

***The Health of Families of Children with
Disabilities:
Report from a National Roundtable***

February 2, 2011

* The views reported in the proceedings are those of the participants and do not necessarily reflect the views of the federal government.

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Executive Summary

A surprising number of Canadian children grow up with chronic mental or physical health problems, although estimates of prevalence vary dramatically across the many available definitions. The number of Canadian children aged 0-19 years who have a physical disability is estimated to be between 7-8%, while 10-12% of children have some degree of cognitive deficit or learning disability. While different definitions of childhood health problems will continue to be applied for different purposes, it is clear that a substantial proportion of Canadian children and their families must cope with chronic childhood health problems.

Caregivers play a central role in the lives of children, and the well-being of each is inextricably linked to the other's well-being. Caring for a child involves considerable demands on time, energy, and finances. Such demands can, however, be much greater for parents of children with disabilities. Clearly documented demands include increased time (everyday care, medical appointments), higher medical costs ranging from 2.5 to 20 times typical amounts, greater childcare challenges (respite care, accommodation in regular programs), more employment constraints (work schedule, choice of occupation), lower income, as well as greater stress, anxiety about the future, and lack of sleep. While many families cope well with these challenges, these additional personal and financial pressures can amount to a significant burden.

A growing body of literature is now revealing that challenges shouldered by families of children with disabilities can be associated with an increase in a wide variety of both physical and psychological health concerns. Caregivers of children with disabilities have been shown to report a greater number of chronic physical conditions as well as exhibit poorer psychological health, including greater stress, distress, emotional problems, and depression compared to caregivers of children without disabilities. These findings are consistent in showing that there is an important relationship between child disability and caregiver health.

On November 5th, 2010, the Ottawa Hospital Research Institute (OHRI) hosted an invitational roundtable on the health of caregivers of children with disabilities funded by the Canadian Institutes of Health Research (CIHR) and Health Canada. The purpose of this roundtable was to engage parents, researchers, clinicians, policy makers, and representatives of non-government organizations in a process designed to facilitate the development of tools and approaches to support families of children with disabilities.

The roundtable agenda was developed around four key objectives that were successfully achieved: (1) Discuss the findings of recent CIHR-funded studies focused on the health of Canadian caregivers of children with disabilities. (2) Consult with stakeholders and decision makers about what issues need to be informed by future research. (3) Initiate the development of practical, research-based knowledge tools and approaches that will be useful for supporting the health of caregivers of children with disabilities. (4) Improve links and exchanges among researchers, policy makers, and caregivers committed to improving the health of caregivers of children with disabilities.

Participants first engaged in an activity individually and in groups to focus on "What needs to be done?" They then identified seven priority areas to support families of children with disabilities. Next, they brainstormed and discussed "What action can we take?" in each of the priority areas.

Several key messages and recommendations emerged from these discussions, and these can be summarized as follows:

1. Increase caregiver capacity to navigate effectively through the health care system.
2. Reduce caregivers' feelings of powerlessness.
3. Embed caregiver health into existing policy frameworks.
4. Identify key messages for dissemination.
5. Provide caregiver relief / respite.
6. Promote system change to improve support for caregivers.
7. Develop a theme template to organize information on existing programs and policies across the nation.

This meeting report includes the discussions and group work of these seven priority areas.

Research Overview

Situation

- In Canada, more than 500,000 people younger than 20 years have some form of disability.
- Approximately 155,000 children from 5 to 14 years of age live with activity limitations; of these, 43% live with severe limitations.
- The number of children with disabilities is on the rise, in part because of advances in technology that improve life expectancy of people who previously did not survive.
- Medical costs of children with disabilities can range from 2.5 to 20 times greater than average health care costs.
- As many as 25% of the population may need to care for someone with a disability at some point in their life.

Impact on Family Life

- Caregivers play a central role in the lives of children and their own wellbeing is inextricably linked to that of their children.
- Compared to families of typical children, caregivers of children with disabilities experience:
 - increased time demands (everyday care, medical appointments)
 - higher medical costs (2.5 – 20x typical amounts)
 - greater childcare challenges (respite care, special accommodation in regular programs)
 - more employment constraints (work schedule, choice of occupation)
 - lower income
 - greater stress, anxiety about the future, lack of sleep
- Caring for a child with a disability may result in an increase in a wide variety of both physical and psychological health concerns for caregivers.

Emerging Concepts

There is increasing evidence that there is an important relationship between child disability and caregiver health.

- The medical model for caring for a child with a disability is changing, from a child focused approach to one that addresses child issues within the larger context of the family environment. **Family-centred** policies and services seem to benefit the well-being of both caregivers and their families, but need to be explored in more detail.
(See Appendix: “What is Family-Centred Service?”)
- The notion of the ‘severity’ of child health problems, while still commonly discussed, may not be a key determinant of caregiver health. Some families may deal well with a child with ‘severe’ disabilities, while other families may be challenged. We believe that the notion of ‘complexity’ of child health issues may be more useful, but needs further study and clarification.
- The World Health Organization’s International Classification of Functioning, Health and Disability provides a useful framework for understanding the interaction of the biological and functional impacts of diseases and disorders, in the context of environmental and personal factors that influence the individual expression of a condition. There is recognition of the great importance of ‘participation’ (engagement in life situations) as a goal for most people and the resulting challenge of realizing participation even in the face of biomedical or psychological disorders.

Meeting Proceedings

Opening Statements

On November 5th, 2010, the Ottawa Hospital Research Institute (OHRI) hosted an invitational roundtable on the health of caregivers of children with disabilities funded by the Canadian Institutes of Health Research (CIHR) and Health Canada. The purpose of this roundtable was to engage parents, researchers, clinicians, policy makers, and representatives of non-government organizations in a process designed to facilitate the development of tools and approaches to support families of children with disabilities.

Dr. Dafna E. Kohen, Health Analysis Division, Statistics Canada and Adjunct Professor, Department of Epidemiology and Community Medicine, University of Ottawa, opened the meeting by acknowledging that it was being held in Algonquin territory. She commented that the high percentage of participant responses to the pre-meeting survey (95%) reflected the enthusiasm of those taking part and thanked the funders – OHRI, CIHR and Health Canada – for supporting this important event. Dr. Kohen emphasized that the diversity of participants invited was intended to support an inclusive approach to addressing knowledge translation challenges with respect to research relevant for families of children with disabilities.

Facilitator Dorothy Strachan took participants through the roundtable agenda and guidelines for working together, emphasizing the importance of an inclusive and collaborative approach to the various perspectives in the room. She reviewed the survey results with participants and pointed to how these had been accommodated in the agenda.

Keynote Presentations

Two dynamic presentations framed different perspectives on translating knowledge into action with respect to caregiver health.

The first speaker, Dr. Jamie C. Brehaut, Scientist, Ottawa Hospital Research Institute and Assistant Professor, Department of Epidemiology and Community Medicine, University of Ottawa, provided an overview of what current research has to say about caregiver health.



Dr. Jamie C. Brehaut

His talk focused on an epidemiological perspective and emphasized the increasing political will for constructive change on issues related to caregiver health. Key points included the following ideas: 1) there are clear, measurable physical and psychological consequences of caring for a child with a disability; 2) these health issues are not limited to a small number of families with the most severely disabled children – this is a public health issue that affects as many as one quarter of Canadian families; 3) caregiver health is increasingly affected by more complex caregiving situations; 4) caregiver health problems do not necessarily compound over time; 5) there are positive aspects of caregiving that we need to know more about. Dr. Brehaut closed by asking the central question for this event: “What actionable messages should become the focus of discussion, and should motivate future research and future knowledge translation activities?”

Points from the discussion

- Although the literature has a tendency to separate the two groups, there may be commonalities between caring for children with disabilities and caring for the elderly. What lessons can be learned from the much larger literature on caring for the elderly and applied to caring for children with disabilities?

The second speaker was Ian Brown, a prominent Canadian journalist who has won several literary awards for his recent book *The Boy in the Moon*, a memoir of his experiences raising his severely disabled son, Walker.



Ian Brown

Mr. Brown's experiences provided a compelling, detailed, and rich caregiver/caregiver and family perspective on the often overwhelming challenges and joys of caring for a child with a disability.¹ Mr. Brown also made several recommendations for future research and suggestions for policy changes, including: 1) a 'disability app' that would help families navigate the bureaucracies of health care and disability in Canada; 2) better training/support for parents regarding everyday tasks such as feeding and diapering/toileting needs of children with complex needs; 3) prioritizing families of children with complex health conditions for portable, shareable, electronic medical records, that families could easily access; and 4) a greater acknowledgement that family caregivers are experts in their child's care. Mr. Brown concluded by stressing that many lessons can be learned by caring for disabled people and that there are the benefits of accepting disabled people for who they are and learning from them.

Points from the discussion

- Much of the past research in childhood disability has ignored the impact on family members.
- Researchers gravitate to where funding is available. A lack of focus on a particular area does not necessarily reflect a lack of interest or importance.
- "There is a kind of soundproof curtain that comes down around you when you have a disabled child. It can be helpful at times but it does have an isolating effect."
- The perspective of family physicians is an important one as they are often the first point of contact, yet they don't receive training in how to help caregivers with their special needs.

¹ See Brown, I. (2009). *The boy in the moon*. Random House. ISBN: 978-0-307-35710-6

What Needs to be Done?

In the morning session, participants engaged in a small group activity to identify top priorities for change to support the health of caregivers of children with disabilities in Canada.

The following criteria were used to help shape each group's top 2 priorities:

- I. Address critical caregiver health issues that have been identified earlier in this workshop. In this context, "critical" means: of highest importance, crucial, where there is a crisis or turning point.
- II. Have strong potential for significant impact on the health of Canadian caregivers through various knowledge translation activities, policy development, interventions, tool development, etc.
- III. Have strong potential for partnerships where individuals, groups, institutes and organizations can work together collaboratively to leverage each others' intellectual capital and resources.

After reviewing all top priorities identified in the small groups, participants identified seven priority areas for action:

- A. Increase Caregiver Capacity to Navigate Effectively through the Health Care System
- B. Reduce Caregivers' Feelings of Powerlessness
- C. Embed Caregiver Health into Existing Policy Frameworks
- D. Identify Key Messages for Dissemination
- E. Provide Caregiver Relief / Respite
- F. Promote System Change to Improve Support for Caregivers
- G. Develop a Theme Template to Organize Information on Existing Programs and Policies across the Nation

Afternoon session: How to do it?

In the afternoon session, participants self selected into small groups focused on each of the 7 priority areas they had identified.

Each group described the challenge for its priority area and developed recommended action steps to address that priority.

Finally, each group reported back to the larger group by giving a short presentation. Differences among approaches taken by each group on selected topics reflect their enthusiasm for, and experience, in the areas they selected.

Meeting Recommendations

A. Increase Caregiver Capacity to Navigate Effectively through the Health Care System

The challenge is to incorporate, across jurisdictions, key elements of a caregiver support system for families of children with disabilities both electronically and with access to advocates and advisors.

What do we “know” that works in this priority area that we are not doing?

- Effective communication
- Clear, common point of entry into the system
- Well positioned and informed advocates
- Transparency of systems

What are the barriers to doing what we know works?

- “Turf issues” and “silos” in the system
- Geographical, contextual, language, and cultural challenges
- Lack of financial resources to increase caregiver capacity to navigate through the health care system
- Lack of early identification of those with special needs

What strengths/opportunities are in place to support doing what we know works?

- Other exemplary systems already exist (Cancer Care Ontario) to provide proof of concept
- Internet supports

Next Steps

1. Design and field test a state of the art navigation system (including a website) for caregivers.
2. Enhance capacity for early screening and diagnosis for developmental delay.

Future Research Topics and Questions

1. Identify the needs of caregivers of children with disabilities.
2. Identify the barriers to navigating the health care system.
3. Collect information on how Canadian families currently navigate the health care system and access services.

B. Reduce Caregivers' Feelings of Powerlessness

The challenge is to reduce the isolation, powerlessness, and lack of social supports for caregivers.

What do we “know” that works in this priority area that we are not doing?

- Caregiver facilitators and ‘navigators’
- Family support groups
- Lists of services easily available to families
- Recognition of the knowledge and expertise of families

What are the barriers to doing what we know works?

- Skepticism regarding the advice given by lay people: this is not deliberate or systematic, which may make it more difficult to address
- Lack of local champions
- Lack of funding
- Education and training are “siloeed”
- The medical-model approach to diagnosing and ‘fixing’ things is often inadequate given the complexity of caregiver realities and the paucity of ‘fixes’

What strengths/opportunities are in place to support doing what we know works?

- Existing lay home visiting programs, parenting programs
- Some existing programs provide models for best practices (e.g., ‘nurturant’ models² of support)
- There is an opportunity to adapt existing knowledge exchange networks to fit the needs of caregivers

Next Steps

1. Develop models for engaging caregivers in the education and training of health professionals.
2. Identify models of best practices with respect to caregiver support.
3. Adapt existing knowledge exchange networks for caregivers.

Future Research Topics and Questions:

1. What can we learn from ‘nurturant’ models of support that would impact on caregiver health?
2. What can we learn from the literature on caregivers for the elderly that could inform caregivers of children with disabilities?

² This model is based on the values of empathy and mutual responsibility. For example, the nurturant parent model describes a parenting model where parents develop close bonds with their children through positive interactions and teach them empathy and responsibility towards others and toward society.

C. Embed Caregiver Health into Existing Policy Frameworks

The challenge is to embed the concepts and evidence concerning elements of caregiver health into existing and new policy frameworks, program models, and decision-making tools for different reception communities.

What do we “know” that works in this priority area that we are not doing?

- Alberta’s legislation on "family supports"; this model has not yet been evaluated or expanded
- Techniques and models of knowledge translation exist that need to be implemented at the national level
- Evidence that family-centred service can improve caregiver health

What are the barriers to doing what we know works?

- There is relatively little known about specific interventions that will improve caregiver health
- There is a lack of understanding about meaning/implications of family-centred decision-making

What strengths/opportunities are in place to support doing what we know works?

- Alberta legislation: family supports are in place for children with disabilities
- Caregiver health is embedded in some existing policies. (e.g., Children's Mental Health activity as part of the Alberta Children and Youth Initiative (ACYI))
- There are existing sources of data for evaluation (Manitoba Health Policy Institute, Alberta legislation, the Manitoba Focus on Kids initiative)
- Can identify the relevant populations in different jurisdictions

Next Steps

1. Create common measures and outcomes on caregiver health and well-being that can be measured nationally.
2. Review the scientific literature: ask what we know now that improves caregiver health and then determine next steps toward implementation.
3. Review and analyze policies and programs that pertain to caregivers of children with disabilities (e.g., Public Private Partnership models).

Future Research Topics and Questions

1. Study policy-related concepts like family-centred service, communication with policy makers.
2. Examine the effects of specific policy initiatives (e.g., Family Support for Children with Disabilities legislation).

D. Identify Key Messages for Dissemination

The challenge is that in order to position the importance of the health of caregivers as a public policy issue in Canada, these messages need to be tailored to the appropriate target audiences. Key messages might include:

- Caregivers of children with disabilities are vulnerable to health problems.
- These impacts are then also experienced by the children.
- The impact on health is not limited to caregivers of the most severely disabled children.
- Information and support are available to address these challenges.

What do we “know” that works in this priority area that we are not doing?

- Adopt a multi-mechanism approach (e.g., advocacy, local engagement, media, champions, stories) to encourage change in public policy
- Identify political champions (e.g., ministers, senators, health critics) and targeting them with actionable messages
- Encourage networking, collaboration, communication among the ministries of education, health and social services to reduce bureaucracy, reconcile policies and enable change

What are the barriers to doing what we know works?

- Lack of knowledge among decision makers about the scope of the problem, and that it should be considered a public health problem
- Silos in the system (federal/provincial/territorial governments, within and between hospital, community and professions, across ministries within a jurisdiction) all lead to duplication, gaps and misunderstandings
- Lack of clear sources of funding for getting the message out
- Social barriers related to children with developmental disabilities and their caregivers may contribute to a general lack of appreciation of the problem
- The range of individual family challenges and needs
- The potential loss of key academic and educational resources (e.g., *CanChild*⁴ Centre for Childhood Disability Research in Hamilton) through lack of sustained funding

What strengths/opportunities are in place to support doing what we know works?

- Opportunities presented by upcoming federal-provincial-municipal elections
- Caregiver benefits already on the radar of the Liberal party (Mr. Ignatieff's October 2010 announcement)
- Leading health writers might want to support this issue
- Some evidence exists in the knowledge translation literature about how to incorporate research into policy decision-making (e.g., John Lavis at McMaster).
- College of Family Physicians of Canada has a special interest in providing care for those with disabilities across the life span
- *CanChild*³ can provide a virtual home and other support for messaging
- National/international exposure opportunities (e.g., The International Association for the Scientific Study of Intellectual Disabilities (IASSD) conference in Halifax in July 2012)

³ *CanChild* Centre for Childhood Disability Research is an internationally renowned research and educational centre founded in 1989 with funding (until 2009) from the Research Branch of the Ontario Ministry of Health and Long-Term Care.

Next Steps

1. Summarize lessons from the National Roundtable.
2. Prepare statements tailored to various audiences (e.g., federal/provincial/territorial governments, health professionals, related academics, non-government organizations, local groups, researchers, media, politicians, champions) about the importance of caregiver health as a public health issue
3. Share the consultation report with CIHR and the broader research and KT community to encourage continued research support
4. Establish regular networking meetings for researchers, health policy makers, and caregivers

E. Provide Caregiver Relief/Respite

The challenge is to provide regular, individually tailored parental relief/respite.

What do we “know” that works in this priority area that we are not doing?

- A public awareness campaign around need/use of respite
- A centralized triage system to access respite
- A human resources strategy for the development and training of service workers
- Life planners for people with developmental disabilities after they reach adulthood
- Parents should be able to provide input into funding decisions

What are the barriers to doing what we know works?

- Front line workers are not well informed about available resources and services
- Excessive paperwork/forms for funding applications are a drain on families
- Caregiver guilt, stress and worry about requiring relief

What strengths/opportunities are in place to support doing what we know works?

- Interested organizations already exist (e.g., Canadian Caregivers Coalition)

Next Steps

1. Create a partnership among existing organizations such as the Canadian Caregivers Coalition to address issues like: identification of existing resources and how to access them, assistance with life planning, provision of respite care.
2. Develop a media campaign around messages about children with disabilities, their families, costs, medical impact for caregivers, etc.

Future Research Topics and Questions

1. Describe the presence/need for respite care across jurisdictions.
2. Examine the costs and benefits of respite care. Is there a net benefit from respite services (for caregivers, children, family relationships, health care system)?

F. Promote System Change to Improve Support for Caregivers

The challenge is to refocus priorities and systems to centre on the families of children with disabilities.

What do we “know” that works in this priority area that we are not doing?

- Proactive planning in advance of key life transitions
- Independent living centres focused on adults with disability/needs
- Coordination of services

What are the barriers to doing what we know works?

- Lack of adaptability/flexibility of existing programs
- Different services have different mandates, finances, and human resources support
- The focus is often still on the child with disabilities and not on the caregiver and the family more broadly.

What strengths/opportunities are in place to support doing what we know works?

- Examples of successful models exist (e.g., Centre Local de Services Communautaires [CLSC] in Quebec)
- Meetings of interested organizations (e.g., National Roundtables) to create new motivation and directions

Next Steps

1. Establish a research base on the hidden costs of a lack of focus on caregiver health.
2. Create a national task force to develop, implement, and evaluate pilot projects based on case study models focused on outcomes. Disseminate the results, focusing on efficacy and applicability.
3. Make a case for considering hidden costs and benefits associated with caregiving (i.e. economic implications for employment, governments, and systems). Emphasize caregivers as an unrecognized valuable resource.

Future Research Topics and Questions

1. What is the cost to employers of complex caregiving situations experienced by employees (e.g., in lost time, use of health benefits, leave, absenteeism, etc.)?
2. What is the cost to the health system of poor caregiver health (e.g., increased expenditures for both caregiver and child)?
3. What is the cost to quality of life of families, (e.g., family with caregiver as caregiver, impact on siblings and family dynamics)?
4. What makes a caregiver “resilient”?

G. Develop a Theme Template to Organize Information on Existing Programs and Policies across the Nation

The challenge is to develop a template of key themes that will organize information on programs and policies on a central, national website

What do we “know” that works in this priority area that we are not doing?

- Websites are widely accessible, but need to be known, respected, appropriately ‘populated’ and carefully organized to be useful

What are the barriers to doing what we know works?

- Resources and policies are available for families but are difficult to find
- This topic is vast in scope and there are varying interests
- Few services are available at the national level; most of what is available is organized by provinces
- Resources will be required to collect information and update it on a regular basis

What strengths/opportunities are in place to support doing what we know works?

- There is a recognized need for this type of information sharing
- Partnerships with families exist across the country in various forms and in various jurisdictions

Next Steps

1. Identify key contacts and existing similar resources.
2. Create a draft template of themes.
3. Get input from caregiver groups.
4. Develop a pilot research demonstration project.

Future Research Topics and Questions

1. Planning: What kind of information do families want/need? What about the needs and preferences of children and youth?
2. Mine website usage information for suggestions on how to improve its usefulness.
3. Develop a framework for maintenance and updating of information.

Closing

Dr. Peter Rosenbaum concluded the roundtable by commenting on the dynamic and constructive energy of the participants and his hope that some of that energy will be reflected in the various results of the meeting. He mentioned that Canadian research – and consultations like this one focused on knowledge translation are an excellent example – is highly regarded internationally. It is thanks to organizations like CIHR that Canada is able to continue to do research on the health of caregivers of children with disabilities.

Dr. Rosenbaum also highlighted the volume of research that has already been done that isn't being used in practice. "We don't need more research, we need to apply what we already have discovered" is a common sentiment in much of health care research, and is a cornerstone of CIHR's focus on knowledge translation. He emphasized the need to keep the focus on the health of the entire family, given the number of Canadian families directly affected by disability.

Regarding the often-used acute care approach to disability, Dr. Rosenbaum stressed that we need to move away from the idea that children with disabilities have medical problems that "need to be fixed". Instead, this biomedical approach needs to be a part of a larger set of tools, including the World Health Organization's ICF framework, which focuses on functional ability within a larger environment. Greater engagement of both parents and health care professionals in enterprises like the National Roundtable is key to improving the supports available to families of children with complex lives.

In terms of future outcomes arising from the national roundtable, Dr. Rosenbaum said that both a briefing note and a report on the proceedings would go out to all involved. He encouraged participants to do their part in maintaining the vital momentum that has been generated and translating that goodwill into concrete action. The more the ideas promoted in this event gain traction and currency, the greater the benefit to caregiver health.

Dr. Dafna Kohen closed the workshop by thanking all involved for their insightful and practical contributions to the consultation including participants, Steering Committee members, leaders and managers, administrative staff, and external consultants. She confirmed that a communiqué would be distributed to all followed by a report on the consultation, and encouraged everyone to use these documents to communicate with colleagues, families, health professionals, other researchers and friends about the need for urgent action to support the health of caregivers of children with disabilities.

Summary of the Participants' Feedback on the Roundtable

1. Overall, from my perspective, I would describe this workshop as:

<i>unsuccessful</i>					<i>successful</i>	
1	2	3	4	5		
		(1)	(1)	(9)	(1)	(23)
N = 35	Average = 4.6					

2. What did you like most about the workshop?

- Organization and facilitation (24), e.g.,
 - I. Facilitator did an excellent job.
 - II. Session was productive and action oriented—an opportunity to discuss caregiver needs and research priorities.
 - III. Pre-meeting survey was a great idea.
 - IV. The approach balanced presentations and interactive discussions.
 - V. We addressed a huge amount of information.
- Presentations (14), e.g.,
 - I. Speakers were phenomenal; both were excellent and informed.
 - II. They did a great job of setting the stage—very good choices.
- Mix of participants (14), e.g., they:
 - I. Brought multidisciplinary perspectives on the health of families.
 - II. Had a variety of perspectives and came from diverse and interesting backgrounds.
 - III. Represented a wealth of experience.
- Opportunity to network (11), e.g.,
 - I. Exchange information, hear about what others do, and learn about their current projects.
 - II. Interact with others whom I don't normally have contact with.
 - III. Meet so many inspiring people and share their ideas.

3. What did you like least about the workshop?

- Nothing (18)—I enjoyed all aspects of the day.
- Too much was packed into a one day agenda. (5)
- We needed more time for networking, meeting other participants and sharing perspectives (4)
- The room was a bit cramped and stuffy. (2)
- It was a challenge to keep on task when the task was so big.
- It was not quite as focused on caregiver health as I would have liked.
- It would have been beneficial to have had more caregivers from other provinces.
- Perhaps have a policy maker address how research and advocacy can be translated into policy change for the benefit of families and children with disabilities.
- There were lots of different perspectives in the room: where do they meet?

4. Further comments:

- Thank you for the opportunity to attend. (9)
- Well done. Congratulations. It was a super experience. (3)
- Need to focus on networking and future work (7), e.g.,
 - i. I definitely want to know more about what people are doing.
 - ii. I hope this network continues to build momentum and stay focused on the issues.
 - iii. I am excited to have been part of such a dynamic and energetic group.
 - iv. I look forward to the report.
 - v. We could have pushed harder for continued contact/networking.
- Please follow-up with the speakers and how they motivated the success of this roundtable.
- Please make a list of participants available.

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Appendix

PRESENTS

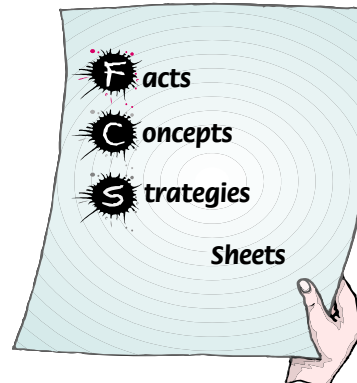
This FCS Sheet is #1 of an 18 part series on family-centred service.

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.



What is Family-Centred Service?

“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

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 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 "family-centred 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).

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 Krieger 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 family-centred 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.org

785-864-7600

CanChild Centre for Childhood Disability Research

www.fhs.mcmaster.ca/canchild

905-525-9140 ext. 27850

Frank Porter Graham Child Development Center

www.fpg.unc.edu

919-966-2622

Kennedy Krieger Institute

www.kennedykrieger.org

1-888-554-2080

PREMISES, PRINCIPLES, AND ELEMENTS OF FAMILY-CENTRED SERVICE

1st Premise (basic assumption)		2nd Premise (basic assumption)		3rd Premise (basic assumption)	
<ul style="list-style-type: none"> Parents know their children best and want the best for their children. 		<ul style="list-style-type: none"> Families are different and unique. 		<ul style="list-style-type: none"> 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)					
<ul style="list-style-type: none"> 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. 		<ul style="list-style-type: none"> Each family and family member should be treated with respect (as individuals). 		<ul style="list-style-type: none"> 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	Service Provider Behaviours	Expectations and Rights of Families	Service Provider Behaviours	Expectations and Rights of Families	Service Provider Behaviours
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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 socio-economic). Believe and trust parents. Communicate in a language understandable by parents. 	<ul style="list-style-type: none"> Have their needs and concerns taken into account. Feel welcome and supported in the level of participation they choose. 	<ul style="list-style-type: none"> 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 family-to-family support and the use of natural community supports and resources. Recognize and build on family and child strengths.

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.

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 and building on parent and family strengths and 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 wait lists
- FCS Sheet #18 – Are we really family-centred? Checklists for families, service providers and organizations

Want to know more about family-centred service?

Visit the *CanChild* website: www.canchild.ca

Or call us at 905-525-9140 ext. 27850