expiratory flow (PEF) and forced expiratory volume in first second.”
- Patient- and Family-Centered Care of Children in the Emergency Department
 - “This article reviews the principles of PFCC and their applicability to the pediatric patient in the emergency department; and it discusses a model for integrating PFCC that is modifiable based on existing resources”
 - “Families who are provided with PFCC are more satisfied with their care. Integration of these processes is an essential component of quality care”
- Application
 - Measure of Process of Care Website
 - Overview of Measure of Process of Care and access to the questionnaires
 - Use of the measure of process of care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting.
 - Assessment of MPOC effectiveness
 - “The MPOC tools have been found useful in enabling disability service providers to identify areas for improvement and move towards providing services that are more family centred.”
 - Evaluating change: Using the Measure of Processes of Care-Service Provider as an outcome measure for performance and confidence in family-centred care
 - Assessment of MPOC effectiveness
 - “The MPOC-SP and the MPOC-Con are sensitive measures suitable for evaluating individual and group changes following training. When designing professional

development programmes, managers and educators should consider the interrelation between self-efficacy and implementing acquired knowledge and skills in FCC.”

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