

**Children with Disabilities in Ontario:
A Profile of Children's Services**

**Part 1:
Children, Families And Services**

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

PART 1: CHILDREN, FAMILIES AND SERVICES

INTRODUCTION

Why Examine Service Delivery for Children with Disabilities in Ontario?

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 method and philosophy 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).

In the early 1990s, *CanChild* Centre for Childhood Disability Research conducted surveys of families and service providers to gain increased understanding about family-centred service 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 individual-izing service (King, Law, King, & Rosenbaum, 1998).

Because of the changes that have occurred in children's rehabilitation services over the past several years, we believed 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 parents, service providers, and CEOs/managers of organizations 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.

How Will the Survey Data Be Reported?

The data from this survey are presented in three parts. Part 1 is contained in this document. The contents of the three parts are as follows:

Part 1:

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

Part 2:

- descriptions of service providers and the centres/organizations providing services to children with disabilities
- perceptions of services provided, from the perspective of families and service providers, including changes since the early 1990s
- information about families' and service providers' beliefs about participation in family-centred service

Part 3:

- information about the factors associated with parents' perceptions of family-centred service and their satisfaction with services

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. Participating organizations 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, and their perceptions of service delivery and 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 will be provided in Part 2 of the 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, 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 may 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.

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%. The remainder of this report provides 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 analysed for a return rate of 79%. Standard follow-up procedures were also used. Details about the service providers and organizations will be contained in Part 2 of the report.

WHAT DID WE FIND?

Background Note about the Data:

The findings from this survey are presented both in text and table form. We generally report on the total sample (N=494), but for some sections we report on subgroups and provide the number of participants (“n”) for these categories. The values presented in the tables are percentages unless indicated otherwise.

A. The Children

The ages of children reported in this survey range from 2 months to 20 years of age. As can be seen from Table 1, 35.8% of the children are preschool age (i.e., between 0-5 years old), while approximately 60% are school age children (i.e., between 6-17 years old). Similar to findings in other research about childhood disability, there were more boys (63.2%) than girls in this sample.

Table 1

What Do We Know About the Children?

Child's Age	Child's Gender
0 - 2 years	Male
3 - 5 years	Female
6 - 8 years	
9 - 11 years	
12 - 14 years	
15 - 17 years	
≥ 18 years	
	Additional Health or Development Problems (Respondents could indicate more than one)
	Behavioural disorder
	Communication/Speech delay
	Developmental delay
	Epilepsy or seizure disorder
	Hearing loss
	Learning disorder
	Visual impairment
	Other (not elsewhere categorized) *
	Number of Health or Development Problems
	1 problem
	2 problems
	3 - 4 problems
	≥ 5 problems
Child's Primary Health or Development Problem	
Acquired brain injury	
Autism/Pervasive developmental disorder (PDD)	
Cerebral palsy	
Communication disorder	
Developmental coordination disorder	
Developmental delay	
Muscle disease	
Spina bifida/Hydrocephalus	
Syndrome*	
Other (not elsewhere categorized)*	

* Specific information about children with “Syndrome” or “Other” as their primary problem is not provided in Table 1. The kinds of syndromes that children have included Down, fetal alcohol, Prader-Willi, Tourette, William and various other chromosomal disorders. The “Other” category is comprised of various descriptions that reflect diseases, disorders or conditions related to bone, brain, heart, metabolic, bowel, respiratory, and nervous systems, as well as cancer, and learning and motor difficulties. The “Other” category for additional problems contained similar kinds of conditions. Because both of the “Other” categories contain such a wide variety of problems, the data for children in these categories are not presented in subsequent tables in this report.

Primary Health or Development Problem

Table 1 also presents information on the children's primary health or development problems. Cerebral palsy was the most common primary problem (25.3% of the sample or 125 children). The next most common primary health or development problems in this sample were developmental delay (13.6%), communication disorder (12.6%), syndrome (12.3%), and spina bifida/hydrocephalus (6.5%).

Age at "Diagnosis"

In the survey we asked parents to indicate "how old was your child when the health or development problem was first diagnosed?". The responses indicated that children were quite varied in their age at the time of diagnosis. The results were also puzzling - for example, 27% of parents said that their children with developmental coordination disorder were diagnosed before one year of age, a clinically curious finding! Inspection of the data suggests that parents may have interpreted the question in one of three possible ways: 1) when they were first concerned about their child's development; 2) when they were first told formally that their child had a specific condition or "diagnosis"; or 3) they reported the age (developmental stage) at which the child's problem may have started (e.g., during gestation, at delivery). We are unable to tease apart these three important issues, and so have not presented these data in table form.

Additional Problems

Parents were asked to indicate if their child had any problems in addition to the primary health or development problem. The most frequently occurring additional problems (apart from the primary problem) included communication/speech delay (43.1%), developmental delay (37.9%), and learning disorder (32.4%). Additional problems of lesser frequency included visual impairment, behavioural disorder, epilepsy or seizure disorder, and hearing loss.

We also looked at the total number of problems children have (i.e., the primary problem plus any additional problems). Few children have only a single health or development problem. The majority of children in the survey (over 77%) have two or more health or development problems. In fact, over 50% have more than three health or development problems.

Table 2 provides a profile of the additional health or development problems experienced for each primary problem. By looking across any row, you can see the frequency of additional problems experienced by children with a particular primary problem. For example, 40.0% of children with an acquired brain injury have a learning disorder. Looking down a column provides some sense of how common some of the additional problems are across all children. For example, communication or speech delay as an additional problem is experienced by many children.

Table 2

What Additional Health or Development Problems Do Children Have?

Primary Problem	Additional Health or Development Problem						
	Behaviour Disorder	Developmental Delay	Epilepsy	Hearing Loss	Learning Disorder	Communication/Speech Delay	Visual Impairment
Acquired brain injury (n=15)	26.7	66.7	26.7	0.0	40.0	46.7	46.7
Autism/Pervasive developmental disorder (n=25)	20.0	60.0	20.0	8.0	32.0	68.0	4.0
Cerebral palsy (n=125)	14.4	47.2	27.2	9.6	28.0	41.6	28.8
Communication disorder (n=62)	14.5	19.4	3.2	19.4	19.4	N/A	4.8
Developmental coordination disorder (n=11)	45.5	27.3	9.1	9.1	63.6	27.3	18.2
Developmental delay (n=67)	16.4	N/A	19.4	9.0	37.3	71.6	16.4
Muscle disease (n=11)	27.3	36.4	0.0	9.1	9.1	36.4	0.0
Spina bifida/Hydrocephalus (n=32)	3.1	43.8	6.3	3.1	40.6	25.0	28.1
Syndrome (n=61)	31.1	68.9	9.8	29.5	44.3	70.5	34.4

• Rows and columns do not add to 100% because a child can have multiple additional problems.

Commentary:

We suspect that the number of problems may be under-reported. Parents may have indicated a primary problem (such as cerebral palsy or a syndrome) but no other additional problems, knowing that the “diagnostic” label encompasses various difficulties. For example, parents know that cerebral palsy is a term used for a variety of disorders that primarily affect a child’s movements. These disorders are caused by an impairment of brain function before birth or early in life. Depending on its location and severity, the brain impairment may also cause other developmental problems (including mental retardation, seizures, language disorders, learning disabilities, and vision and hearing problems). Some

parents, therefore, may have only checked a certain primary problem with the understanding that various problems are part of this disorder. Others may have checked various additional problems to describe the full nature of their child's condition, some of which may be part of the primary problem.

These data (particularly in Table 2) about the children's primary and additional problems dispel some myths about children with disabilities, and about what the "diagnostic" label may mean. For example, as outlined above, saying that children have cerebral palsy (or a syndrome, or PDD, or developmental coordination disorder) does not mean they have "just" that disorder. Children with a primary problem of a communication disorder have other problems as well. Most children with a disability experience a cluster of health and development problems, and the "diagnostic" label does not necessarily reflect the extent of children's developmental or functional problems.

In summary, the data in Tables 1 and 2 tell us that:

- ◆ *few children with disabilities have only a single health or development problem*
- ◆ *over half of the children have three or more problems*
- ◆ *children with disabilities have multiple and varying needs*

B. The Families

The data in Table 3 show that the families completing this survey live primarily in urban (small or large) communities. Most respondents (85.4%) are from two-parent families. English is spoken in 94.7% of the homes, and most families have one or two children (64.8%) living at home. Most families (85.2%) have one child with a disability, while 14.5% have two or more children with disabilities.

The natural mother completed the survey most often (86.4%). The majority of the respondents are in their 30s (54.5%) or 40s (32.6%), and most respondents (72.3%) have received education beyond high school. A majority of the respondents (61.7%) were employed at the time of the survey, while 77.1% of the respondents' partners (when applicable) were employed. Most families (53.4%) have an income between \$30,000 and \$75,000. Approximately 20% of respondents belong to a parent support group.

Table 3

What Do We Know about the Families and Respondents?

Type of Community		Age of Respondent		
Major urban	38.9	20 - 29 years	7.9	
Small urban	41.1	30 - 39 years	54.5	
Rural	18.8	40 - 49 years	32.6	
Missing	1.2	50 - 59 years	3.6	
		≥ 60 years	0.4	
		Missing	1.0	
Family Type		Educational Level of Parents		
Two-parent family	85.4		Mother	Father
Single-parent family	14.4	Elementary	1.0	2.2
Missing	0.2	Some high school	5.3	8.1
		Completed high school	20.2	15.0
		Some college/technical training	13.2	9.7
		Completed college/ tech. training	32.0	22.7
		Some university	7.3	5.5
		Completed university	18.8	21.5
		Missing	1.2	2.6
		N/A (single-parent family)	1.0	12.8
Language Spoken at Home		Employment Status		
English	94.7	Respondent employed	61.7	
French	2.4	Spouse employed (where applicable)	77.1	
Other	1.0	Missing	2.6	
Missing	1.8			
Total Number of Children at Home		Family Income		
1 child	22.5	< \$15, 000	6.1	
2 children	42.3	\$15, 000 - 29, 999	11.7	
3 children	26.7	\$30, 000 - 44, 999	16.8	
≥ 4 children	8.3	\$45, 000 - 59, 999	18.0	
Missing	0.2	\$60, 000 - 74, 999	18.6	
		≥ 75, 000	23.1	
		Chose not to provide	1.4	
		Missing	4.3	
Number of Children with a Disability		Belong to a Parent Support Group		
1 child	85.2	No	77.9	
2 children	11.7	Yes	20.4	
3 children	1.8	Missing	1.6	
4 children	0.8			
6 children	0.2			
Missing	0.2			
Relationship of Respondent to Child				
Natural mother	86.4			
Natural father	5.7			
Adoptive mother	5.3			
Foster mother	1.6			
Stepfather	0.2			
Missing	0.8			

In summary, the data in Table 3 tell us that:

- ◆ *most families have only one child with a disability and most of these families have additional children at home*
- ◆ *most respondents were employed mothers over 30 years of age who had completed high school or more years of education*

Commentary:

These findings about the sociodemographic features of the families in this survey are generally comparable to other studies of families of children with disabilities conducted in Ontario (Cadman, Rosenbaum, Boyle, & Offord, 1991; King, King, Rosenbaum, & Goffin, 1999; King, Rosenbaum, & King, 1996, 1997). Inspection of Statistics Canada data on marital status, employment status, and income show that families in this survey are similar to others in the province except that they have a child with a disability, and the additional concerns and challenges that this situation presents (Statistics Canada, 1998). They might be slightly more educated. In summary, a comparison with other Ontario data suggests that this sample is representative of families of children with disabilities receiving services in Ontario, and of Canadian families in general.

C. Services Received

What Services Did Children Receive?

The most frequent types of services received by these children in the past year were occupational therapy (67.8%), speech-language pathology (53.6%), physiotherapy (53.0%), visits to a pediatrician (49.4%) and visits to the family physician (49.0%). We also know that 28.5% did not receive the services of a pediatrician nor a family physician in the past year. Several services were received by relatively few (by $\leq 10\%$ of the sample). These include genetic counseling, nursing, nutrition, psychology/psy-chometry, social work or counseling, technology access, and transition services. Details about the frequency of all services received are listed in Table 4. It should be noted that the list of services to which parents responded contained mostly health and rehabilitation, and some educational services. Other kinds of services (e.g., community and social services) were not addressed in this survey.

In this sample, 27.1% of the families were involved in at least one “alternative” or complementary therapy such as visits to a chiropractor (11.3%), herbal medicine (6.9%), homeopathic medicine (5.7%), vitamin therapy (4.5%), massage therapy/Shiatsu (3.4%), and craniosacral therapy (3.2%). Other alternative therapies were accessed by less than 3% of the sample.

Table 4

What Services Did Children Receive and How Often?

Service Received	n	% of total N	How Often the Service Was Received (in %s)		
			Occasionally*	Once/month	> Once/month
Audiology	129	26.1	89.2	2.3	4.7
Augmentative communication	65	13.2	55.3	12.3	29.2
Dentistry (specialized)	81	16.4	87.6	3.7	3.7
Early childhood education	65	13.2	3.0	3.1	90.8
Family physician	242	49.0	78.1	9.9	6.2
Genetic counselling	43	8.7	95.4	0.0	0.0
Medical clinics/services	135	27.3	75.6	12.6	6.7
Nursing	39	7.9	23.1	2.6	74.4
Nutrition	50	10.1	66.0	14.0	16.0
Occupational therapy	335	67.8	40.6	20.9	34.9
Optometry	115	23.3	93.0	2.6	0.9
Orthotics/Prosthetics	145	29.4	89.7	2.1	2.8
Pediatrician	244	49.4	76.2	13.9	6.6
Physiotherapy	262	53.0	39.7	19.5	37.4
Psychology/Psychometry	44	8.9	77.3	6.8	9.1
Recreation therapy	63	12.8	17.4	7.9	66.7
Rehabilitation engineering	64	13.0	86.0	1.6	9.4
Resource teaching	140	28.3	7.1	6.4	78.6
Serv. coordination/Case management	107	21.7	66.3	12.1	16.8
Social work or counselling	42	8.5	33.3	16.7	42.9
Specialized Services at Home	148	30.0	2.8	4.7	85.1
Speech-language pathology	265	53.6	32.5	13.6	48.1
Technology access	17	3.4	64.7	5.9	29.4
Transition services	9	1.8	66.6	0.0	11.1
Other **	73	14.8	43.9	16.4	34.2

The percentages (reading across from columns “Occasionally” to “> Once/month”) add to approximately 100% due to rounding and missing data for some services.

* Two response options (“once a year or less” and “a few times a year”) were combined and called “Occasionally”.

** This category was created for responses that did not fit the options provided to the respondent.

How Often Were Services Received?

In Table 4, we see that many services were received “occasionally” by a high proportion (>66%) of children. Also, a high proportion of children received some services frequently (i.e., great than once/month). These services include early childhood education, nursing, recreation therapy, resource teaching, and the Specialized Services at Home Program. Over half of the children received the most frequently received services (i.e., occupational therapy, speech-language pathology, physiotherapy) once a month or more often.

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

- ◆ *many different services are accessed to meet the needs of children with disabilities*
- ◆ *numerous services are provided on a regular basis (once a month or more often)*
- ◆ *the most frequently received services are occupational therapy, speech language pathology, and physiotherapy*

How Many Services Were Received and How Many Locations Were Used?

The data presented in Table 4 tell us the proportion of children who received certain services. Using that information, we determined how many different services each child received in the past year. Table 5 shows that a small percentage of children (9.5%) received only one service, while the vast majority of children received 2 or more services, including 42.1% who received 7 or more services.

Table 5

How Many Services Were Received and How Many Locations Were Used?

Number of Services Received		Number of Locations Services Received from	
1 service only	9.5	1 location	16.8
2 - 3 services	19.8	2 - 3 locations	27.1
4 - 6 services	27.9	4 - 6 locations	41.1
≥ 7 services	42.1	≥ 7 locations	14.4
Missing6	Missing6

Parents also were asked to indicate from where the services were received using categories such as community care access centre, community living association, hospital or clinic (either local or outside their region), chil-

dren's treatment/rehabilitation centre, private agency and school. We calculated the total number of locations by adding all the different places used. The results show that a small number of children (16.8%) received their services from only one location. Most children received their services from 2-6 different locations (68.2%), while some children (14.4%) went to 7 or more locations for services. Analysis shows that there is a statistically significant and high correlation between services and locations ($r_{492} = .79, p = .000$). This very close relationship means that as children receive more services, they almost always go to more places for these services.

Commentary:

It is important to note that the number of services received includes both frequently occurring as well as less frequently occurring services. One could remove the infrequent services from this number, however this would not present the reality of all the services that children receive, and the full impact that this has on both the children themselves and their parents. The fact is that families deal with multiple service providers and multiple service locations.

In summary, the data in Table 5 tell us that:

- ◆ *the majority of children receive many services from many different places or agencies*
- ◆ *as the number of services increases, so does the number of locations used; this is almost a direct linear relationship*

How Many Services Were Received by Children with Each Primary Problem?

While Table 5 showed the number of services received for the whole sample, Table 6 presents the percentages of children with each primary problem who received 1 service, 2-3 services, 4-6 services or 7 or more services in the past year. For all primary problems (except communication disorder), the majority of children received four or more services. Approximately $\frac{1}{3}$ of the children with communication disorder received only one service.

Table 6

How Many Services Were Received by Children with Each Primary Problem?

Primary Problem	Number of Services Received			
	1 Service	2 - 3 Services	4 - 6 Services	≥ 7 Services
Acquired brain injury (n=15)	0.0	0.0	40.0	60.0
Autism/Pervasive developmental disorder (n=25)	12.5	16.7	29.2	41.7
Cerebral palsy (n=125)	0.8	18.4	28.0	52.8
Communication disorder (n=62)	37.7	23.0	31.1	8.2
Developmental coordination disorder (n=11)	9.1	36.4	18.2	36.4
Developmental delay (n=67)	9.0	17.9	26.9	46.3
Muscle disease (n=11)	0.0	9.1	36.4	54.5
Spina bifida/ Hydrocephalus (n=32)	6.3	21.9	28.1	43.8
Syndrome (n=61)	1.6	18.0	24.6	55.7

For each Primary Problem, the percentages in the rows add to approximately 100% due to rounding.

In summary, the data in Table 6 tell us that:

- ◆ *while most children receive many services, there is considerable variability in the service needs of children with different primary problems*

How Many Services Were Received by Children of Various Ages and Primary Problems?

Table 7 shows the number of services received and the age groupings of the children for certain primary problems. We can see, for example, that of the young children with cerebral palsy, 13.8% received 3 or fewer services, 27.6% received 4-6 services, and 58.6% received 7 or more services. This is similar to those 5-12 years, but there is a higher proportion of older children (over 13 years) who received three or fewer services compared with young children. Most children with a syndrome, no matter what age, received many services.

Table 7

How Many Services Were Received by Children of Various Ages and Primary Problems?

Primary Problem*	Age Group	(n)	Number of Services Received			
			1 Service	2 - 3 Services	4 - 6 Services	≥ 7 Services
Cerebral palsy (n=125)	0-4 yrs	(29)	0.0	13.8	27.6	58.6
	5-12 yrs	(64)	0.0	15.6	26.6	57.8
	13-16 yrs.	(24)	4.2	29.2	25.0	41.7
	≥ 17 yrs.	(8)	0.0	25.0	50.0	25.0
Developmental delay (n=67)	0-4 yrs	(23)	4.3	26.1	8.7	60.9
	5-12 yrs	(37)	10.8	13.5	32.4	43.2
	13-16 yrs.	(7)	14.3	14.3	57.1	14.3
	≥ 17 yrs.	(0)	–	–	–	–
Communication disorder (n=62)	0-4 yrs	(15)	26.7	26.7	33.3	13.3
	5-12 yrs	(41)	37.5	22.5	35.0	5.0
	13-16 yrs.	(5)	60.0	20.0	0.0	20.0
	≥ 17 yrs.	(1)	100.0	0.0	0.0	0.0
Syndrome (n=61)	0-4 yrs	(8)	0.0	0.0	25.0	75.0
	5-12 yrs	(45)	0.0	22.2	22.2	55.6
	13-16 yrs.	(6)	0.0	0.0	50.0	50.0
	≥ 17 yrs.	(2)	50.0	50.0	0.0	0.0
Spina bifida / Hydrocephalus (n=32)	0-4 yrs	(11)	0.0	9.1	45.5	45.5
	5-12 yrs	(9)	11.1	44.4	11.1	33.3
	13-16 yrs.	(9)	11.1	22.2	22.2	44.4
	≥ 17 yrs.	(3)	0.0	0.0	33.3	66.7

* Includes only the 5 most common problems since the breakdown by service and age becomes less meaningful when numbers are so small.

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

- ◆ *the number of services children received varies by age*
- ◆ *this variation by age occurs both within and between groups of children with certain primary problems*
- ◆ *children continue to receive services into and through adolescence, suggesting that their problems are long-term*

What Are the Children with Various Primary Health or Development Problems Like?

Table 8 presents information on several features about children with each primary health or development problem whose families participated in this survey. These features include the average age of the children with the problem, what kinds of additional problems they have, what services they received in the past year, how many services they received, and how many locations they used to obtain these services. Reading across the row for any primary problem gives a profile of the children with this problem, and brings together some of the findings presented in previous tables.

Within any given primary problem, there is a cluster of additional health or development problems. Developmental delay, communication/speech delay, and learning disorders are experienced by a substantial percentage of children within most of the primary problem groups. This highlights the complexity of children’s needs which is reflected in the various and numerous services they receive.

Commentary:

From a review of the information in Table 8, it becomes apparent that broad category labels such as “cerebral palsy” or “syndrome” do not convey a true sense of the complexity associated with these conditions. Note as well that there is a lot of variation both within and across these categories, illustrating the importance of seeing each child as a unique individual. Equally important in these profiles is the picture of potential challenges faced by parents raising a child whose development can be very different from that of a “typical” child.

In summary, the data in Table 8 tell us that:

- ◆ *children have complex needs*
- ◆ *the diagnostic labels used for children’s problems may not adequately describe their unique needs and situations*

Table 8
A Profile of Children

Primary Problem	Child's Age (Average)	Additional Problems (Displays only 4 highest percentages)	Services Received (Displays those with $\geq 33\%$)	Number of Services Received				Number of Locations Used			
				1	2-3	4-6	≥ 7	1	2-3	4-6	≥ 7
Acquired brain injury (n=15)	9.0	66.7 have Developmental delay 46.7 have Communication/Speech delay 46.7 have Visual impairment 40.0 have Learning disorder	80.0 received Occupational therapy 80.0 received Physiotherapy 73.3 received Speech-language pathology 66.7 visited Family physician 46.7 visited Pediatrician 40.0 received Orthotics/Prosthetics 33.3 received Audiology 33.3 received Optometry 33.3 received Rehabilitation engineering 33.3 received Resource teaching 33.3 received Specialized Services at Home Program	0.0	0.0	40.0	60.0	0.0	20.0	53.3	26.7
Autism/ Pervasive developmental disorder (n=25)	7.4	68.0 have Communication/Speech delay 60.0 have Developmental delay 32.0 have Learning disorder 20.0 have Behavioural disorder	72.0 received Speech-language pathology 68.0 received Specialized Services at Home Program 56.0 received Occupational therapy 40.0 visited Family physician 40.0 visited Pediatrician	12.0	16.0	28.0	40.0	12.0	32.0	36.0	16.0
Cerebral palsy (n=125)	9.3	47.2 have Developmental delay 41.6 have Communication/Speech delay 28.8 have Visual impairment 28.0 have Learning disorder	84.0 received Occupational therapy 84.0 received Physiotherapy 60.0 visited Family physician 55.2 received Orthotics/Prosthetics 52.0 visited Pediatrician 36.8 received Speech-language pathology 34.4 received Specialized Services at Home Program	0.8	18.4	28.0	52.8	10.4	24.8	48.0	16.8
Communication disorder (n=62)	7.5	19.4 have Developmental delay 19.4 have Hearing loss 19.4 have Learning disorder 14.5 have Behavioural disorder	91.9 received Speech-language pathology 35.5 received Audiology	37.1	22.6	30.6	8.1	45.2	25.8	25.8	1.6
Developmental coordination disorder (n=11)	8.0	63.6 have Learning disorder 45.5 have Behavioural disorder 27.3 have Developmental delay 27.3 have Communication/Speech delay	100.0 received Occupational therapy 54.5 received Resource teaching 45.5 visited Family physician 45.5 received Physiotherapy	9.1	36.4	18.2	36.4	18.2	63.6	18.2	0.0

Primary Problem	Child's Age (Average)	Additional Problems (Displays only 4 highest percentages)	Services Received (Displays those with ≥ 33%)	Number of Services Received				Number of Locations Used			
				1	2-3	4-6	≥7	1	2-3	4-6	≥7
Developmental delay (n=67)	7.0	71.6 have Communication/Speech delay 37.3 have Learning disorder 19.4 have Epilepsy or seizure disorder 16.4 have Visual impairment 16.4 have Behavioural disorder	74.6 received Speech-language pathology 71.6 received Occupational therapy 49.3 received Physiotherapy 49.3 visited Pediatrician 46.3 visited Family physician 37.3 received Audiology 34.3 received Resource teaching	9.0	17.9	26.9	46.3	16.4	28.4	46.3	9.0
Muscle disease (n=11)	9.4	36.4 have Developmental delay 36.4 have Communication/Speech delay 27.3 have Behavioural disorder 9.1 have Hearing loss 9.1 have Learning disorder	81.8 visited Pediatrician 72.7 received Physiotherapy 54.5 received Speech-language pathology 54.5 visited Medical services/clinics 36.4 visited Family physician 36.4 received Genetic counselling 36.4 received Orthotics/prosthetics	0.0	9.1	36.4	54.5	0.0	36.4	54.5	9.1
Spina bifida/ Hydrocephalus (n=32)	9.4	43.8 have Developmental delay 40.6 have Learning disorder 28.1 have Visual impairment 25.0 have Communication/Speech delay	65.6 received Physiotherapy 62.5 received Occupational therapy 59.4 visited Medical services/clinics 56.3 visited Family physician 50.0 received Orthotics/Prosthetics 46.9 visited Pediatrician 37.5 received Specialized Services at Home Program 34.4 received Resource teaching	6.3	21.9	28.1	43.8	18.8	21.9	50.0	9.4
Syndrome (n=61)	8.7	70.5 have Communication/Speech delay 68.9 have Developmental delay 44.3 have Learning disorder 34.4 have Visual impairment	83.6 received Occupational therapy 65.6 visited Pediatrician 59.0 received Speech-language pathology 57.4 visited Family physician 50.8 received Physiotherapy 45.9 received Audiology 42.6 received Optometry 42.6 received Specialized Services at Home Program 41.0 received Resource teaching	1.6	18.0	24.6	55.7	9.8	16.4	45.9	27.9

For the Most Frequently Received Services, From Where Did Children Receive Them and How Old Are These Children?

We examined more closely those services that were received most frequently - i.e, occupational therapy (OT), speech-language pathology (SLP), and physiotherapy (PT). We wanted to see from where the children received these services, and whether there were differences in relation to the children's ages. The data in Table 9 show that most preschoolers received services through children's treatment centres (CTCs), while most school age children (5-12 years) received services either through CCACs or CTCs. Some children receiving SLP were provided this service through their school. Adolescents received fewer of these services (OT, SLP or PT) than children in the other age categories. For adolescents receiving OT or PT, most of these services were provided through CCACs or CTCs, while for those receiving SLP over half received this service through a CCAC.

Table 9

For the Most Frequently Received Services, From Where Did Children Receive Them and How Old Are These Children?

Age of Child	Service*	n	Locations/Coordinating Agencies*									
			CCAC		CTC		School		Combination*		Other**	
			n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
0-4 years	OT	71	7	(9.9)	55	(77.5)	0	(0.0)	3	(4.2)	6	(8.5)
	SLP	85	15	(19.7)	60	(70.6)	0	(0.0)	3	(3.5)	7	(8.2)
	PT	73	10	(13.7)	56	(76.7)	0	(0.0)	4	(5.5)	3	(4.1)
5-12 years	OT	200	88	(44.0)	93	(46.5)	3	(1.5)	12	(6.0)	4	(2.0)
	SLP	146	48	(32.9)	57	(39.0)	20	(13.7)	6	(4.1)	15	(10.3)
	PT	137	51	(37.2)	69	(50.4)	2	(1.5)	8	(5.8)	7	(5.1)
13-16 years	OT	43	17	(39.5)	21	(48.8)	0	(0.0)	4	(9.3)	1	(2.3)
	SLP	17	10	(58.8)	2	(11.8)	1	(5.9)	3	(17.6)	1	(5.9)
	PT	34	11	(32.4)	16	(47.1)	1	(2.9)	2	(5.9)	4	(11.8)
17 or more years	OT	16	8	(50.0)	7	(43.8)	0	(0.0)	1	(6.3)	0	(0.0)
	SLP	6	3	(50.0)	1	(16.7)	1	(16.7)	0	(0.0)	1	(16.7)
	PT	12	5	(41.7)	5	(41.7)	0	(0.0)	0	(0.0)	2	(16.7)

• Services: OT = Occupational therapy; SLP = Speech-language pathology; PT = Physiotherapy

▪ Locations: CCAC = Community Care Access Centre; CTC = Children's Treatment Centre

* Some children received a single service at multiple locations or had the service coordinated by more than one agency, described as combination of locations.

** Total of all other locations/agencies combined.

In summary, the data in Table 9 tell us that:

- ◆ *most preschoolers received OT, SLP or PT services from children's treatment centres*
- ◆ *most children 6 years or older received OT, SLP or PT services from children's treatment centres or community care access centres; this varies by age and type of service*

SUMMARY

This survey provides detailed information about children with disabilities and their families, and the services they received in the past year. The sample is generally representative of children with disabilities and their families in Ontario. The data show that service delivery is a complex issue.

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 Children with Disabilities Tell Us that:**
- ◆ *children with disabilities have multiple, varying and complex needs*
 - *few children have only a single health or development problem*
 - *over half of the children have 3 or more problems*
 - ◆ *children continue to receive services into and through adolescence, suggesting that their problems are long-term*
 - ◆ *the diagnostic labels used for children's problems may not adequately describe their unique needs and situations*
- The Findings about the Families Tell Us that:**
- ◆ *most families have only one child with a disability and most of these families have additional children at home*
 - ◆ *most respondents were employed mothers over 30 years of age who had completed high school or more years of education*
- The Findings about the Services that Children and Families Received Tell Us that:**
- ◆ *many different services are accessed to meet the needs of children with disabilities*
 - ◆ *numerous services are provided on a regular basis (once a month or more often)*
 - ◆ *the most frequently received services are occupational therapy (OT), speech-language pathology (SLP), and physiotherapy (PT)*
 - *most preschoolers received OT, SLP or PT services from children's treatment centres*
 - *most children 6 years or older received OT, SLP or PT services from children's treatment centres or community care access centres; this varies by age and type of service*
 - ◆ *the majority of children receive many services from many different places or agencies*
 - *as the number of services increases, so does the number of*

- *locations used; this is almost a direct linear relationship*
- *the number of services children received varies by age and this variation occurs both within and between groups of children with certain primary problems*
- *while most children receive many services, there is considerable variability in the service needs of children with different primary problems*

How Will the Findings Be Useful?

- For **parents**, the findings will be useful in these ways...
- ✓ The findings suggest that many parents likely face **similar issues** in parenting a child with multiple, complex needs (few children have a single health or development problem). Although the needs of individual children vary, the complexity of their needs is something that many families have in common.
 - ✓ Because children's needs often are long-term and complex, families should be prompted by the findings to plan for their child's continuing needs.
 - ✓ The findings confirm parents' often-mentioned perception that they need to go to many locations for services for their child. Information about the complex and continuing needs of children, and about the multiple locations accessed for services, supports the view that service coordination is of utmost importance for these families.
- For **service providers and administrative decision makers**, the findings will be useful in these ways...
- ✓ The findings provide useful information about the nature of the children who receive services and the types of services offered across Ontario; this information can be used in **developing programs** to address gaps in service delivery.
 - ✓ The findings suggest that, due to the complex nature of their needs, it is important to continue to provide **comprehensive and individualized services** for children with disabilities. This further implies that therapists and clinicians require **specialized expertise and experience** to deliver effective services.
 - ✓ As many service providers and managers are already aware, diagnostic labels often may not adequately describe the unique needs and situations of children. The information in this report could be used to develop **"profiles" of children's needs and services** that more adequately reflect the complexities.
- For **legislative policy makers**, the findings will be useful in these ways...
- ✓ The findings show that services currently are accessed from many locations, which likely means that parents do not perceive services as well-coordinated (an issue to be addressed in later reports in this series). This has implications for **interagency coordination** of service delivery.
 - ✓ The findings can be used to explore whether certain groups of children are under-served, with corresponding implications for system-wide **program development and funding**.

A LOOK FORWARD

The data presented in this Part 1 report focus on children with disabilities, their families and the services they received. As noted at the beginning of this document, there will be two other parts that will report on our survey about service delivery for children with disabilities in Ontario.

In Part 2:

We will provide information about the service providers who completed the survey, and background information about the centres/organizations which responded to the survey. We will describe the measures that were used to assess perceptions of service delivery from the perspectives of parents and service providers.

Here are some highlights from Part 2:

- Family-centred service is highly valued by both parents and service providers.
- Both parents and service providers indicate that the following aspects of family-centred service are being done well - Enabling and Partnership, Providing Specific Information about the Child, and Respectful and Supportive Care.
- Data from parents demonstrate improvements in the following aspects of family-centred service - Enabling and Partnership, and Providing Specific Information about the Child.
- 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.

In Part 3:

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

Here are some highlights from Part 3:

- Parents report that services are less family-centred when their children receive services from a greater number of locations.
- 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.
- Service providers are more likely to report behaving in a family-centred manner when they feel they can implement family-centred service effectively.
- 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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<u>Location of Organization</u>	<u>Name of Organization</u>
Burlington	Community Care Access Centre 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