



CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Centre of Excellence for Children and Adolescents with Special Needs

Access, Use and Impact of Early Intervention
Services in Nova Scotia: A Parent Perspective

SpecialLink Symposium, Winnipeg, Manitoba

August 20-23 2008

www.coespecialneeds.ca

Production of this document has been made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

<<La production de ce document a été rendue possible grâce à une contribution financière provenant de l'agence de santé publique du Canada. Les vues exprimées ici ne représentent pas nécessairement les vues de l'Agence de santé publique du Canada.>>

Lakehead
UNIVERSITY



CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Presenters:

Kim Kienapple, Ph. D. Co-Director
Mount Saint Vincent University
Department of Child & Youth Study
Halifax, Nova Scotia

Adele McSorley, Site Coordinator
Mount Saint Vincent University
Halifax, Nova Scotia





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Our Structure

- Established in 2000
- Funded by the Public Health Agency of Canada
- National Children's Agenda
- Sponsored and administered by Lakehead University in Thunder Bay
- 5 equal national partners





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Mandate

To produce knowledge about children and adolescents with special needs in rural and northern Canada and transfer it to those who can use it to make a difference in the lives of these children

Target Audiences

Service providers, policy makers, parents, researchers





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Sample: Parents of preschool age children with special needs in Nova Scotia

Purpose:

- ☐ Determine what support services parents use
- ☐ How parents access services
- ☐ What difference those services make to parents and their children





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Questions:

1. Why do parents ask for help?
2. Who do parents go to for help?
3. What kind of help do parents want?
4. Which professionals and services do parents identify as most helpful and why?



CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Presentation Overview:

Disability Rates

Types of Early Support Services

Research Method

Results

Implications



Table 4
Type of disabilities among children with disabilities, by age group, Canada, 2006

| Type of disability | Age groups | | | | | |
|----------------------------|--------------------|-------------------|----------------|--------------|----------------|--------------|
| | 0 to 4 years | | 5 to 14 years | | Total | |
| | number | % | number | % | number | % |
| All categories | 27,540 | 100.0 | 174,810 | 100.0 | 202,350 | 100.0 |
| Hearing ¹ | 3,270 ^E | 11.9 ^E | 20,020 | 11.5 | 23,290 | 11.5 |
| Seeing ¹ | 3,030 ^E | 11.0 ^E | 16,680 | 9.5 | 19,710 | 9.7 |
| Speech ² | ... | ... | 78,240 | 44.8 | 78,240 | 44.8 |
| Mobility ² | ... | ... | 23,160 | 13.2 | 23,160 | 13.2 |
| Agility ² | ... | ... | 37,240 | 21.3 | 37,240 | 21.3 |
| Learning ² | ... | ... | 121,080 | 69.3 | 121,080 | 69.3 |
| Developmental ² | ... | ... | 53,740 | 30.7 | 53,740 | 30.7 |
| Psychological ² | ... | ... | 60,310 | 34.5 | 60,310 | 34.5 |
| Delay ³ | 17,090 | 62.1 | ... | ... | 17,090 | 62.1 |
| Chronic ¹ | 19,230 | 69.8 | 116,340 | 66.6 | 135,570 | 67.0 |
| Other ¹ | 1,810 ^E | 6.6 ^E | 6,290 | 3.6 | 8,100 | 4.0 |

Note: The sum of the categories is greater than the population with disabilities because persons could report more than one type of disability.

1. Applies to all children under 15.

2. Applies to all children aged 5 to 14.

3. Applies to children aged 0 to 4.

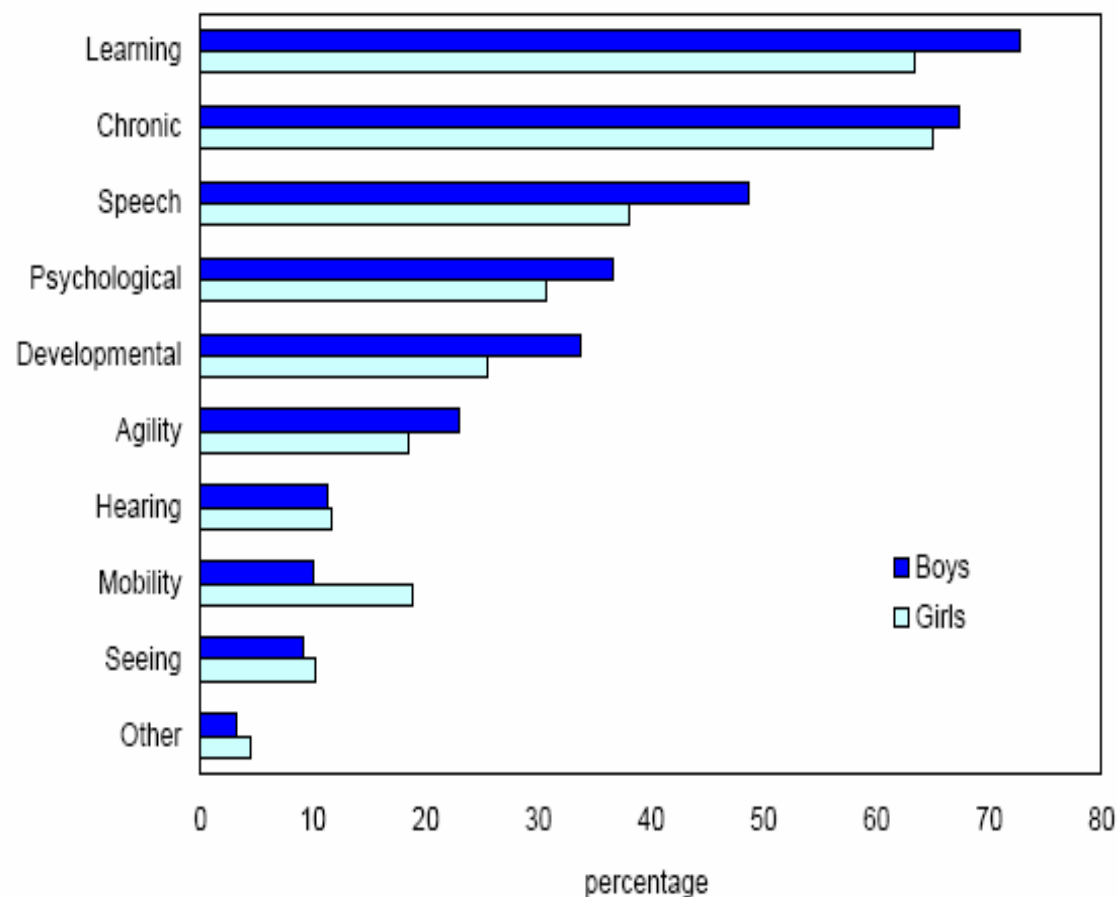
^E use with caution

... not applicable

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Chart 10

Types of disabilities among children with disabilities aged 5 to 14 years, by sex, Canada, 2006



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Table 5

Number of disabilities reported for children aged 0 to 4 years with disabilities, Canada, 2006

| Number of disabilities | Children aged 0 to 4 years with disabilities | |
|------------------------|--|--------------|
| | number | % |
| Total | 27,540 | 100.0 |
| One | 13,730 | 49.9 |
| Two | 11,360 | 41.2 |
| Three or more | 2,450 | 8.9 |

Note: The sum of the values for each category may differ from the total due to rounding.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.



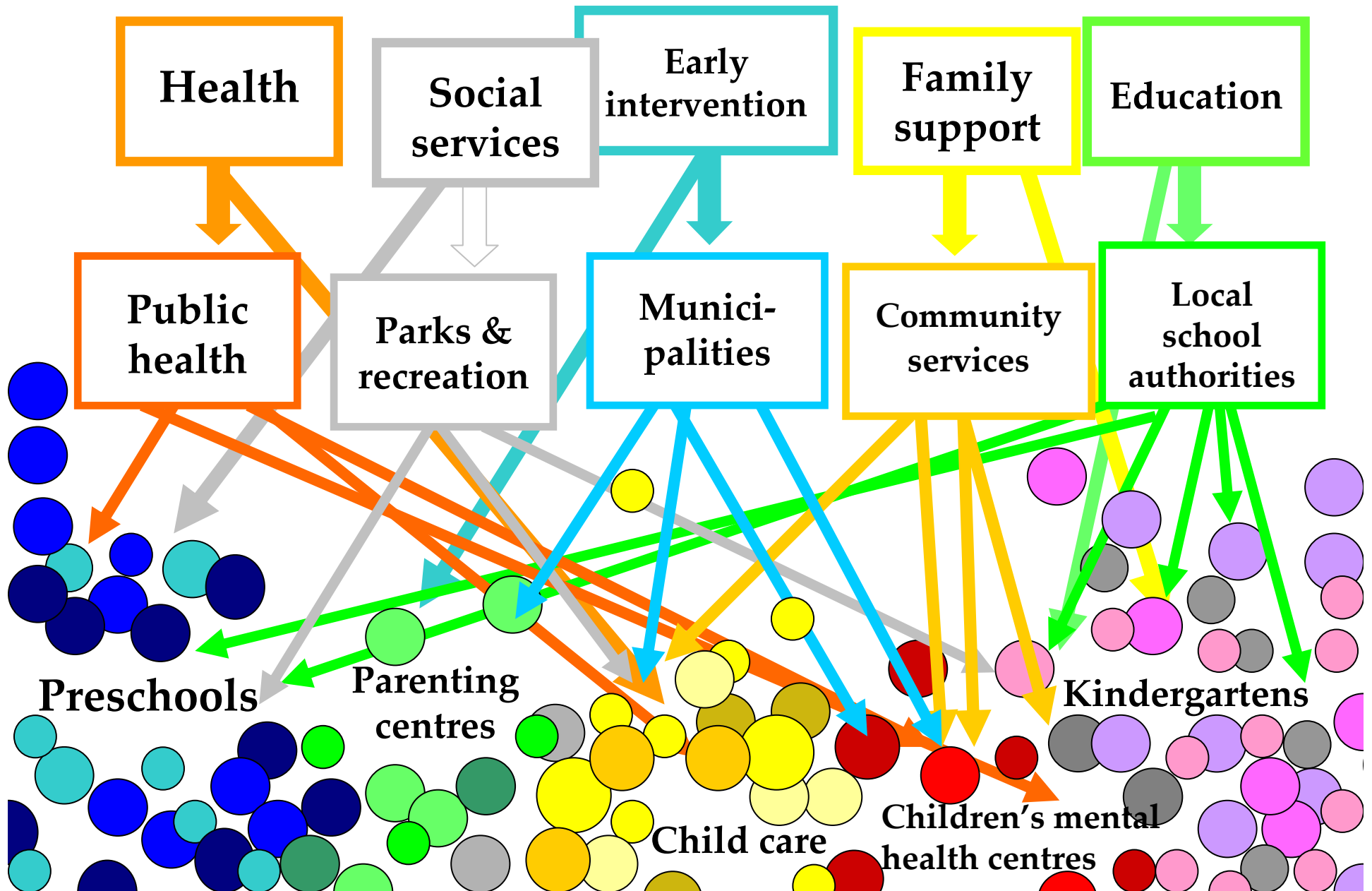
CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Types of Early Support Services



Chaos



Early Support Services in Nova Scotia:

- ☐ Assistive Technology
- ☐ Behavioural Therapy (EIBI,ABA,PRT)
- ☐ Child Care
- ☐ Early Intervention Programs
- ☐ Family Resource Programs
- ☐ Health Professionals
- ☐ Medical Care & Treatment
- ☐ Speech & Language Therapy
- ☐ Respite Care





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Child Care:

- ☐ Small businesses
 - ☐ Profit and nonprofit
 - ☐ Supported by fees & grants
 - ☐ **Fees paid by parents** or government on behalf of parents



Supports for children with special needs in child care programs:

- ☐ Supported Child Care
- ☐ Partnerships for Inclusion



Early Intervention Programs in Nova Scotia (18)

Early Intervention is

- ☐ *Provision of specialized services to families with children between birth and school age who are either at risk for or have a diagnosis of developmental delay*
- ☐ *Services emphasize the continued development of functional skills through planned interactions to minimize the effects of the child's condition*
- ☐ *Consultation, information, support and services designed to meet the individual needs of each child and family are delivered in the child's home and may be extended to community-based programs.*





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

Nova Scotia Early Intensive Behaviour Intervention Program for Young Children with Autistic Spectrum Disorder

- Pre-school children ***randomly selected*** from children diagnosed with autism
- divided into two groups of equal numbers
 - above age four
 - below age four

NS Early Intensive Behaviour Therapy:

- first six months for 15 hours per week
- gradually reduced over six months to
 - 10 hours per week for 3 months
 - 5-6 hours per week for next 3 months).
- Training provided to parents during the year
- After the first year:
 - children who do not enter school have six more months treatment.
 - children entering school have consultative services





Children and Adolescents with Special Needs

Research Method

- ☐ Survey Development
- ☐ Ethics Approval
- ☐ Identify & Contact Sample
- ☐ Participation
 - ☐ Internet
 - ☐ Printed Survey
 - ☐ Telephone Interview





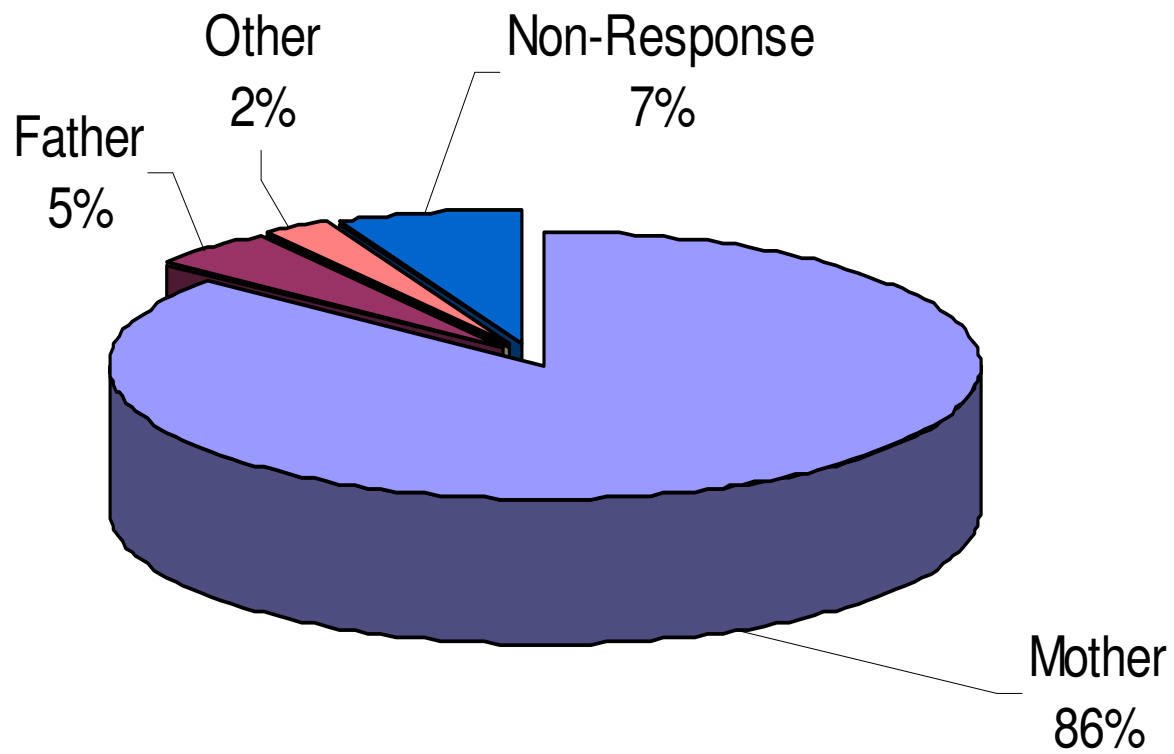
CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING

Children and Adolescents with Special Needs

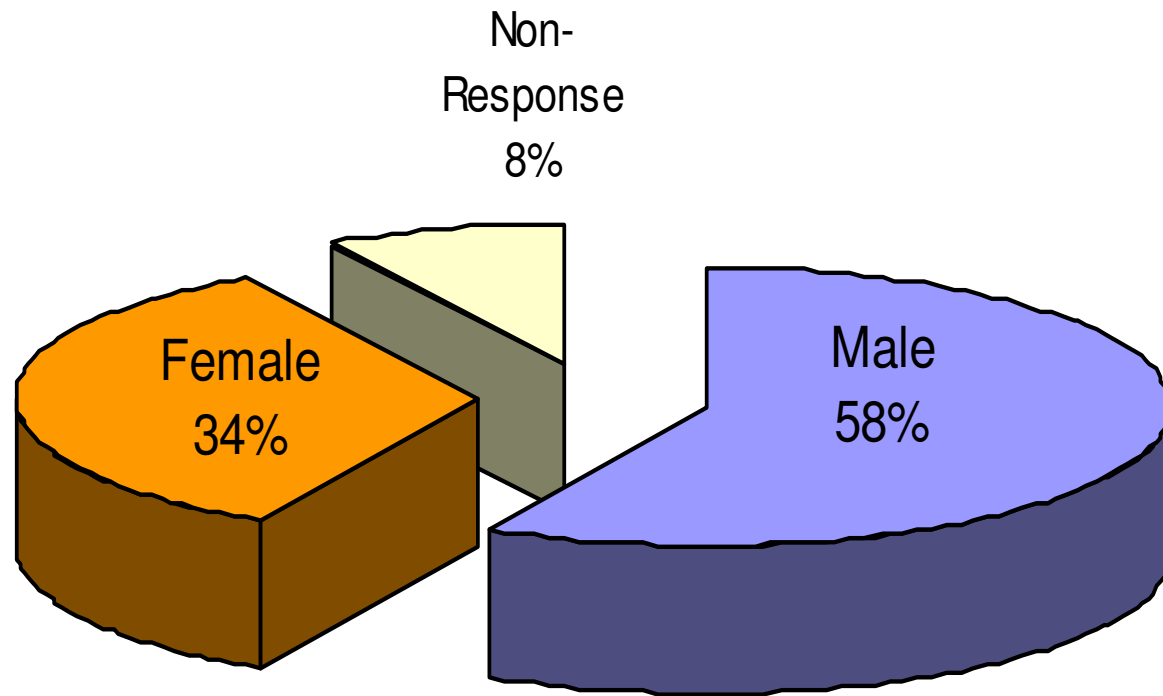
Question 1: Why do parents ask for help?



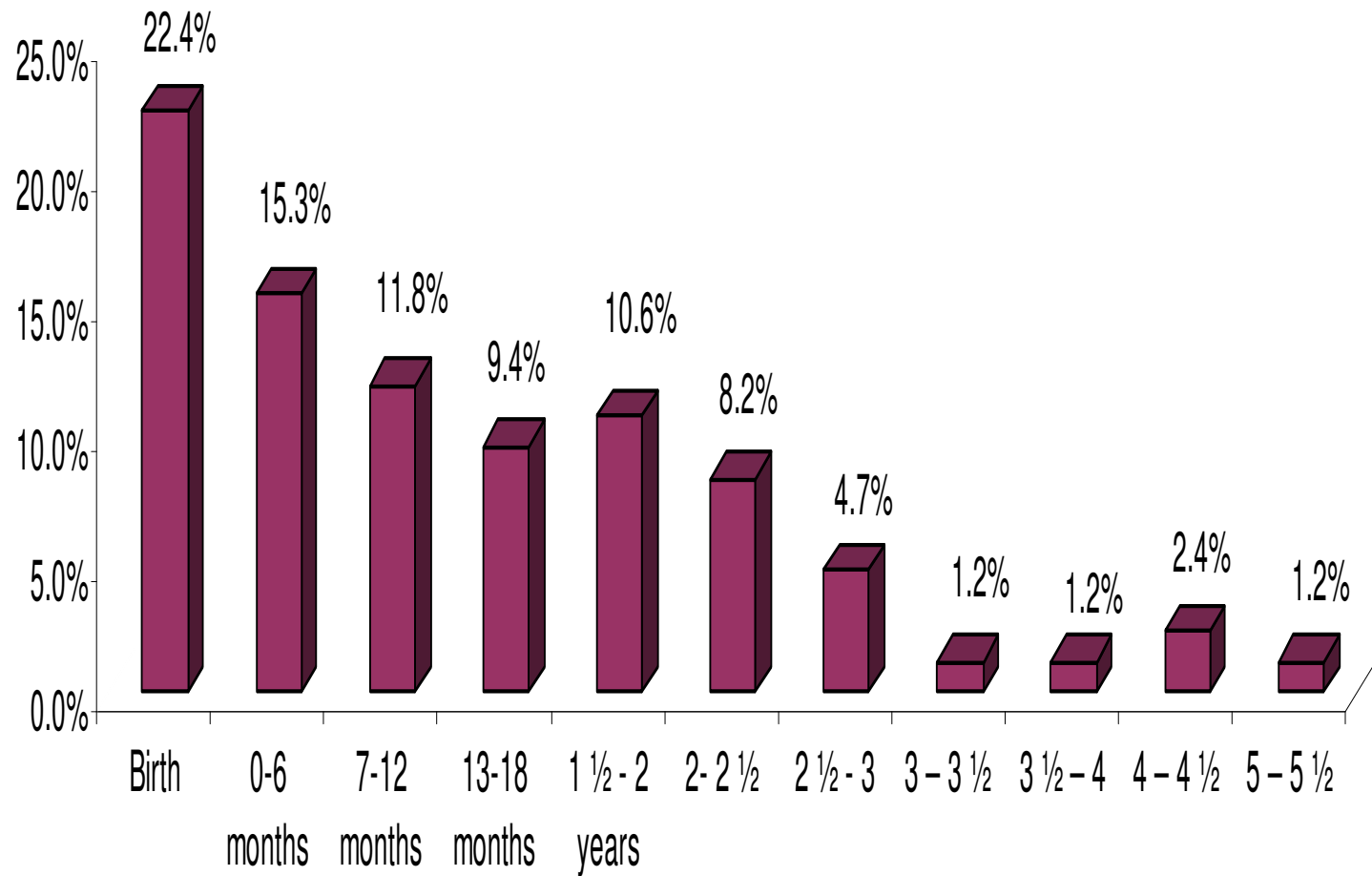
Who participated?



Child's Gender



How old was your child when you first had concerns?



Reasons for concern

- ❖ 1st month barely opened eyes ever
- ❖ Never started to use words till after 2 years old
- ❖ Seemed not to hear me when I spoke
- ❖ Always crying
- ❖ Frequent night terrors often very violent
- ❖ No compassion for animals- hurts them
- ❖ Doesn't sleep like a baby

...continued

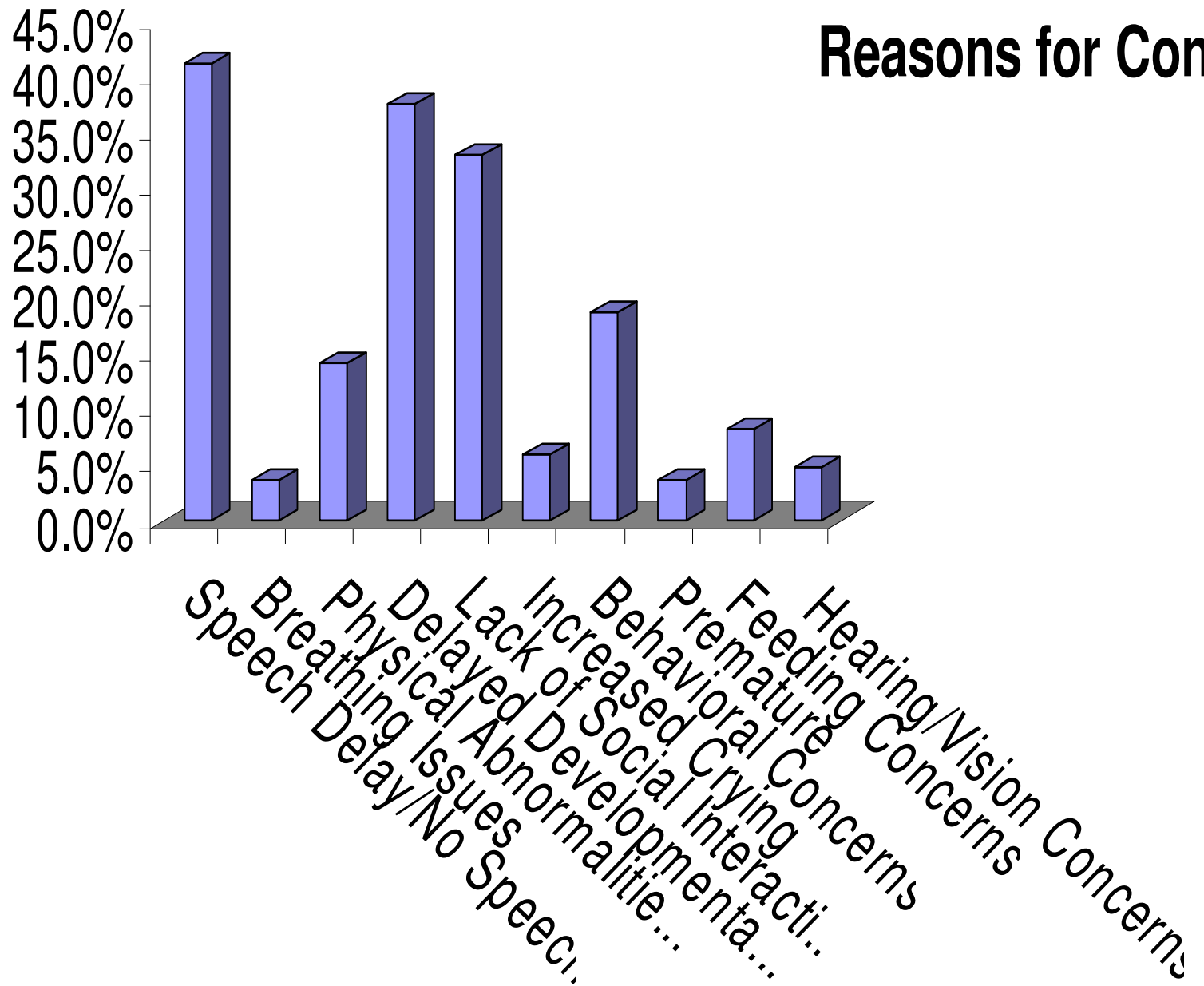


Reasons for concern

- ❖ Excelled through first year of life, then regressed significantly
- ❖ Didn't try to roll over, or sit up or really cry or babble
- ❖ No pointing
- ❖ Not talking, would only drink from one cup and use one particular bowl to eat from
- ❖ No eye contact, no answering to name after ruling out hearing problem, no pointing, no babbling, toe walking



Reasons for Concern





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Question 1: Why do Parents Ask for Help?

Answer: Interaction and Communication Concerns





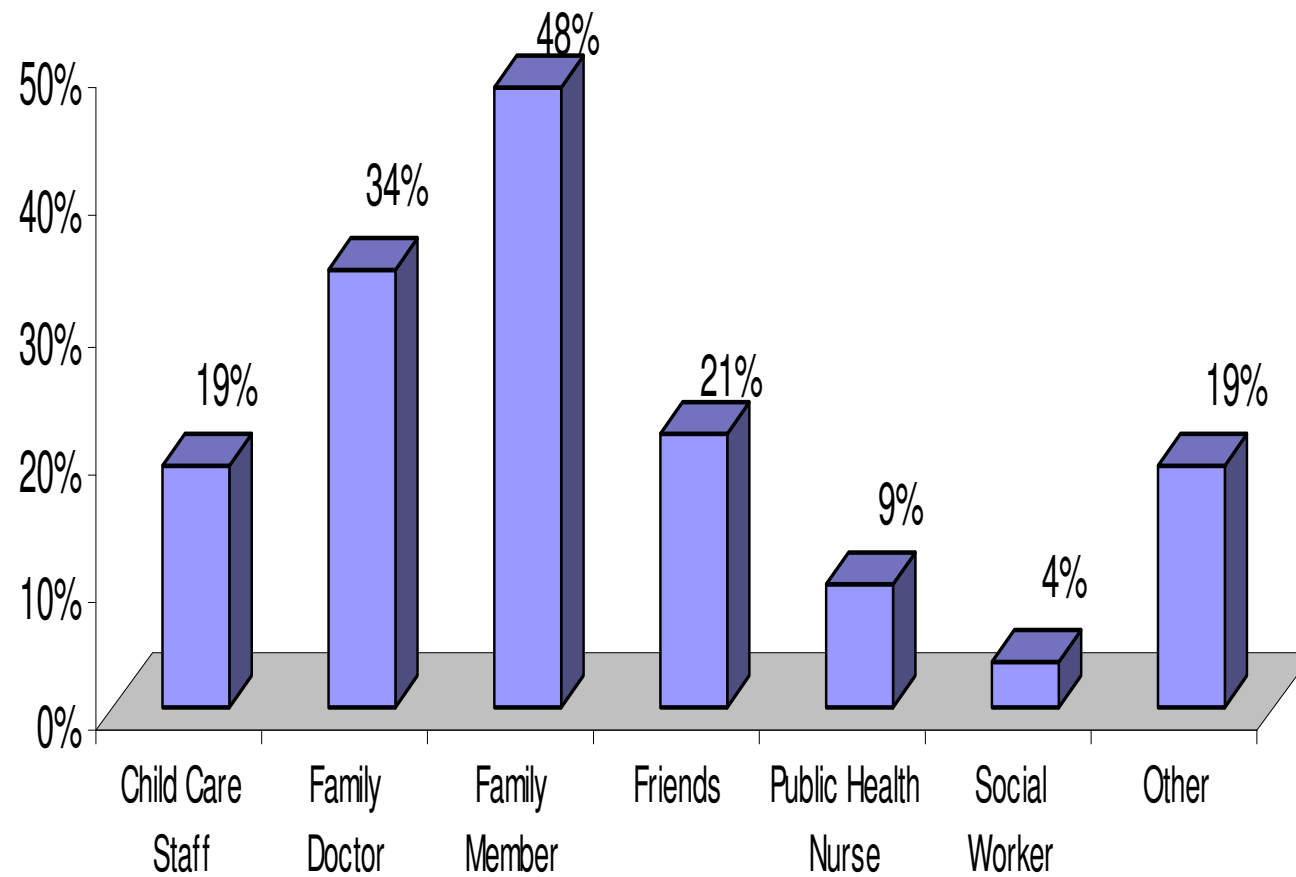
CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

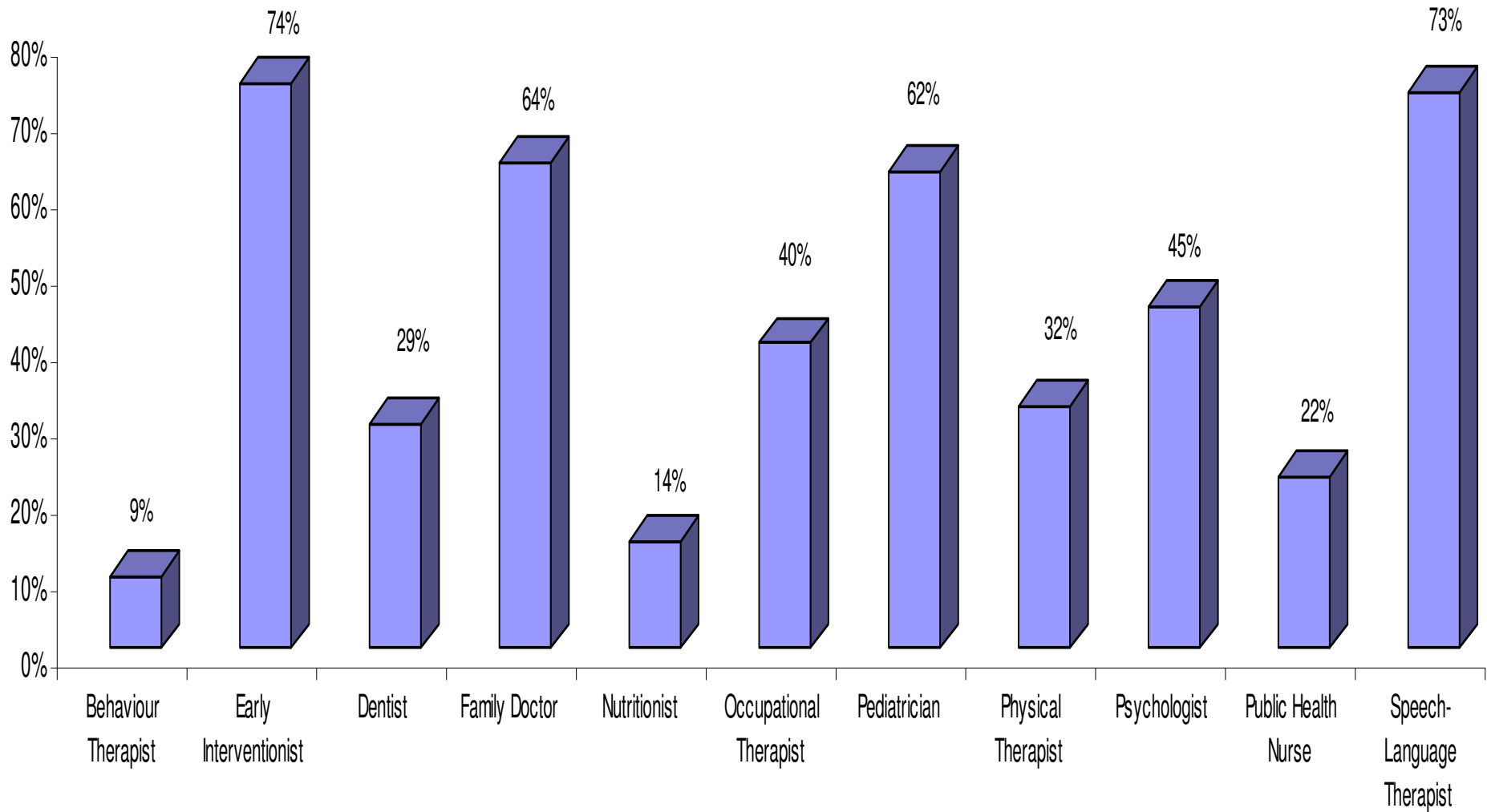
Question 2: Who do Parents go to for help?



Who else expressed concerns?



Professionals Visited





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Question 2: Who do parents ask for help?

Answer:

Early Interventionist

Speech-language Therapist

Family Doctor

Pediatrician





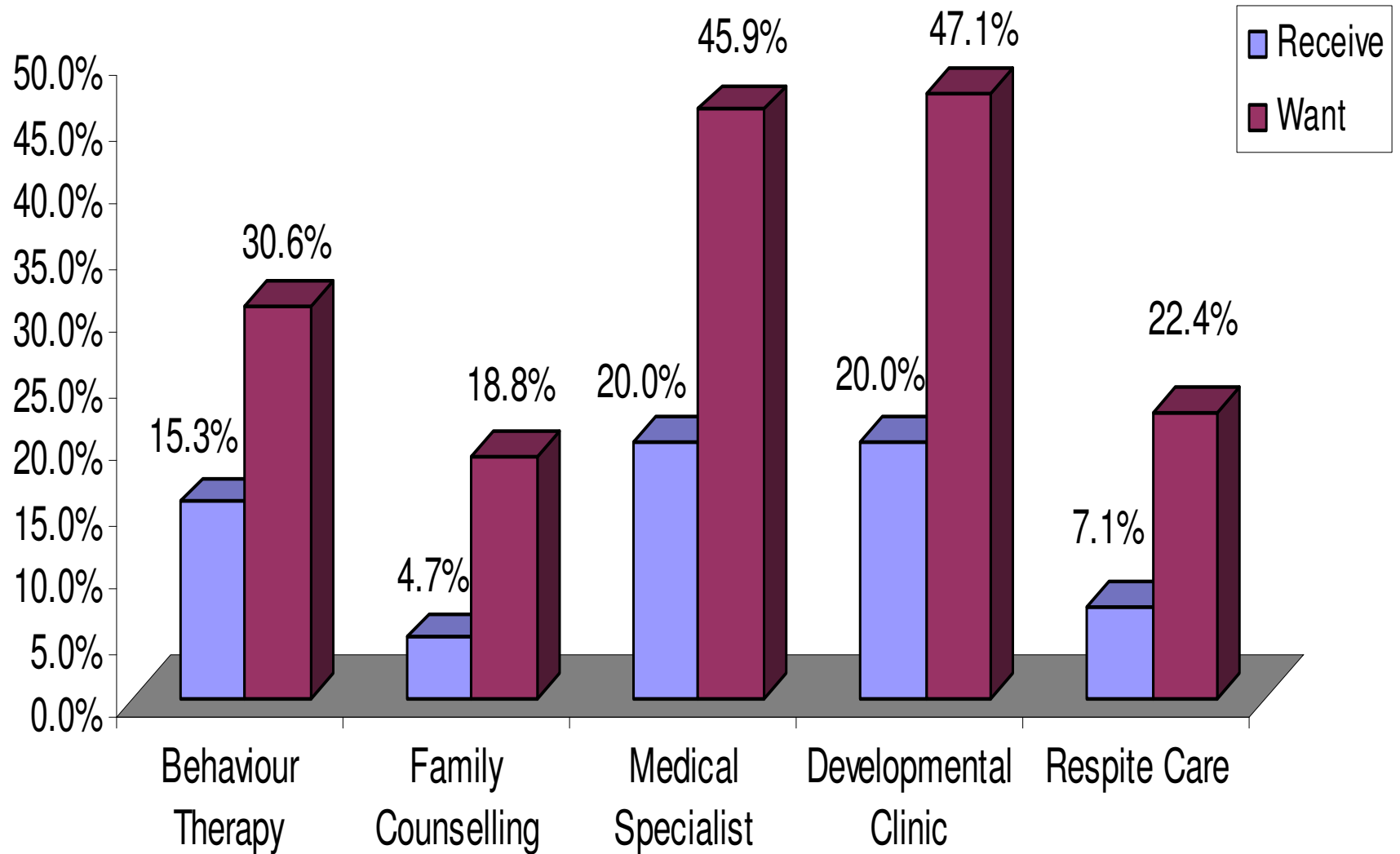
CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

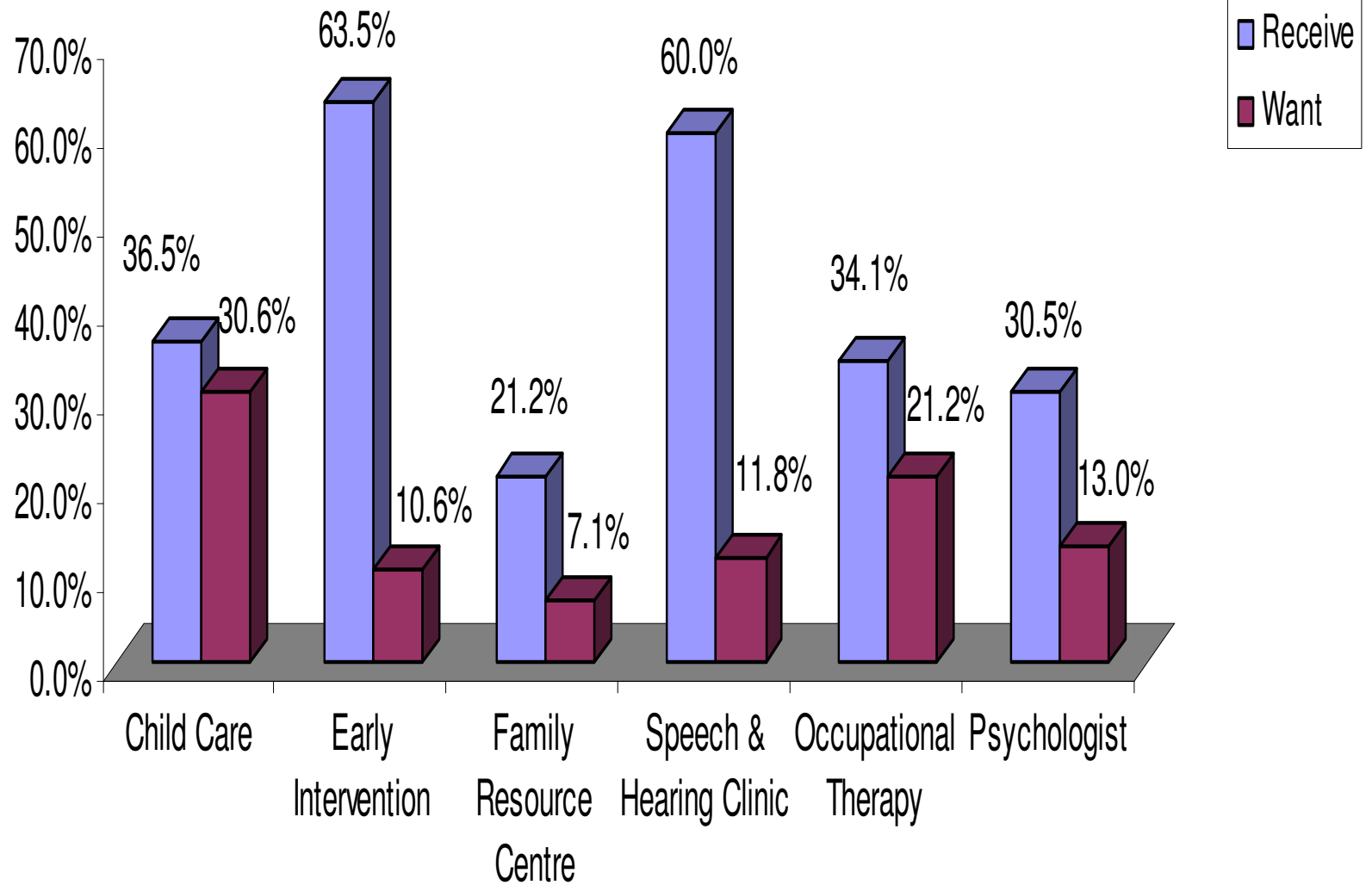
Question 3: What kind of help do parents want?



Services Received and Services Wanted



Services Received and Services Wanted





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Question 3: What kind of help do parents want?

Answer:

Developmental & Behavioural Clinic

Medical Specialist

Family Counseling

Respite Care





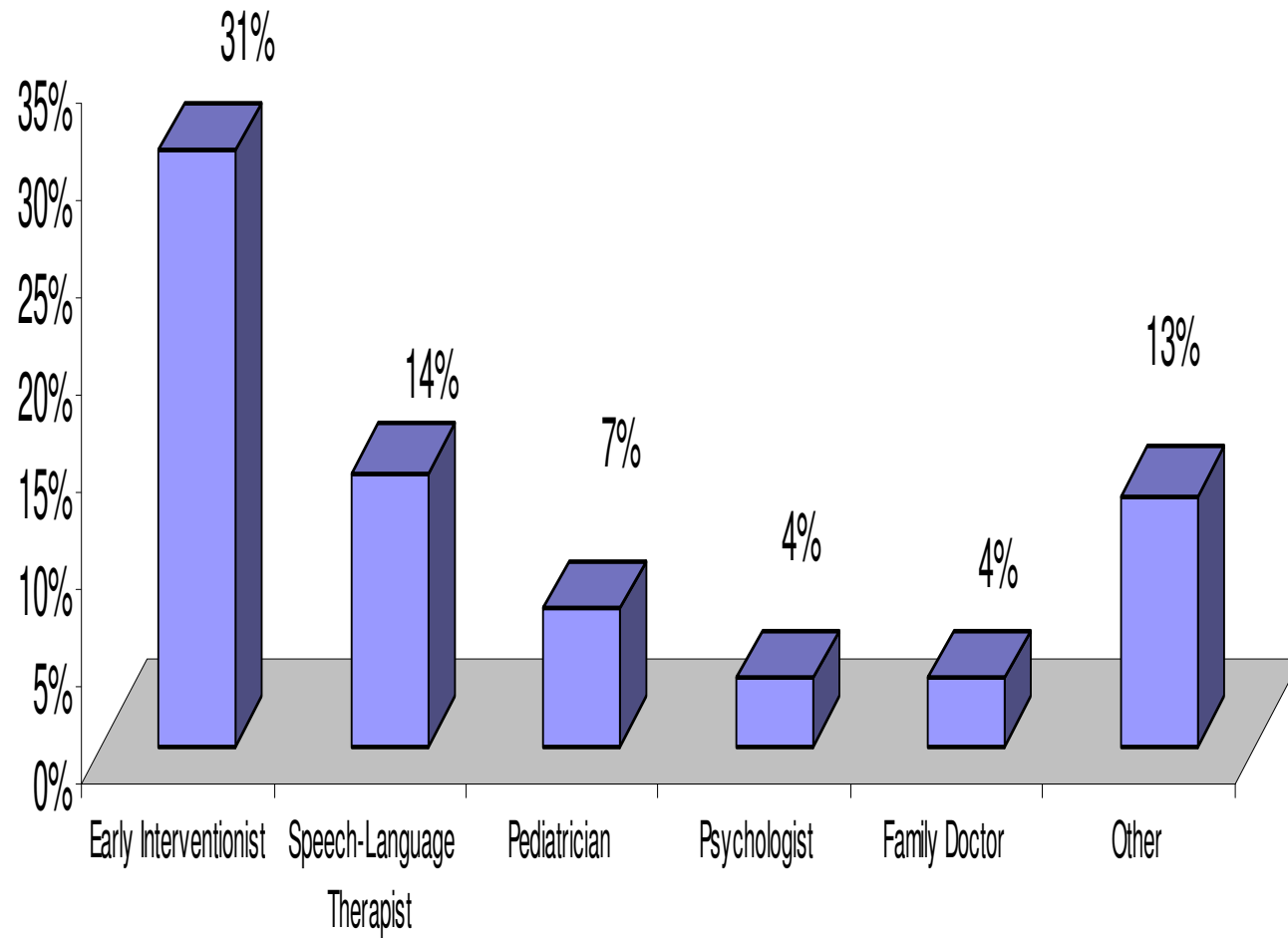
CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

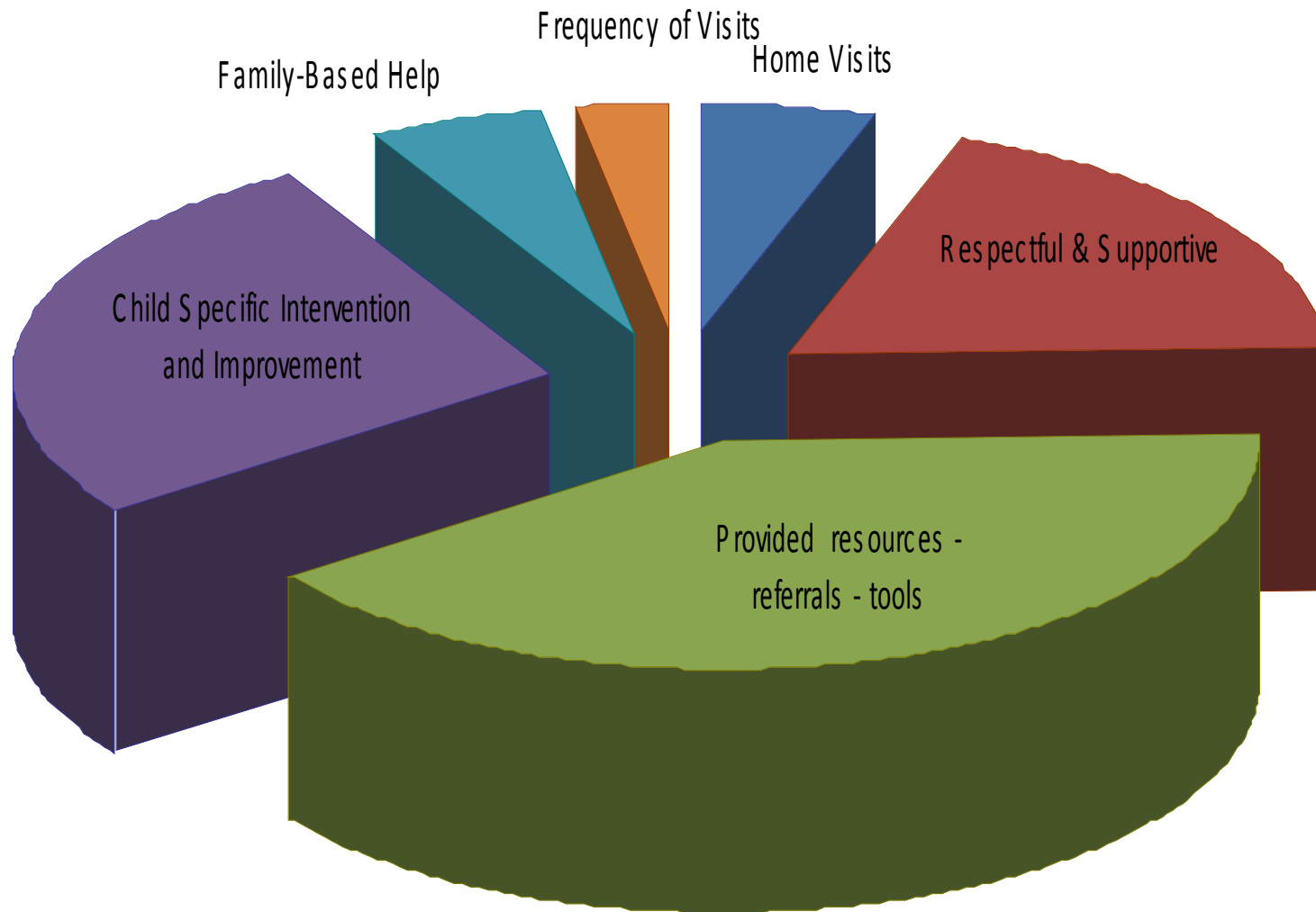
Question 4: Which professionals and services do parent identify as most helpful and why?



Most Helpful Professionals



Why an Early Interventionist is Helpful





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Answer: Why was this professional helpful?

- ☐ Provided information, resources, referrals
- ☐ Child improved in their care
- ☐ Respectful and Supportive to child & family
- ☐ Provided tools and ways parents can help their child





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Implications for Professionals Working with Children with Special Needs

- ❖ Parent concerns are predictive
- ❖ Age of concern/diagnosis are times when child is in childcare
- ❖ Provide parents with practical and realistic information, resources, ways to help their child
- ❖ Interact with parents in respectful and supportive ways
- ❖ Listen – do not rush to offer solutions
- ❖ Establish effective relationships with other service providers





CENTRES OF EXCELLENCE FOR CHILDREN'S WELL-BEING
CENTRES D'EXCELLENCE POUR LE BIEN-ÊTRE DES ENFANTS

Children and Adolescents with Special Needs
Les enfants et les adolescents ayant des besoins spéciaux

Contact Information:

Kim Kienapple

(902) 457-6199 or
Kim.Kienapple@msvu.ca

Adele McSorley

(902) 457-6585 or
Adele.McSorley@msvu.ca