



Service Priorities for Parents of Children with Special Needs

JD McLennan¹; F Ng¹; R McWilliams²; M Caza¹

URL: <http://www.offordcentre.com/integration/>

Background

Early intervention and child development services have often been described as fragmented and difficult for parents to access. Reform efforts may be directed toward reducing system fragmentation and difficulty in access, but do not always take into consideration the perspectives of caregivers. A priority of the "Integration of Health and Social Services for Young Children and Their Families" study was to understand the service experiences of caregivers.

Objective:

- To identify service reform priorities.

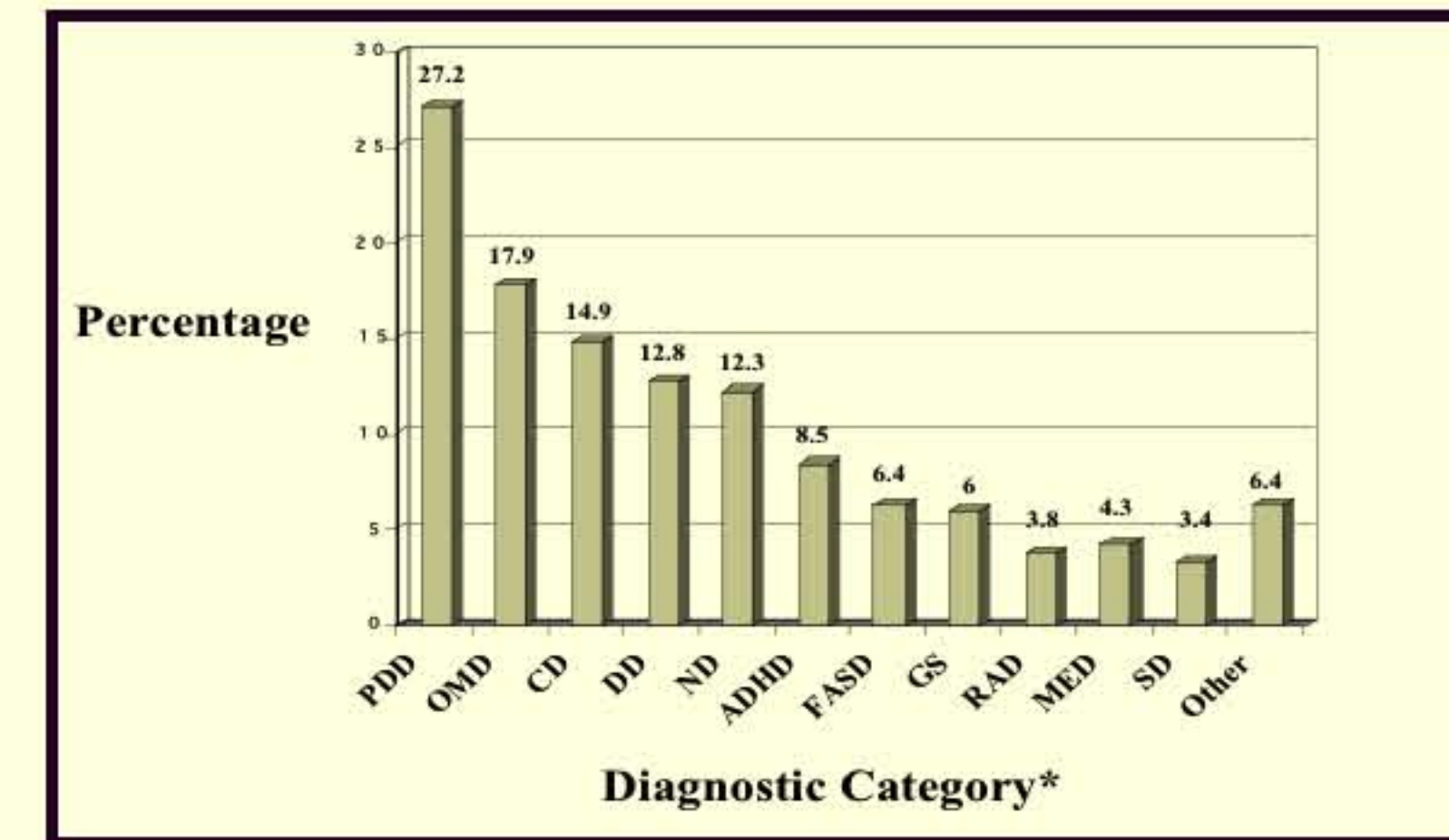
Methods

- Caregivers completed a service utilization questionnaire developed specifically for the study.
- N=235 caregivers of children with special needs from 4 specialty centers in Alberta and Ontario, Canada, (response rate, 20%).
- Survey included a 19-item scale made up of common service delivery issues and asked caregivers to rate:
(a) whether the issue posed a problem for them and if so,
(b) how severe a problem the issue had been for them.

Sample Characteristics

- 83% of caregivers were biological mothers.
- Families' median income was \$51,890.
- Caregivers' education:
 - 8% completed high school;
 - 18% completed some post-secondary education;
 - 27% had a university degree;
 - 30% had a technical certificate or diploma.
- 67% of the caregivers' children were boys.

Figure 1: Caregiver-Reported Diagnoses, Collapsed Categories



*PDD – pervasive developmental disorder
OMD – other mental disorders
CD – communication disorders
DD – developmental delays
ND – neurological disorders
ADHD – attention deficit hyperactivity disorder
FASD – fetal alcohol spectrum disorder
GS – genetic syndromes
RAD- reactive attachment disorder
MED – other medical or physical problems
SD – seizure disorders
Other – other problems.

Results Summary

Most frequently reported problem:

- Repetition of story to different professionals.

Most severe problem:

- Lack of specific treatment for child's condition.

Problems which are both frequent and severe:

- Lack of information about services that are available for my child.
- Wait list for assessment.
- Lack of available services.

Infrequent or Not Severe Problems:

- Too many assessments.
- Services are located in different places.

Table 1: Caregiver-reported service problems

Service Issue	% Endorsed	Severity Ranking	Severity Mean**
1. Repetition of story to different professionals	69.7	14	2.7
2. Lack of information about available services	53.0	5	3.4
3. Navigating health and social services system	51.7	9	3.2
4. Services are located in different places	47.9	19	2.2
5. Wait list for assessment	44.9	5	3.4
6. Lack of available services	43.2	4	3.5
7. Obtaining services is a problem	41.9	8	3.3
8. Wait list to begin treatment	41.0	9	3.2
9. Lack of specific treatment for child's condition	37.2	1	3.8
10. Not enough treatment	35.0	2	3.6
11. Lack of information about child's condition	32.9	5	3.4
12. Coordinating (my) child's care	32.5	12	2.9
13. Inconsistent information about child from various professionals	28.2	13	2.8
14. Lack of communication between professionals	27.8	14	2.7
15. Need more information from professionals about child's condition	22.2	11	3.0
16. Treatments are burdensome on family	21.8	18	2.5
17. Wait list for respite	20.1	2	3.6
18. Inconvenient appointment times	18.8	14	2.7
19. Too many assessments	15.4	17	2.6

Implications:

Service system problems that are both frequent and severe are indicative of systemic failures that should receive priority attention.

Recommendations:

Service priorities derived from the perspective of caregivers include:

- Improving the availability of information about services.
- Improving the wait times for assessments.
- Increasing the amount of available services.

**Severity mean was determined using data only from those caregivers who indicated a service issue was a problem.

Acknowledgements:

The Canadian Health Services Research Foundation, the Alberta Heritage Foundation for Medical Research (AHRMR), and the Ontario Ministry of Health and Long Term Care provided funding support for the study. The Canadian Institutes for Health Research and AHFMR provides salary support for the first author.

Parents are thanked for the time they spent providing the research team with details of their service experiences.

Academic Affiliations:

- Community Health Sciences, Faculty of Medicine, University of Calgary, Alberta, Canada.
- Vanderbilt University, Center for Child Development, Vanderbilt Medical Center, School of Medicine, Nashville, Tennessee, USA.