CanChild
Centre for Childhood Disability Research

CHILDREN WITH DISABILITIES IN ONTARIO: A PROFILE OF CHILDREN'S SERVICES

PART 2: PERCEPTIONS ABOUT FAMILY-CENTRED SERVICE DELIVERY
FOR CHILDREN WITH DISABILITIES

OVERVIEW TO THE SURVEY REPORT

How Will the Survey Data Be Reported?

This document is Part 2 of a three-part report on an Ontario-wide survey about family-centred service delivery, which was conducted in 1999. The Introduction and Methodology sections of this Part 2 contain some of the same information that was presented in Part 1. It is repeated here (with slight modifications and additions) to place the survey data in context. In the Introduction we expand upon the definition of family-centred service (FCS) and what is involved in providing services in this manner. Within the Methodology section, we have added information on the representativeness of the sample of service providers, and on the involvement of the participating organizations. Readers who are familiar with Part 1 may wish to skim through these two sections.

The contents of the three parts of the survey's report are as follows:

Part 1:
(distributed in January, 2000)

C   a description of the methods used for the survey
C   characteristics of children with disabilities and their families
C   a description of services currently provided to children with disabilities and their families

Part 2:
(the current document)

C   descriptions of service providers and the centres/organizations providing services to children with disabilities
C   information about families' and service providers' beliefs about participation in family-centred service
C   information about barriers to implementing family-centred service, as perceived by service providers and CEOs

	C	perceptions of services provided, from the perspective of families and service providers, including changes since the early 1990s
	C	parents' judgments about satisfaction with care
Part 3: (planned for October, 2000)	C	information about what type of factors are associated with parents' perceptions of family-centred service and their satisfaction with services

INTRODUCTION TO THE SURVEY

What is Family-Centred Service Delivery? The nature of service delivery for children with disabilities and of the parent-service provider relationship have changed dramatically over the past 20 years. In contrast to the traditional professional-directed style of child-centred care, there is a new approach, referred to as Family-Centred Service (FCS). FCS is a philosophy and method of service delivery for children and parents which emphasizes a partnership between parents and service providers, focuses on the family's role in decision-making about their child, and recognizes parents as the experts on their child's status and needs (Hostler, 1994; Rosenbaum, King, Law, King, & Evans, 1998). The guiding principles of family-centred service include:

C   Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child.

C   Parents should have ultimate responsibility for the care of their children.

C   Each family member should be treated with respect (as individuals).

C   The needs of all family members should be considered.

C   The involvement of all family members should be encouraged (Rosenbaum et al., 1998).

What Role Do Service Providers Have in Family-Centred Service? To deliver services consistent with the guiding principles of FCS, service providers exhibit particular behaviours that respect and support families and enhance their partnership with families. These behaviours generally include, but are not limited to: collaboration with families about assessment and treatment of children; listening to families and identifying their needs; provision of individualized services; encouraging participation by all family members; clear, ongoing communication with families; and resolution of differences through negotiation (Rosenbaum et al., 1998). (See Appendix 1 for more information about principles of FCS and service provider behaviours.)

How Is Family-Centred The goals and needs of families change over time and service providers

Service a Dynamic Process?

need to be responsive to these changes (Viscardis, 1998). FCS, therefore, is not a static, one-time service initiative, but a dynamic process between families and service providers as equal partners (King, Law, King, & Rosenbaum, 1998; Rosenbaum et al., 1998). Likewise, service providers need educational, financial and time supports from administrators to carry out family-centred service delivery (Winton & Crais, 1996). Administrators and managers provide the context in which FCS is conducted.

Why Examine Service Delivery for Children with Disabilities in Ontario?

In the early 1990s, *CanChild* Centre for Childhood Disability Research conducted surveys of families and service providers to gain increased understanding about FCS and to monitor its implementation in Ontario. We found that FCS was widely supported but that certain aspects of this approach were more difficult to implement. These challenging areas included providing information to parents, being flexible, coordinating services, responding appropriately to needs, and individualizing service (King et al., 1998).

Because of the changes that have occurred in children's rehabilitation services over the past several years, we thought it would be useful to conduct another survey of services for children with disabilities and their families across Ontario. The purpose of this survey was to gain knowledge about services provided and perceptions of these services from several perspectives. We re-examined how services are provided to children with disabilities and their families, using data collected concurrently from those involved in family-centred service delivery: parents, service providers, and CEOs/managers of organizations in Ontario which provide rehabilitation services.

Who Conducted this Survey?

This survey was conducted by *CanChild* Centre for Childhood Disability Research at McMaster University. *CanChild* is a health system-linked research unit funded since 1989 by the Ontario Ministry of Health, with a formal partnership with the Ontario Association of Children's Rehabilitation Services (OACRS) and its 19 children's rehabilitation centres across the province. *CanChild* has been actively involved in family-centred service research in collaboration with OACRS. OACRS is committed to the philosophy and implementation of FCS and many of the centres have made changes in their approaches to services with children over the past several years. In the past two years, *CanChild* has also begun more interactions with Community Care Access Centres (CCACs), which organize and manage services such as the School Health Support Services Program for children with disabilities.

METHODOLOGY (WHAT WAS DONE)

How Were Organizations and Survey Participants Identified?

This cross-sectional survey involved parents of children with disabilities, service providers, and executive directors or managers of children's rehabilitation services. Twenty-two centres/organizations were invited to participate in this survey, and 16 were able to do so at the time. Organizations participating in the survey included ten OACRS centres and six CCACs. These agencies are the two major providers of rehabilitation services for children with disabilities and their families in Ontario, and were selected to represent both urban and rural centres and all regions across the province of Ontario to ensure representativeness of the sample. (See Acknowledgements at end of report for a listing of the participating organizations.)

Parents were randomly selected from those currently receiving services from each participating organization. Parents of children of all ages and diagnoses served by these agencies were eligible. The only exclusion criterion was the inability of parents to respond to English-language questionnaires. Parents were first contacted through a mailing from their organization. This mailing included a letter from the researchers describing the study, accompanied by a letter from their centre introducing the research group to the parents. A questionnaire package was then mailed from *CanChild* directly to those parents who consented to participate.

All service providers involved in the provision of rehabilitation services to children with disabilities were eligible to participate. Since the centre/agency had agreed to participate on behalf of its staff, a package prepared by *CanChild* was sent to randomly selected service providers via each centre's mail system. This package included a covering letter explaining the study and the questionnaires, and was returned directly to *CanChild*.

What Information Was Collected?

The study was reviewed and approved by the Research Ethics Board at McMaster University. Data were collected from February through September, 1999.

Parents were sent a package of materials requesting information about their child with a disability, the nature of services received, their beliefs about participating in family-centred service, their perceptions of service delivery, and their judgments about satisfaction with care.

Service providers completed a package that included the same questionnaire on beliefs about family-centred service that parents completed, a measure of their perceptions of their own family-centred

behaviours, and a demographic form.

CEOs/managers completed a questionnaire requesting information about key structural features of their organizations, clients and service providers. This form was developed by the research team and asked questions such as the number of clients served, the nature of services provided, amount of information and/or services provided, global budgets, and changes in any of these features in the past five years. CEOs/managers also completed the questionnaire on beliefs about family-centred service.

Details about the measures used in this survey are provided in Appendix 2 of this report.

What Procedures Were Used to Obtain a Representative Sample?

The sample size was based on previous studies and was large enough to provide meaningful data across the province and individualized feedback to each participating organization. Our goal was to have 30-40 parents and a minimum of 20 service providers for each centre/agency. For those centres with a staff of 60 or less, 20 randomly selected service providers were sent a questionnaire package. Larger centres (i.e., > 60 staff) randomly selected 33% of their staff to receive the package.

Since we used a random sample of parents, these participants are likely representative of families receiving children's rehabilitation services from the participating organizations. We cannot conclude that the sample is representative of all families of children with disabilities as some may not be receiving services. We do, however, have reason to believe that the majority of children with a primary health or development problem such as cerebral palsy, retardation, a syndrome, spina bifida, or acquired brain injury are receiving services, so this sample is likely to be representative for those groups. This may not be the case for children with developmental delay, communication disorder, autism/pervasive developmental disorder, developmental coordination disorder, or muscle disease. This could be because these children do not always or primarily receive services from OACRS centres or CCACs, the nature of services they receive may vary across the province, and there is a small sample size for some of these conditions.

As will be seen in Section B of this report, the service providers who responded to this survey represent a range of disciplines with a variety of experiences in service delivery. These respondents characterize the constellation of service providers typically found in these organizations in Ontario.

Who Was Involved?

From the 641 consenting parents, 494 questionnaires were returned and

analysed. Standard follow-up procedures were used to ensure an adequate return rate of 77%. Part 1 of this report (dated January, 2000) provided information about the children, parents and families who participated, and the services they receive.

From the 411 service providers who were sent survey packages, 324 questionnaires were returned and analyzed for a return rate of 79%. Standard follow-up procedures were also used. Of the 16 participating organizations, 15 completed questionnaires from CEOs/managers were received for a response rate of 94%. Details about the service providers and organizations are contained in this Part 2 of the survey's report.

WHAT HAVE WE LEARNED?

Background Note About the Data:

We report on the data gathered from multiple perspectives; i.e, from CEOs, service providers and parents. Because of the volume of information, 'what have we learned' is presented in several sections as outlined below:

Section A:	Background Information about the Organizations
Section B:	Background Information about the Service Providers
Section C:	Beliefs about Participating in Family-Centred Service Delivery (Data from service providers and parents)
Section D:	Perceptions of Systemic and Personal Barriers to Implementing Family-Centred Service (Data from service providers and CEOs)
Section E:	Perceptions about the Process of Family-Centred Service Delivery (Data from service providers and parents)
Section F:	Judgments of Satisfaction with Services (Data from parents)

The information for sections C-F was measured by various instruments which are described briefly at the beginning of each section and also detailed in Appendix 2. The material presented in these sections follows what we think is a logical progression. We first report information about the respondents' beliefs and attitudes about FCS. Next we present what we have learned about the experience of either receiving (parents) or providing (service providers) FCS. In the last section we report the findings concerning parental satisfaction with the services they are currently receiving from the organizations involved in this survey.

The findings from this survey are presented in both text and table form. We generally report on the total sample of service providers (*N*=324) and

parents (*N*=494), but for some sections we report on subgroups and provide the number of participants ("*n*") for these categories. Note that the background information on parents was reported in the Part 1 document.

A. About the Organizations

What Information Did the Organizations Provide?

Data were received from 15 of the 16 organizations participating in this survey. These data allow us to describe the organizations' general characteristics and to identify features of how they operate that are related to family-centredness of service delivery.

What 'Size' Are these Organizations?

The organizations can be classified into three categories (small, medium, or large). Several factors were taken into consideration when determining 'size", but because of the variations within these factors, the categorization was based primarily on the population of the catchment area with the annual budget as a secondary consideration. Populations of catchment areas ranged from 104,000 to over 2.5 million people. CEOs were provided on the survey form with four choices on budget amount; these ranged from < $1 million to > $5 million.

There are four organizations that are considered *large*. These are organizations with catchment populations over one million and budgets greater than $5 million.

Four organizations are classified as *medium* in size. They have catchment populations ranging from 350,000 to 550,000. Similar to the larger organizations, most of these organizations (3 out of 4) have budgets greater than $5 million.

There are seven organizations classified as *small*. The population catchment area ranges from 104,000 to 200,000 people. The budgets are more variable than the medium or large organizations - three organizations have budgets > $5 million; one is between $2.1 to 5 million; and three are between $1-2 million.

What Is the Nature of Family-centredness in these Organizations?

There were several questions on the CEOs' survey form that related to the family-centredness of these service delivery organizations and changes in FCS that may have been implemented in the past five years. These data are summarized below. The number of organizations and the percentages (%) are based on data from 15 organizations:

<	12	(80.0%)	have formally adopted a family-centred approach to service delivery
<	8	(53.3%)	have someone at their organization who provides guidance and leadership in implementing FCS
<	10	(66.7%)	have implemented FCS strategies
<	9	(60.0%)	have shared their FCS implementation strategies with other organizations
<	10	(66.7%)	have requested information from other organizations on their FCS implementation strategies
<	10	(66.7%)	have provided or taken part in workshops or other activities to educate staff and/or families about FCS
<	10	(66.7%)	provide information about FCS service to families
<	10	(66.7%)	have a resource centre or library for parents and clients

We examined these features and identified to what extent they are common across organizations. It is clear that there are ten organizations (66.7%) who have formally adopted FCS and have created a cohesive family-centred culture within their organization. These ten organizations have provided training workshops for staff, and have made several changes in how they operate in a more family-centred way. These changes include: intake procedures, handling of waiting lists, parent involvement in goal setting, parents' involvement in meetings, information provided to parents about the organization of services, communication with parents, and user-friendly reports written for and accessible to parents. Nine of the ten organizations also have a resource centre, have changed the amount of information they provide to families, and have requested information from other organizations about family-centred strategies. Eight of the ten organizations have someone to lead or champion FCS implementation, have shared strategies with others and have provided information to families about FCS.

Does Organizational Size Affect Family-Centred Culture?

Analysis of the size of the organizations (small, medium, or large) and its relationship with the family-centredness of the organizations was not statistically significant. This means that the family-centred culture of an organization is not affected by its size.

Later in this report, we present observations and comment about the relationship between a family-centred culture within the organizations (based on the information provided by CEOs), and parents' and service providers' perceptions of their experiences with FCS.

In summary, these data tell us that:

g   *the organizations participating in this survey were varied in size (i.e., catchment population and budget)*

g   *there is a high level of managerial endorsement of FCS principles*

g   *most organizations (67%) foster a family-centred climate through various strategies and practices (including training of staff, enabling families to be more involved and informed about their child's care and the services available)*

g   *size does not affect an organization's ability to be family-centred*

B. About the Service Providers

What Are the Features of the Service Provider Respondents?

As can be seen in Table 1, the service providers represented one of 19 primary areas of work (disciplines). The most frequently represented disciplines were occupational therapy (24.4%), speech language pathology (19.1%) and physiotherapy (18.5%). This is consistent with data provided by parents (as reported in Part 1) that their children received occupational therapy, speech therapy and physical therapy most frequently of all services provided. It also concurs with the report, Role Review of Children's Treatment Centres (ARA, 1999) which identified these as the three core services.

Most service providers (82.1%) described their primary role as one of service provision (i.e., direct care of children and/or their families). Service providers performed a variety of service activities with direct therapeutic services (88.9%), and consultation (82.4%) being the most prominent. Most service providers engaged in more than one type of service activity. The majority (66.7%) were employed full time.

Table 1

About the Service Providers
(*N* = 324)

(Values are %)

Primary Area of Work

Audiology	0.3
Augmentative communication	3.4
Developmental pediatrics/Pediatrician	1.2
Early childhood education	0.6
Nursing	5.6
Nutrition	3.1
Occupational therapy	24.4
Orthotics/Prosthetics	0.6
Parent support services	0.3
Physiotherapy	18.5
Psychology/Psychometry	1.5
Recreational therapy	1.2
Rehabilitation engineering	0.9
Service coordination/Case management	6.5
Social work	4.9
Speech-language pathology	19.1
Technology access	0.3
Transition services	0.3
Other	4.6
Missing	2.5

Position Description

Clinical specialist*	4.3
Clinical/Program manager	6.8
Service provider	82.1
Other	6.2
Missing	0.6

Types of Services Provided

(Respondent could choose more than one)

Consultation	82.4
Direct service	88.9
Education (of parents/families)	76.9
Education (of service providers)	58.3
Management	21.0
Program development	49.1
Service coordination	28.1
Other	8.0

Work Status

Full-time	66.7
Part-time	33.0
Missing	0.3

Number of Clients Seen in a Month

(For Full-Time Service Providers)

1 - 25 clients	25.5
26 - 50 clients	31.0
51 - 75 clients	14.8
76 - 100 clients	14.8
>100 clients	7.9
Missing	6.0

Experience in Pediatric Rehabilitation

$\leq$ 1 year	9.2
1.01 - 5 years	25.3
5.01 - 10 years	26.1
10.01 - 15 years	17.3
15.01 - 20 years	11.3
> 20.01 years	7.2
Missing	3.1

Number of Years at Organization

$\leq$ 1 year	14.5
1.01 - 5 years	28.5
5.01 - 10 years	28.6
10.01 - 15 years	18.5
15.01 - 20 years	7.2
> 20 years	2.1
Missing	0.6

Trained/Educated in Family-Centred Service

Yes	61.4
No	36.4
Missing	2.2

* Defined in questionnaire by examples provided: "clinical researcher, education liaison, coordinator, etc.".

What Experience and Training Do Service Providers Have?

Most service providers (61.9%) have had more than five years of professional practice in pediatric rehabilitation, but their experience level ranged from less than one year to more than thirty years of practice. Over 56% of service providers had been employed in their current jobs for longer than five years. Most service providers see a substantial number of clients per month: approximately ⅓ of them see 26-50 clients while over ⅓ see more than 50 clients per month. A further breakdown of the number of clients seen by discipline (see table in Appendix 3) indicates much variability both within and between disciplines. Over 60% of service providers had received training or education in methods of family-centred service provision.

Commentary

Specific expertise in pediatric rehabilitation has been shown to be important on many levels of service delivery for children with disabilities and their families. This expertise helps to ensure that service providers are working effectively with children and families; are able to draw on the skills and expertise of colleagues; and are reducing variation, waste, and duplication of resources (Lane & Ross, 1998; Berger Rainville, Cermak, & Murray, 1996; Tanenbaum, 1999). Furthermore, such expertise ensures that the services provided are cost effective (Borbasi, 1999). Specific competencies are also important in interacting with children and families. Such skills include effective communication; understanding the importance of parent-child interaction and the caregiving environment; and helping parents provide an environment that supports the development of the child (Case-Smith, 1994).

In summary, the data in Table 1 tell us that:

g   *service providers from 19 different disciplines completed the survey, with the highest percentage of them being occupational therapists, speech language pathologists or physiotherapists*

g   *most service providers are employed full time*

g   *most respondents have considerable experience in service delivery both in terms of number of clients seen on a regular basis and years in the pediatric rehabilitation field*

g   *while many service providers (61%) were educated in family-centred service provision, there is room for more training in FCS*

C.	About Beliefs about Participating in Family-Centred Service Delivery

How Were Beliefs about Participating in Family-Centred Service Assessed?

Parents and service providers completed a questionnaire on beliefs about **Participating in a Family-Centred Approach to Service**. (Full details and reference information on this measure are provided in Appendix 2.) This measure contains 28 statements about beliefs or attitudes towards family-centred service. These statements are conceptually and statistically grouped into five areas, yielding the scales outlined below.

Participating in a Family-Centred Approach to Service

Scale Name	Example of an Item
Beliefs about Positive Outcomes from FCS	A FCS approach will be more beneficial to children than a traditional approach to service delivery.
Beliefs about the Practical Feasibility of Implementing FCS	Compared to traditional practice, family-centred service will increase the work of service providers.*
Beliefs about Negative Outcomes for Service Providers	In a FCS approach, service providers will be unsure how to share roles with families.*
Beliefs about Self-efficacy to Implement FCS	I am confident that I am able to work with others in a family-centred way.
Beliefs about FCS Principles	It is important for family members to feel that they are treated with respect by service providers.

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* Note that some items were "reverse scored".

Respondents rated the extent to which they agreed or disagreed with each statement using a 7-point equal interval scale. A rating of 1 indicates "strongly disagree" and a 7 indicates "strongly agree". For each of the five scales, a score is calculated as the average of all the items in that scale. A higher score indicates stronger ("more positive") beliefs regarding FCS concepts and issues in implementation. Beliefs data from parents and service providers are presented in Table 2.

Note: In some of the tables that follow, we present the mean, median, and/or standard deviation. The mean (M) is the average score, the median is the mid-point, and the standard deviation (SD) is a measure of variability.

**What Were Parents'
Beliefs about Family-
Centred Service?**

Parents' scores indicated that they held the strongest beliefs about *FCS Principles* (*M* = 6.05) and *Self-efficacy to Implement FCS* (*M* = 5.94). The average score (*M* = 4.36) for the *Feasibility of Implementing FCS* scale indicates that parents acknowledge the existence of barriers.

**What Were Service
Providers' Beliefs about
Family-Centred Service?**

Service providers exhibited the strongest beliefs about *Self-efficacy to Implement FCS* (*M* = 5.99) and *FCS Principles* (*M* = 5.94). Their scores on the *Feasibility of Implementing FCS* (*M* = 4.37), indicates that they believe that barriers to implementation of FCS do exist.

Table 2

Beliefs about Participating in a Family-Centred Approach to Service

Data from Parents (*N* = 494) and Service Providers (*N* = 324)

Scale		*n**	Mean	Median	*SD***
Beliefs about Positive Outcomes from FCS	Parent	482	5.71	5.71	0.80
	Service Provider	322	5.76	5.86	0.78
Beliefs about the Feasibility of Implementing FCS	Parent	481	4.36	4.29	0.62
	Service Provider	322	4.37	4.43	0.65
Beliefs about Negative Outcomes for Service Providers	Parent	481	5.07	5.20	1.24
	Service Provider	322	5.77	5.80	0.88
Beliefs about Self-efficacy to Implement FCS	Parent	480	5.94	6.00	1.00
	Service Provider	321	5.99	6.00	0.81
Beliefs about FCS Principles	Parent	482	6.05	6.20	0.71
	Service Provider	321	5.94	6.00	0.71

* The "*n*" varies due to missing data.
** *SD* = Standard deviation.

**How Do the Beliefs of
Parents and Service
Providers Compare?**

Parents and service providers expressed generally positive beliefs about family-centred service as a method of service delivery. Both groups highly endorsed beliefs about *Self-efficacy to Implement FCS* and *FCS Principles*. Both groups responded similarly on each of the five scales about beliefs in FCS. There was one exception to this pattern. Service providers believed more strongly about there being negative outcomes of FCS for service providers (*M* = 5.77) than did parents (*M* = 5.07). This difference was statistically significant (*p* < .000).

Commentary:

Service providers may have agreed more strongly with statements about

the potential negative outcomes of FCS for service providers because they are more aware of these outcomes than are parents.

Do Beliefs about Family-Centred Service Differ by Discipline?

Service providers are not a homogenous group; they differ in their training, skills, focus and areas of responsibility, and may hold different beliefs about FCS. Thus, the five belief scale scores were examined further for those primary areas of work (discipline) with the highest number of respondents. These included occupational therapists (*n*=78), speech-language pathologists (*n*=61), physiotherapists (*n*=60), service coordinators (*n*=21), nurses (*n*=18), and social workers (*n*=16).

Table 3

Beliefs about Participating in Family-Centred Service Delivery

Service Providers' Data from Most Frequently Represented Disciplines (*N* = 324)

| Service* | *n* | % of Total *N* | Mean for Each Scale | | | | |
| | | | Beliefs about . . . | | | | |
			Positive Outcomes from FCS	Practical Feasibility of Implementing FCS	Negative Outcomes for Service Providers	Self-efficacy to Implement FCS	FCS Principles
OT	78	24.1	5.82	4.25	5.67	5.86	5.86
SLP	61	18.8	5.59	4.33	5.79	5.92	5.79
PT	60	18.5	5.50	4.29	5.75	5.87	6.00
ServCoord/ CaseMgmt	21	6.5	6.19	4.48	5.76	5.79	5.90
Nursing	18	5.6	5.80	4.10	5.44	6.01	6.14
Social work	16	4.9	6.33	4.75	6.01	6.55	6.45

* OT = Occupational therapy; SLP = Speech-language pathology; PT = Physiotherapy; ServCoord/CaseMgmt = Service coordination/Case management.

Table 3 shows that the responses of service providers from all six disciplines were very positive. However, these professionals differed significantly on the following three scales: *Positive Outcomes from FCS*, *Practical Feasibility of Implementing FCS,* and *FCS Principles* ($p < .05$). The mean scale scores ranged from 5.50 to 6.33 for *Positive Outcomes*, from 4.10 to 4.75 for *Practical Feasibility of Implementing FCS*, and from 5.79 to 6.45 for *FCS Principles*.

Social workers, followed by **service coordinators**, believed more

strongly in positive **Commentary**
outcomes of FCS as
well as with existence
of fewer barriers to
FCS. **Social workers**
and **nurses** indicated
the strongest agreement
among the six
disciplines with
principles of family-
centred service.

The strong
identification by social
workers, service
coordinators and nurses
with these aspects of
family-centred service
delivery is likely
reflective of the service
roles these
professionals play with
families. These
professionals work
closely with the entire
family and are
frequently called upon
to help identify and
access services for
families and advocate
for their needs.

In summary, the data in Tables 2 and 3 tell us that:

g   *both parents and service providers believed strongly in the*
    utility of family-centred service
g   *both parents and service providers held similarly stronger*
    beliefs about principles of FCS and about their self-
    efficacy to implement FCS than about other aspects of
    FCS
g   *not surprisingly, parents and service providers differed in*
    their beliefs about the negative outcomes of FCS, with
    service providers holding stronger beliefs

What Factors Are Perceived as Challenges to Implementing Family-Centred Service?

Although the **Participating in a Family-Centred Approach to Service** questionnaire contained a scale (with 7 items) about the practical feasibility of implementing FCS, service providers and CEOs were also asked to respond to 12 separate statements about barriers to implementing FCS. These 12 statements described types of significant challenges to FCS and were used to capture specific information about the types of systemic and personal barriers that service providers and CEOs may encounter.

In this context, a barrier is a real or perceived attitude, skill or resource that may help or hinder the effectiveness of family-centred service provision. The statements about barriers were found in the literature (e.g., Law, Brown, Barnes, King, Rosenbaum, & King, 1997; Rosin, 1996), and modified with permission from a survey developed at Thames Valley Children's Centre in London (King, Gilpin, Siess, Laurindo, Wighton, Harris, Duncan, & Enright, 1997).

Respondents rated each statement about a barrier on a 1 to 7 equal interval scale with 1 being defined as "strongly disagree" and 7 as "strongly agree". We examined each statement separately so the ratings are not combined into a total score. The data we report in Table 4 are the percentages of respondents who used the top two categories of agreement (i.e, rated a statement as a 6 or 7).

As can be seen in Table 4, the highest percentage of respondents indicated three primary barriers to providing family-centred service: *limited time resources, limited human resources,* and *limited financial resources.* For both the service provider and CEO groups, these three barriers were perceived by more respondents as challenges. *Lack of support and direction from management* and *lack of guidance and advice around family-centred issues* had the next highest percentage of agreement by respondents who were service providers. For CEOs, the barrier with the next highest percentage of agreement was *lack of guidance and advice around family-centred issues.* Respondents did not find most of the 12 statements to be challenges to implementing FCS (as indicated by the relatively low percentages). However, barriers about the system in which family-centred service is delivered (e.g., limited resources, lack of support) were more prominent than barriers related to individuals (e.g., skills, confidence).

Table 4

Perceived Challenges to Implementing Family-Centred Service

Statement	Number (%) of Respondents Indicating Strong Agreement*			
	Service Providers (*N* = 324)		CEOs (*N* = 15)	
Limited time resources	197	(60.8)	5	(33.4)
Limited human resources	163	(50.3)	4	(26.7)
Limited financial resources	161	(49.7)	4	(26.7)
Lack of support and direction from management	87	(26.9)	1	(6.7)
Lack of guidance and advice around family-centred issues	74	(22.8)	2	(13.3)
Lack of knowledge	52	(16.0)	1	(6.7)
Lack of skills	50	(15.4)	1	(6.7)
Low priority in terms of my role at the organization	36	(11.1)	1	(6.7)
Not having the confidence to provide family-centred service	35	(10.8)	1	(6.7)
Co-workers' negative attitudes about the importance of family-centred service	28	(8.6)	1	(6.7)
Lack of interest in family-centred service on the part of co-workers	25	(7.7)	0	(0.0)
Lack of personal interest	23	(7.1)	1	(6.7)

* "Strong Agreement" means responding with either 6 or 7 on a 7-point response scale where 7 = "Strongly Agree".

Table 4 also shows that respondents thought that personal interest, knowledge, skills or confidence in carrying out family-centred service were much less likely to be barriers (only 7.1-16.0% of respondents indicated agreement with these barriers). What is interesting here are the perceptions of respondents about the self-efficacy of service providers to provide family-centred services. Service providers believe in their ability to conduct family-centred service and do not view a lack of knowledge, skills or confidence as major barriers. CEOs also believe in the abilities of service providers to implement FCS.

Finally, Table 4 indicates differences in the relative strength of the beliefs held by service providers and CEOs. For example, 60.8% of service providers compared with 33.4% of CEOs expressed strong agreement with the statement about *limited time* as a barrier to family-centred service. A similar pattern of a much higher percentage of agreement by service providers is noted for *limited human resources, limited financial resources, lack of support and direction from management,* and *lack of guidance and advice around family-centred issues.* Thus, service providers were more likely to perceive systemic barriers to the implementation of FCS than were CEOs.

In summary, the data in Table 4 tell us that:

g　　*the major barriers to implementing family-centred service were seen as time resources, human resources, and financial resources*

g　　*both groups of respondents perceived systemic barriers (e.g., time resources) to be more of a hindrance to FCS than were personal barriers (e.g., confidence)*

g　　*service providers were more likely to endorse the presence of system-level barriers than were CEOs*

E. About Perceptions of the Process of Family-Centred Service Delivery

How Were Parents′ Perceptions about Service Delivery Assessed?

Parental perceptions about FCS were assessed using the **Measure of Processes of Care** (**MPOC**). (Full details and reference information on this measure are provided in Appendix 2.)   The **MPOC** questionnaire was created several years ago by members of *CanChild* to measure 'the extent to which' parents experienced a variety of behaviours of service providers that reflect the essential features of FCS. The 20 items in the measure are aspects of care that parents had identified in earlier studies to be behaviours of providers that they felt were important to decrease (parental) stress and reduce worries (King, Rosenbaum, & King, 1995).

The items group together statistically and conceptually into five scales, each reflecting a particular concept or theme. The following provides the names of the scales and an example of an item from each scale:

MPOC-20

Scale Name	Example of an Item
	To what extent do the people who work with your child...
Enabling and Partnership	... provide opportunities for you to make decisions about treatment?
Providing General Information	... have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?
Providing Specific Information about the Child	... provide you with written information about what your child is doing in therapy?
Coordinated and Comprehensive Care for the Child and Family	... look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?
Respectful and Supportive Care	... treat you as an individual rather than as a 'typical' parent of a child with a disability?

The response options for each item range from 1-7. Each option is labeled; e.g., 1 = not at all; 4 = to a moderate extent; 7 = to a very great extent. A scale score is the average of the item scores for that scale. Thus each scale score can vary from 1.00 to 7.00, and has the same meaning as the response option of the same value. Higher scale scores reflect 'better' (more family-centred) services.

The **MPOC** used in earlier studies had 56 items and **MPOC-20**, the version used in the current survey, contains 20 of those same items. Since changes were made in the labels for the response options on **MPOC-20**, minor statistical adjustments were done to enable a fair comparison between the information from the present study and what we learned from studies in Ontario over the past few years. (Those organizations that have used or currently are using **MPOC-56** may wish to compare their data to the "adjusted'" means in Table 5. Data in Appendix 4 provide "unadjusted" mean scores which can be used for future comparisons to MPOC-20).

How Did Parents Perceive Services?

As seen in Table 5, the mean scale scores ranged from 4.28 to 5.72. The overall pattern of scores in the current survey is quite high; however there is a relatively lower score on the scale assessing *Providing General Information* in contrast to the scores on the scales that measure interpersonal behaviours of providers.

**How do Parents'
Perceptions Compare
with Data from an
Earlier Study?**

Parents in the current 1999 survey reported higher scores on the scales assessing *Enabling and Partnership* and *Providing Specific Information about the Child,* compared with a 1992 *CanChild* study with 653 families (shown as Previous - A data set). In both the current and 1992 surveys, *Providing General Information* had a lower mean score than the other aspects of service delivery.

Table 5

Parents' Perceptions about Service Delivery

MPOC-20 Scales Scores Compared with a Previous Data Set

Scale	Data Set *	*n* **	Mean	Median	*SD***
Enabling and Partnership	Current	453	5.46	5.81	1.54
	Previous - A	629	5.19	5.33	1.37
Providing General Information	Current	422	4.28	4.40	1.77
	Previous - A	581	4.22	4.20	1.73
Providing Specific Information about the Child	Current	458	5.54	5.74	1.46
	Previous - A	638	5.10	5.33	1.59
Coordinated and Comprehensive Care for Child and Family	Current	464	5.49	5.58	1.38
	Previous - A	602	5.44	5.75	1.42
Respectful and Supportive Care	Current	465	5.72	6.00	1.28
	Previous - A	636	5.62	6.00	1.26

*   The data set "Previous - A" was collected in 1992 as part of a study to develop **MPOC-56** and included 653 parents, most of whom received services through 1 of 13 OACRS centres.
** The "*n*" varies due to missing data.
***SD = Standard deviation.

**How Were Service
Providers' Perceptions
about Family-Centred
Service Assessed?**

Recently members of *CanChild* have developed a measure of the self-perceptions of service providers (known as the **Measure of Processes of Care for Service Providers**, or **MPOC-SP**) about the care and services they provide. **MPOC-SP** is based very closely upon the items and scales of **MPOC**. This was done on the assumption that since **MPOC** is meant to assess what parents feel are the most important behaviours of service providers, it is appropriate to assess 'the extent to which' service providers feel able to do these behaviours. (See Appendix 2 for details and reference.)

MPOC-SP is made up of 27 items, each (like **MPOC**) being a behaviour

of a service provider that reflects some aspect of service delivery that is family-centred. These items group into four scales as follows (and an example of each is included):

MPOC-SP

Scale Name	**Example of an Item**
	To what extent did you...
Showing Interpersonal Sensitivity	... take the time to establish rapport with parents and children?
Providing General Information	... provide advice on how to get information or to contact other parents (e.g., informing parents of assistance programmes, or counselling how to work with other service providers)?
Communicating Specific Information about the Child	... provide parents with written information about their child's condition, progress or treatment?
Treating People Respectfully	... trust parents as the "experts" on their child?

As with **MPOC**, each item is scored from 1 to 7, and the scale score is the average of the item scores for that scale. Thus each scale score can vary from 1.00 (where none of the behaviours described by those items is being performed by the respondent) to 7.00 (where everything described has been provided 'to a very great extent'). Higher scale scores reflect 'better' (more family-centred) behaviours. No overall score is computed.

How Did Service Providers Perceive Services?

The mean scale scores ranged from 4.68 to 5.83, and overall are high. As noted from the parents' data, *Providing General Information* is done relatively less well than the other more interpersonal aspects of service delivery.

Table 6

Service Providers' Perceptions about Service Delivery

MPOC-SP Scale Scores (N = 324)

Scale	n*	Mean	Median	SD**
Showing Interpersonal Sensitivity	319	5.07	5.10	0.86
Providing General Information	306	4.68	4.80	1.30
Communicating Specific Information about the Child	298	5.50	5.67	1.10
Treating People Respectfully	323	5.83	5.89	0.70

* The "n" varies due to missing data.
**SD = Standard deviation.

How Do Service Providers′ Perceptions Compare with Data from an Earlier Study?

We have some information about changes over time in service providers' perceptions of how they have delivered services. In 1994, *CanChild* conducted a mailed survey, involving all 20 rehabilitation centres in Ontario, asking service providers about the family-centredness of their service delivery. Three hundred and nine service providers (a return rate of 54%) took part in this survey, representing a variety of disciplines (including speech-language pathology, physiotherapy, occupational therapy, early childhood education, and social work). The measure used in this 1994 survey was the **Family-Centered Program Rating Scale** (**FamPRS**; Murphy & Lee, 1991).

Although we used the **MPOC-SP** in the current survey, the two measures can be compared on four aspects of family-centred service. Both measures provide conceptually similar information about the following behaviours of service providers: providing general information to families, encouraging partnership and collaboration, respecting families, and providing specific information about the child.

In 1994, the **FamPRS** findings indicated that service providers were doing well in encouraging partnership and collaboration, respecting families, and providing specific information about their child. The provision of general information was a relatively weak area. In the current survey, using **MPOC-SP**, we see the same pattern of findings as in 1994. Looking at Table 6, one can see that *Treating People Respectfully* has the highest scale mean, followed by *Communicating Specific Information about the Child*. The lowest mean is for the scale titled *Providing General Information*, although the mean of 4.68 indicates that this is happening from a moderate to a fairly great extent. Service

providers therefore report that they feel they are doing well with respect to the interpersonal aspects of service delivery and the provision of relevant information to families on a one-on-one basis. The provision of general information about the nature of disabilities and available services in a community therefore continues to be the area reported to be least well done but, again, this is being done quite well.

Does Providers' Experience Relate to their Perceptions about Service Delivery?

Earlier data (in Table 1 and on p. 11) indicated that service providers had considerable experience in service delivery for children with disabilities. We examined whether there was any relationship between years of experience in pediatric rehabilitation and their self-reported **MPOC-SP** scale scores. We found that years of pediatric experience correlated with the three **MPOC-SP** scales that are most closely associated with interpersonal aspects of service delivery (*Showing Interpersonal Sensitivity*, *Communicating Specific Information about the Child*, and *Treating People Respectfully*). The significant correlation coefficients ranged from .14 to .32.

Commentary

We recognize that years of experience in the pediatric rehabilitation field is closely related to overall experience and age of respondents. However, it seems likely that clinical maturity is an important aspect of people's comfort in providing services in a family-centred manner, as this approach requires flexibility and "people" skills that may take more time to develop than the "technical" aspects of service providers' professions.

Does Organizational Size Affect Perceptions of Services?

We examined whether perceptions of services varied by size of the organizations which was described as small, medium or large (see p. 7). For parents, there were no statistically significant differences among the three sizes of organizations for any of the **MPOC-20** scales. For service providers however, there was a significant difference for one of the **MPOC-SP** scales, *Providing General Information*. The means for service providers at small, medium and large organizations are 4.43, 4.56, and 5.10, respectively. This indicates that service providers at larger facilities perceive that they/their organization are significantly better at providing information to parents (e.g., about different concerns, how to connect with others for information).

Does Organizational Culture Affect Perceptions of Services?

As you will recall (from p. 8), there were ten organizations in this survey that fostered a more family-centred culture through various strategies and practices. We examined whether perceptions about services differed between these ten organizations and those that were judged to be less family-centred. Findings indicate that these 10 more family-centred organizations are perceived by both parents and service providers to be significantly better in providing general and specific information.

Commentary

Both parents and service providers report that general information is the

aspect of service delivery that is being least well done. There appears to be little overall change with respect to meeting families' needs for general information over the past five years. Managers and administrative decision makers could consider devoting more resources to the provision of general information - an important area of need for parents of children with disabilities. Managers and decision makers should also consider what effective strategies for providing information could be developed and implemented.

In summary, the data in Tables 5 and 6 tell us:

g   *that family-centred service is highly valued by both parents and service providers*

g   *how parents and service providers experience services:*
   - *both parents and service providers indicate that the following aspects of family-centred service are being done well - Respectful and Supportive Care, Providing Specific Information about the Child, and Enabling and Partnership (Showing Interpersonal Sensitivity)*
   - *parents and service providers also indicate that aspects of providing family-centred service that are influenced by system level issues, such as Providing General Information, are not done as well*

g   *how perceptions have changed over time:*
   - *data from parents demonstrate improvements in the following aspects of family-centred service - Enabling and Partnership, and Providing Specific Information about the Child*
   - *service providers in 1994 and in 1999 report a similar pattern with respect to the delivery of family-centred services: they are doing well with respect to the interpersonal aspects of service delivery, and in providing specific, child-related information but less well in providing general information to families*

g   *that organizations with a more family-centred culture are better at providing general and specific information*

g   *that size of organization has no effect on parents' perceptions of services but service providers' at larger organizations report they are significantly better at providing general information*

F. About Judgments of Satisfaction with Services

How Was Parental Satisfaction with Services Assessed?

This survey included a widely-used standardized measure of parents' satisfaction with services, the **Client Satisfaction Questionnaire** (**CSQ**; see Appendix 2 for details and reference). The **CSQ** contains eight items designed to assess a respondent's overall satisfaction with the program or service being evaluated. Respondents indicated their degree of satisfaction with the services using a 4-point response scale which varied from one question to another. A summed total score can range from 8 to 32. Higher scores indicate greater satisfaction.

How Did Parents Judge their Satisfaction with Services?

The overall pattern of scores showed that parents used virtually the whole range of options when answering the **CSQ**. Scores ranged from 11 to 32. As seen in Table 7 (first row of data), the mean **CSQ** score was 25.89. The median score was 26, meaning half the scores were above this value and half below it. These data indicate that, <u>on average</u>, parents were quite satisfied with the services they have received, but that some parents were very dissatisfied and some were highly satisfied. The data to be examined and reported on in Part 3 of this survey's report will help us to understand better the determinants of satisfaction.

Table 7

Parents' Satisfaction with Services

Compared with Previous Data Sets

Data Set	(*N*)	Year	*n**	Mean	Median	*SD***
Current	(494)	'99	476	25.89	26	5.01
Previous - B	(330)	'93	330	27.20	28	4.47
Previous - C	(164)	'93/94	164	26.23	27	4.94
Previous - D	(151)	'94	149	28.70	31	4.17

* The "*n*" varies due to missing data.
**SD = Standard deviation.
The data sets used for comparison with the current survey are as follows:
<u>Previous - B</u>: This study was part of the work to develop and validate an earlier version of MPOC. Parents were recruited primarily through 13 OACRS centres.
<u>Previous - C</u>: This was a cross-sectional study examining the relationship between parents' perceptions of caregiving (using **MPOC-56**) and their emotional well-being, stress and satisfaction with services. Parents were recruited primarily through six OACRS centres.
<u>Previous - D</u>: This was a quality assurance survey conducted in collaboration with a regional program for children with cleft lip and palate.

How Do Judgments of   The pattern of scores in the current survey is similar to, but slightly lower

Satisfaction Compare with Earlier Studies?

than, **CSQ** scores measured in earlier studies in other programs provided at OACRS centres and related developmental programs for children with special needs. As seen in Table 7, the mean scores ranged from 25.89 to 28.70. The highest mean score ($M = 28.70$) was noted in a 1993 study assessing parental perceptions and experiences with a regional program for children with cleft lip and palate. We had reason to believe that this program was a model of early intervention, provided services that could be obtained (or at least well coordinated) from a single access point, and was able to maintain long-term continuity of providers and programs.

Does Organizational Culture Affect Judgments of Satisfaction?

There were ten organizations in this survey who fostered a more family-centred culture, reflected through use of various strategies and practices (see p. 8). We examined whether judgements about satisfaction differed between these ten organizations and those five which used fewer FCS strategies and practices. Analysis showed a statistically significant difference in parents' judgments of satisfaction between these two groups of organizations, although the actual difference in the satisfaction scores is not large ($M = 26.38$ for more family-centred culture group versus $M = 25.08$ for less family-centred group).

In summary, the data in Table 7 tell us that:

g   *parents in this survey are generally quite satisfied with services, although some parents are very dissatisfied*

g   *parents were slightly less satisfied compared with previous data from similar and different programs of services*

g   *parents' satisfaction was slightly higher in those organizations with a more family-centred culture*

SUMMARY

This survey provides detailed information about the perceptions of family-centred service delivery from the perspectives of parents of children with disabilities, service providers, and CEOs of organizations that provide children's rehabilitation services. The data show that a family-centred approach is endorsed and supported, and in general is being provided well.

In this last section, we bring together what the data in all of the tables tell us. We refer to and build upon the conclusions previously stated. Then we offer suggestions about how the findings will be useful to various users of this information. These users would include **receivers** of the services (children with disabilities, their parents and families), **providers** of services (front-line service providers, and administrative decision makers including managers and CEOs at centres/organizations), and **planners** of services (policy-makers in governmental agencies of health, education, and community and social services).

What Do These Findings Tell Us?

The Findings about the Organizations Tell Us that:

- *there is a high level of managerial endorsement of FCS principles*
- *most organizations (67%) foster a family-centred climate through various strategies and practices (such as training staff in FCS, enabling families to be more involved and informed about their child's care and the services available)*
- *size does not affect an organization's ability to be family-centred*

The Findings about Service Providers' Characteristics Tell Us that:

- *most service providers are employed full time*
- *most respondents have considerable experience in service delivery both in terms of number of clients seen on a regular basis and years in the pediatric rehabilitation field (with an average of 12.8 years in practice and a range of 4 months to 40 years)*
- *while many service providers (61%) were educated in family-centred service provision, there is room for more training in FCS*

The Findings about Beliefs about Participating in Family-Centred Service Tell Us that:

- *both parents and service providers believed strongly in the utility of family-centred service*
- *both parents and service providers held similarly stronger beliefs about principles of FCS and about their self-efficacy to implement FCS than about other aspects of FCS*

g   *not surprisingly, parents and service providers differed in their beliefs about the negative outcomes of FCS, with service providers holding stronger beliefs*

The Findings about Barriers to Implementing Family-Centred Service Tell Us that:

g   *the major barriers to implementing family-centred service were seen as time resources, human resources, and financial resources*

g   *both service providers and CEOs perceived systemic barriers (e.g., time resources) to be more of a hindrance to FCS than were personal barriers (e.g., confidence)*

g   *service providers were more likely to endorse the presence of system-level barriers than were CEOs*

The Findings about Perceptions about the Process of Service Delivery Tell Us that:

g   *family-centred service is highly valued by both parents and service providers*

g   *both parents and service providers indicate that the following aspects of family-centred service are being done well - Respectful and Supportive Care, Providing Specific Information about the Child, and Enabling and Partnership (Showing Interpersonal Sensitivity) - but that aspects of providing family-centred service that are influenced by system level issues, such as Providing General Information, are not done as well*

g   *over the past eight years, parents report improvements in the following aspects of family-centred service - Enabling and Partnership, and Providing Specific Information about the Child*

g   *over the past six years, service providers report a similar pattern with respect to the delivery of family-centred services: they are doing well with respect to the interpersonal aspects of service delivery, and in providing specific, child-related information but less well in providing general information to families*

g   *organizations with a more family-centred culture are better at providing general and specific information*

g   *size of organization has no effect on parents' perceptions of services but service providers' at larger organizations report they are significantly better at providing general information*

The Findings about Judgments about Satisfaction with Services Tell Us that:

g   *parents in this survey are generally quite satisfied with services although some parents are very dissatisfied*

g   *parents were slightly less satisfied compared with previous data from similar and different programs of services*

g   *parents' satisfaction was slightly higher in those organizations with a more family-centred culture*

How Will the Findings Be Useful?

For **parents**, the findings will be useful in these ways…

T The findings indicate that parents see Ontario Children's Rehabilitation Centres and the Community Care Access Centres in this sample as providing services that are **highly family-centred**. These perceptions are fairly stable. The information from the present survey is comparable to information collected in a similar Ontario-wide survey conducted by *CanChild* seven years ago (in 1992). Parents should feel encouraged that their children are receiving good quality care. We know from research that a family-centred approach to service delivery leads to better outcomes (refer to details on next page).

T The findings show that parents and service providers agree about the **importance of family-centred service**. Both groups strongly believe in the principles of family-centred service and believe that services delivered in this way lead to positive outcomes for families. Parents should feel encouraged that both service providers and parents have the same beliefs about how services should be delivered.

T The findings confirm parents' often-mentioned concern about the **lack of appropriate and needed general information** (about the causes and implications of disabilities, and about existing services and eligibility criteria). As in previous *CanChild* studies, parents report that the provision of general information is the aspect of family-centred service that is least well done.

T The findings indicate that services are provided by **highly experienced staff** who have training in a variety of disciplines pertinent to children with disabilities and their families. This experience has been shown to lead to improved services. Parents should be encouraged by this expertise and by the fact that service providers feel confident in their ability to implement family-centred services.

For **service providers and administrative decision makers**, the findings will be useful in these ways…

T The findings provide a **"snapshot" of information about Ontario organizations** that offer services to children with disabilities and their families. The survey provides information (e.g., the number of centres that have formally adopted a family-centred service model, numbers of clients served, and characteristics of staff) that can be used, in reports and proposals, to describe services in Ontario.

T The findings indicate that parents are **satisfied with services and see services as family-centred**. Service organizations in Ontario are doing well in a number of specific areas - informing parents about their child's therapy progress, involving parents in making decisions about services for

their child, and treating parents respectfully and supportively. In fact, there have been improvements over the last seven years in the first two of these areas. Ontario organizations therefore are making a difference in areas that matter to parents. When parents are satisfied with services and perceive services as family-centred, they are more likely to adhere to home treatment programs for their child and other jointly agreed-upon courses of action, and this in turn is associated with better physical, behavioural, and social outcomes for their children (King, King, & Rosenbaum, 1996; Rosenbaum, King, Law, King, & Evans, 1998). We also know that when parents receive family-centred services, they are less likely to experience feelings of distress and depression (King, King, Rosenbaum, & Goffin, 1999). Being satisfied with services and seeing services as family-centred therefore are not only important outcomes in their own right, but they are associated with a host of other outcomes for both children and parents.

T   The findings point to a number of areas that should be considered by organizations seeking to improve their services. These **possible areas for improvement** include: increasing the provision of general information, working to reduce systemic barriers to the implementation of family-centred service, and providing more training to staff about family-centred service. Particular attention might be paid to developing effective strategies for providing general information to parents.

T   The findings indicate that providing professional development activities about family-centred service is well worth the investment. Organizations that provided training in family-centred services to staff members (and had a more family-centred culture overall) were found to provide better family-centred service (in the eyes of both parents and staff members) and these organizations received higher satisfaction ratings from parents.

T   The findings, along with what we know from the literature, indicate that the "ideal organization" delivering services to children and families would have the following characteristics: (1) formal adoption of a family-centred approach to service delivery; (2) experienced staff who are well-trained in family-centred service delivery, believe in the principles of family-centred service, and feel confident in their ability to deliver services in this manner; and (3) implementation of strategies consistent with a family-centred approach, such as family-friendly intake procedures, parent involvement in goal setting, and the presence of a parent resource centre.

T   Parents and service providers strongly believe in the importance and utility of family-centered service. This indicates that service organizations should work to not only ensure the family-centredness of services within their organization, but also to provide a **system of services that are family-centred**. This viewpoint is reflected in the following quote: "To strengthen families and improve the health and well-being of children, a community-based "system" which is comprehensive, coordinated and

family-focused is required" (p. 111, Human Resources Development Canada, 1998).

T The findings strongly suggest that family-centred service should be considered a **"best approach"** to meeting the needs of children with disabilities and their families. The 1999 Role Review of Children's Treatment Centres did not consider family-centred service to be a "best practice". This perception might occur because FCS is about "process" and does not specify <u>what</u> set of services to provide. Family-centred service, however, can be seen as a "best approach" in that it outlines principles and the specific behaviours of service providers that are important to parents, and it is supported by research evidence (see Rosenbaum et al., 1998). Family-centred service specifies <u>how</u> services should be delivered to meet the needs of children and families rather than <u>what</u> types of services should be provided. Both are important aspects of care - the content and the process. The following quote describes the utility of a family-centred service model:

> "…there are encouraging examples of service models which can meet parental needs…they have a number of features in common. They take a holistic approach to assessing and meeting family needs; the importance of relationship building between parents and professionals is recognized; they provide a consistent, single point of contact for the family; they have a flexible, individualized needs-led approach; they focus on parents' own concerns and recognize the importance of understanding parents' own perceptions of the hierarchy of their needs; support provided empowers parents rather than taking control away from them; parents' own expertise with regard to the child and family is recognized and acknowledged" (p. 95, Sloper, 1999).

For **legislative policy makers**, the findings will be useful in these ways…

T The findings indicate the **importance of family-centred service** in the eyes of both parents and service providers. This can be useful in suggesting directions for policies concerning services for children with disabilities and their families.

T The findings show that the **major barriers to implementing family-centred service** concern resources - time, human, and financial resources. Both CEOs and service providers agree that limited resources are the major barrier. If family-centred service is seen as a "best approach" to meet the needs of children with disabilities and their families, then this information may be useful in creating policies to encourage family-centred care, and the resources to carry it out.

T The findings indicate that organizations with stronger cultures of family-centred service actually had better outcomes: Parents experienced the services as more family-centred and were more satisfied with these services. Since family-centredness is also linked to better outcomes for children and better parent well-being, policies endorsing a family-centred

approach will have important payoffs for children and families.

A LOOK FORWARD

The data presented in this Part 2 report focused on the beliefs about participating in FCS, perceptions about family-centred service delivery, and judgments about satisfaction with services. As noted at the beginning, there will be one more document, Part 3, that will report on our survey about service delivery for children with disabilities in Ontario.

In Part 3:

We will provide information on the interrelationships among different aspects of family-centred service.

Here are some highlights from Part 3:

C Parents report that services are less family-centred when their children receive services from a greater number of locations.
C Higher parents' satisfaction with service is related to fewer health or development problems for their child, fewer locations of service and better family-centred service.
C Service providers are more likely to report behaving in a family-centred manner when the feel they can implement family-centred service effectively.
C When service providers report that they provide better family-centred service, parents from the same centre/organization report receiving better family-centred service.

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Location of Organization	**Name of Organization**
Burlington	Community Care Access Centre of Halton
Chatham	Kent County Children's Treatment Centre
Hamilton	Chedoke Child & Family Centre, Children's Developmental Rehabilitation Programme
London	Thames Valley Children's Centre
Mississauga	Erinoak
Oshawa	Grandview Children's Centre
Owen Sound	Grey-Bruce Community Care Access Centre
Pembroke	Community Care Access Centre in Renfrew County
Sarnia	Sarnia and District Children's Treatment Centre
Sault Ste. Marie	Algoma Community Care Access Centre
Simcoe	Haldimand-Norfolk Community Care Access Centre
Sudbury	Sudbury Regional Hospital Children's Treatment Centre
Thunder Bay	George Jeffrey Children's Treatment Centre
Toronto	Bloorview MacMillan Centre
Waterloo	Community Care Access Centre of Waterloo Region
Waterloo	Rotary Children's Centre

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Bonnie Grose	Haldimand-Norfolk Community Care Access Centre
Cate Breaugh	OACRS Consumer Advisory Group
Elaine Whitmore	Community Care Access Centre of Halton
Kathy Meyer	Professional Advisory Committee of OACRS

Premises, Principles, and Elements of Family-Centred Service

Premises (basic assumptions)

- Parents know their children best and want the best for their children.
- Families are different and unique.
- 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)

- Each family should lead the decision-making process concerning the type and amount of support and services they receive.
- Parents should have ultimate responsibility for the care of their children.
- Each family and family member should be treated with respect (as individuals).
- The needs of all family members should be considered.
- The involvement of all family members should be supported and encouraged.

Elements (key service provider behaviours)

Service Provider Behaviours	Service Provider Behaviours	Service Provider Behaviours
to encourage parent decision-making * to encourage parent decision-making in partnership with other team members (to utilize family empowerment strategies) **to assist in identifying strengths** * to assist families in identifying their strengths and building their own resources **to provide information** * to inform, answer and advise parents (to encourage informed choices) **to assist in identifying needs** * to work in partnership with parents and children and help them identify and prioritize their needs from their own perspective **to collaborate with parents** * to collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation) **to provide accessible services** * to provide systems that will not overwhelm families with paperwork and bureaucratic red tape **to share information about the child** * to share complete information about their child's care on an ongoing basis	**to respect families** * to respect the values, wishes, and priorities of families **to support families** * to accept and support decisions made by families **to listen** **to provide individualized service** * to provide flexible and individualized services (and to respond to the changing needs of the family) **to accept diversity** * to be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socioeconomic) **to believe and trust parents** **to communicate clearly** * to communicate in a language understandable by parents	**to consider psychosocial needs of all members** * to consider and be sensitive to the psychosocial needs of all family members **to encourage participation of all members** * to provide an environment that encourages the participation of all family members **to respect coping styles** * to respect the family's own style of coping without judging what is right and what is wrong **to encourage use of community supports** * to encourage family-to-family support and the use of natural community supports and resources **to build on strengths** * to recognize and build on family and child strengths

Appendix 2

General Information about Measures Used in this Survey

There were four specific measures used to collect data from parents, service providers, and CEOs. An overview of the measures is provided on the following table. The information here gives some background about the soundness and use of these measures.

Measure of Processes of Care (20 items) - MPOC-20

MPOC was developed in the early '90s and the MPOC-56 version has been used extensively in Ontario, and also worldwide. It is known to be reliable (that is, people give consistent answers when surveyed from one time to another) and valid (there are, as predicted, strong relationships between people's scores on MPOC and their overall satisfaction with services and their degree of stress in dealing with their child's service providers). The shorter version (MPOC-20) works as well as the 56-item form, and is easier for parents to complete.

King, S., Rosenbaum, P., & King, G. (1995). *The Measure of Processes of Care (MPOC): A means to assess family-centred behaviours of health care providers.* Hamilton, Ontario, Canada: McMaster University and Chedoke-McMaster Hospitals, Neurodevelopmental Clinical Research Unit (now *CanChild* Centre for Childhood Disability Research).

King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of care-giving: Development and validation of a measure of processes. *Developmental Medicine and Child Neurology, 38,* 757-772.

Client Satisfaction Questionnaire - CSQ

This standardized measure of global satisfaction with care and services has good reliability and validity. The CSQ has been used in various program evaluations and human services research, and is easily understood and answered.

Larsen, D.L., Attkisson, C.C., Hargreaves, W.A., & Nguyen, T.D. (1979). Assessment of client/ patient satisfaction: Development of a general scale. *Evaluation and Program Planning, 2,* 197-207.

Participating in a Family-Centred Approach to Service

This measure has been developed by our group at *CanChild* for use in our studies about FCS. Its content was derived from the literature and assesses attitudes, beliefs, and behavioural intentions about FCS.

King, G., Law, M., Kertoy, M., King, S., Rosenbaum, P., & Pollock, N. (2000). *Development of a measure about participating in family-centred service*. Manuscript in preparation.

Measure of Processes of Care for Service Providers - MPOC-SP

This measure, based on the parent version, has been used during its development over the past 3 years with service providers in Ontario and British Columbia. MPOC-SP is known to be reliable (people give consistent answers from time to time). There is some evidence of validity insofar as people respond differently about what they actually do and what they would do in an 'ideal' situation (higher MPOC-SP scale scores). Furthermore there is evidence that professionals in different service disciplines provide somewhat different patterns of MPOC-SP scale scores in ways that are consistent with the roles and responsibilities they assume.

Woodside, J., Rosenbaum, P., King, S., & King, G. (2000). *The Measure of Processes of Care for Service Providers: Design, development, analysis, and properties.* Manuscript in preparation

Detailed Information about Measures Used in this Survey

Features	MPOC-20	CSQ	Participating in FCS	MPOC-SP
What is the measure about?	A 20-item self-report of parents' perceptions of the extent to which specific behaviours of health care providers occur.	This 8-item questionnaire is a self-administered standardized measure which is widely used in program evaluation.	A 28-item measure tapping the extent to which respondents believe in the key assumptions and principles of family-centred service.	A 27-item self-report questionnaire completed by service providers, about their perceptions of the care and service they provide.
Who are the respondents and what do they do?	Parents are asked to indicate how much the action or behaviour happens using 1 of 7 response options from: 1 = "Not at All" 2 = "To a Very Small Extent" 3 = "To a Small Extent" 4 = "To a Moderate Extent" 5 = "To a Fairly Great Extent" 6 = "To a Great Extent" 7 = "To a Very Great Extent".	Parents indicate their satisfaction with the services they received using a 4-point response scale which varies for each question.	This questionnaire is suitable for parents, service providers, and managers. Respondents indicate how much they agree with a statement on a scale ranging from 1 = "Strongly Disagree" to 7 = "Strongly Agree".	Service providers indicate the extent to which they actually display the actions or behaviours described. 1 = "Not at All" 2 = "To a Very Small Extent" 3 = "To a Small Extent" 4 = "To a Moderate Extent" 5 = "To a Fairly Great Extent" 6 = "To a Great Extent" 7 = "To a Very Great Extent".
What kind of scales does the measure give?	Items have been grouped into 5 scales and these reflect the essential features of family-centredness. There is no total score.	N/A	Items have been grouped into 5 scales and these reflect beliefs about family-centred service. There is no total score.	Content and format parallel that of MPOC-20 on which this was based. Items have been grouped into 4 scales.
What are the scale names (short forms) and how many items are in each scale?	**Scale name (number of items)** • Enabling and Partnership (3) • Providing General Information (5) • Providing Specific Information about the Child (3) • Coordinated and Comprehensive Care for Child and Family (4) • Respectful and Supportive Care (5)	N/A	**Scale name (number of items)** • Beliefs about Positive Outcomes from FCS (7) • Beliefs about the Practical Feasibility of Implementing FCS (7) • Beliefs about Negative Outcomes for Service Providers (5) • Beliefs about Self-efficacy to Implement FCS (4) • FCS Principles (5)	**Scale name (number of items)** • Showing Interpersonal Sensitivity (10) • Providing General Information (5) • Communicating Specific Information about the Child (3) • Treating People Respectfully (9)
How are the scales/scores calculated?	Scores for each scale are calculated by averaging the responses of all the items belonging to a scale; therefore the range of scale scores is from 1.00 to 7.00.	A total score is obtained by summing the scores of all 8 items. Scores range from 8 to 32.	Scale scores are calculated by averaging the responses of all items belonging to a scale; therefore the range of scale scores is from 1.00 to 7.00.	Scale scores are calculated by averaging the responses of all items belonging to a scale; therefore the range of scale scores is from 1.00 to 7.00.
What does a score mean?	A higher score means "better" care-giving (i.e., more family-centred).	A higher score means greater satisfaction with care.	A higher score means stronger beliefs towards family-centred service.	A higher score means more family-centred behaviour.

Appendix 3

Number of Clients Seen by Each Discipline
(for Full-time Service Providers *n* = 203*)

	n	Total number of clients seen in a month (Values in %)				
		1 - 25	26 - 50	51 - 75	76 - 100	>100
Audiology	1	0	0	100	0	0
Augmentative communication	9	88.9	11.1	0	0	0
Developmental pediatrics/Pediatrician	2	50	50	0	0	0
Early childhood education	1	100	0	0	0	0
Nursing	8	25	25	25	12.5	12.5
Nutrition	4	25	50	25	0	0
Occupational therapy	46	17.4	37	19.6	21.7	4.3
Orthotics/Prosthetics	2	100	0	0	0	0
Physiotherapy	35	8.6	51.4	17.1	17.1	5.7
Psychology/Psychometry	3	100	0	0	0	0
Recreational therapy	2	0	50	0	0	50
Rehabilitation engineering	2	50	0	0	50	0
Service coordination/Case management	14	57.1	28.6	7.1	7.1	0
Social work	9	11.1	66.7	11.1	0	11.1
Speech-language pathology	52	13.5	26.9	19.2	21.2	19.2
Technology access	1	100	0	0	0	0
Transition services	1	100	0	0	0	0

* Total number of full-time service providers is 216. However, 13 respondents were missing "number of clients seen" information, therefore the *n* = 203.

Appendix 4

Parents' Perceptions about Service Delivery

MPOC-20 Scales - Unadjusted (*N* = 494)

Scale	*n**	Mean**	Median	Mode	*SD***	Min.	Max.	Range
Enabling & Partnership	453	5.11	5.33	7	1.55	1	7	6
Providing General Information	422	4.09	4.2	1	1.77	1	7	6
Providing Specific Information about the Child	458	5.23	5.67	7	1.48	1	7	6
Coordinated & Comprehensive Care	464	5.25	5.42	7	1.39	1	7	6
Respectful & Supportive Care	465	5.4	5.6	7	1.29	1	7	6

* The "*n*" varies due to missing data.
** Refer to p. 19 for explanation of unadjusted means.
****SD* = Standard deviation.