CanChild
Centre for Childhood Disability Research

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

PART 3: FACTORS AFFECTING FAMILY-CENTRED SERVICE DELIVERY FOR CHILDREN WITH DISABILITIES

OVERVIEW TO THE SURVEY REPORT

How Will the Survey Data Be Reported?

This document is a summary of Part 3 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 3 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 Parts 1 and 2 may wish to skim through these two sections.

The contents of the three parts of the survey 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:
(distributed in June, 2000)

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

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	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: (the current document)	C	summary of information about the factors 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 has 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 in a manner 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).

How Is Family-Centred Service a Dynamic Process?	The goals and needs of families change over time and service providers 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 new 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.

What Procedures Were Used to Obtain a Representative Sample?

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.

Who Was Involved?

From the 641 consenting parents, 494 questionnaires were returned and analysed. From the 411 service providers who were sent survey packages, 324 questionnaires were returned and analysed for a return rate of 79%. Of the 16 participating organizations, 15 completed questionnaires from CEOs/managers were received for a response rate of 94%.

WHAT HAVE WE LEARNED?

What Analyses Did We Do?

In Part 2 of the survey report, we described **parents' perceptions of the family-centredness of service delivery** and their **satisfaction with service**. In Part 3, we analyze those data together with other factors that could potentially influence these outcomes.

The analysis indicated that four of these factors have an important and statistically significant influence on parents' satisfaction with and/or perception of service delivery. These four factors and the outcomes that they are related to are:

What Factors Influence Perceptions of Family-Centred Service and Satisfaction with Service

Factor	Attributes Included in this Factor
Family-centred culture at centre/ organization	C presence of family-centred systems and services at a centre (e.g., resource centre, provision of information) [identified by Chief Executive Officer of the organization] C recent changes to make centre more family-centred (e.g., physical setting comfort, provision of information to parents) [identified by Chief Executive Officer of the organization] C changes in last 5 years to make centre more family-centred (e.g., intake procedures, goal setting with parents, user-friendly reports) [identified by Chief Executive Officer of the organization] C beliefs of Chief Executive Officer of the centre about family-centred service C service providers' behaviour in providing family-centred service [measured by *Measure of Processes of Care - Service Provider version*]
Total number of sources of service	C total number of sources/places child goes to receive services [identified by parent report]
Complexity of child's health/ development problem (# of health/ development problems)	C total number of health and development problems that each child has (e.g., communication, mobility, behaviour) [identified by parent report]
Parent beliefs about family-centred service	C stronger beliefs about positive outcomes of family-centred service C weaker beliefs about the negative outcomes of family-centred service C parents' beliefs about their self-efficacy to participate in family-centred service [measured by *Beliefs about Participating in a Family-centred Approach to Service*]

Outcome	Attributes Included in this Outcome
Parent perceptions of family-centred service	C enabling the participation of parents in service delivery C provision of general information to families C provision of specific information about a child to his/her family C provision of coordinated, comprehensive care C provision of respectful and supportive care [measured by *Measure of Processes of Care*]
Parent satisfaction with service	C satisfaction with services [measured by *Client Satisfaction Questionnaire*]

In summary, the data tell us that:

g parents' perceptions that they are receiving family-centred service are influenced by their beliefs about family-centred service and the number of sources of service their children receive

g parents' satisfaction with services is strongly influenced by the perception that services are family-centred, fewer sources of service and the presence of a more family-centred culture at an organization

g when children have more health/development problems, they receive a greater number of sources of service

g when children receive services from more sources, parents report that services are less family-centred

g after the influence of perceptions of family-centred service and family-centred culture on satisfaction with service is accounted for, the remaining influence of the number of sources of service is weak. This suggests that the provision of family-centred service can buffer the negative effects of a greater number of sources of service.

What Other Individual Factors Influence Perceptions about and Satisfaction with Service

We examined the specific association of other factors with parents' satisfaction with and/or perceptions of service delivery, and found the following associations:

C Service providers who feel they can carry out family-centred service effectively report increased family-centred behaviours such as interpersonal sensitivity, provision of information, respectful interactions with families.

C When service providers feel a strong self-efficacy in carrying out family-centred service effectively, parents at that centre/organization report receiving more family-centred services.

C When service providers report providing more family-centred service, parents at that centre/organization also report higher ratings of family-centred services.

C When service providers report providing more family-centred service, parents at that centre/organization report greater satisfaction with services.

How Will these Findings Be Useful?

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

T The findings indicate that parents' beliefs about family-centred service influence their perceptions of family-centred service within a centre or organization. Therefore, it is useful for organizations to provide information to families about family-centred service, what it means and what they should expect.

T These findings confirm what many families have indicated - that services at fewer locations will increase their satisfaction with services.

T The findings confirm that it is appropriate for parents to want services to be provided in a family-centred manner. Provision of family-centred services leads to satisfaction for families.

T The findings show that the family-centred culture of a centre or organization strongly influences satisfaction with service. Parents should be encouraged to work with providers to ensure that a family-centred culture is present within an organization.

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

T The findings confirm that the presence of a family-centred "culture" of a centre or organization strongly influences parents' satisfaction with service, independent of their perceptions of the individual service(s) they receive.

T The findings indicate that the support and active involvement of the Chief Executive Officer of an organization in the development of a family-centred culture is very important to the family-centred culture of an organization.

T The findings further support conclusions from Part 2 of this survey that providing professional development activities about family-centred service is worthwhile.

T The findings suggest to organizations within a community to work together to decrease the number of sources of service for families. This is particularly important for families who have

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children with several problems and who are more likely to receive services from more sources.

T The findings suggest that it is important to ensure that parents and service providers know about family-centred service, and feel comfortable with its implementation. Their active involvement in the design and implementation of services will likely increase their feelings of comfort with family-centred services (Hill, Schwalberg, Zimmerman & Tilson, 1999).

T The findings strongly suggest that family-centred service should be considered a **"best practice approach"** to meeting the needs of children with disabilities and their families. Organizations can evaluate the family-centredness of their services using assessment tools such as the Measures of Processes of Care that were used in this survey.

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

T The findings indicate the **importance of family-centred service** in leading to parents' satisfaction with services.

T The findings indicate that **decreasing the number of sources of service** within a community is an important policy goal since it leads to improved positive perceptions about and satisfaction with service.

T The findings indicate that organizations with a **family-centred culture** have an important influence on outcomes: Parents experienced the services as more family-centred and were more satisfied with these services.

REFERENCES

Hill, I., Schwalberg, R., Zimmerman, B. & Tilson, B. (1999). *Achieving service integration for children with special health care needs: An assessment of alternative Medicaid managed care models. Volume 1: Synthesis of study results.* Washington, DC: U.S. Department of Health and Human Services.

Hostler, S. (Ed.). (1994). *Family-centered care: An approach to implementation.* Charlottesville, VA: University of Virginia, Children's Medical Centre, Kluge Children's Rehabilitation Center.

King, G., King, S., & Rosenbaum, P. (1996). Interpersonal aspects of care-giving and client outcomes: a review of the literature. *Ambulatory Child Health, 2,* 151-160.

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology, 24,* 41-53.

King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers' perceptions of the family-centredness of children's rehabilitation services. *Physical and Occupational Therapy in Pediatrics, 18*(1), 21-40.

Kline, R.. (1998). *Principles and practice of structural equation modeling.* New York: Guilford.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics, 18*(1), 1-20.

Viscardis, L. (1998). The family-centred approach to providing services: A parent perspective. *Physical and Occupational Therapy in Pediatrics, 18*(1), 41-53.

Winton, P.J., & Crais, E. R. (1996). Moving towards a family-centred approach. In P.J. McWilliam, P.J. Winton, & E.R. Crais (Eds.), *Practical strategies for family-centered intervention* (pp. 155-194). San Diego, CA: Singular Publishing Group, Inc.

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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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