

# Where do Young Children in Speciality Care Come From?: A Preliminary Investigation of the Role of Primary Care Physicians

John D. McLennan MD, PhD, FRCPC<sup>1</sup>; Debbie Sheehan BScN, MSW<sup>2,3</sup>

## Abstract

**Introduction:** Young children with mental health and developmental problems may not receive appropriate or timely interventions. Primary care physicians are well positioned to play an important role in the early identification and referral of such children. The objective of this pilot study was to explore the role primary care physicians played for a group of such children.

**Methods:** A single mailing of 1196 self-report questionnaires were sent to parents/caregivers of children under six years of age at four specialty centers in Ontario and Alberta. Key items on the survey included the role of primary care physicians (family physicians and community paediatricians). **Results:** Twenty percent of parents/caregivers returned questionnaires. All children saw either a family physician or a community paediatrician, while 65% saw both. Families were more likely to have come to the specialty centre via a referral from a community paediatrician than a family physician. Ten percent reportedly received no referrals from a primary care physician, while 21% did not receive a referral to a specialty centre from these providers.

**Conclusions:** The majority of children received at least one referral from a primary care physician. Further inquiry is required to determine the timeliness and appropriateness of these referrals.

**Key words:** child, mental disorders, primary health care, referral and consultation

## Résumé

**Introduction:** Les jeunes enfants souffrant de problèmes de santé mentale et de développement risquent de ne pas recevoir les soins qui conviennent dans les délais prescrits. Le médecin traitant est bien placé pour jouer un rôle important dans l'identification et la référence de ces enfants. Cette étude pilote porte sur le rôle du médecin traitant dans ce contexte.

**Méthodologie:** Mille cent quatre-vingt seize questionnaires auto-administrés ont été envoyés aux parents ou aux personnes responsables d'enfants de moins de six ans, dans quatre centres spécialisés en Ontario et en Alberta. **Résultats:** Vingt pour cent des destinataires ont renvoyé le questionnaire. Tous les enfants voyaient soit un omnipraticien soit un pédiatre; soixante-cinq pour cent d'entre eux voyaient un omnipraticien et un pédiatre. Les familles étaient plus souvent référées au centre par un pédiatre que par un omnipraticien. Dix pour cent des enfants n'étaient pas référés par un médecin traitant; vingt-et-un pour cent d'entre eux n'étaient référés ni par un omnipraticien ni par un pédiatre. **Conclusions:** La majorité des enfants étaient référés par un médecin traitant. Une étude ultérieure devra vérifier si ces références sont appropriées et faites dans des délais appropriés.

**Mots clés:** enfant, troubles mentaux, soins de première ligne, référence et consultation

<sup>1</sup> Departments of Community Health Sciences, Psychiatry and Pediatrics, Faculty of Medicine, University of Calgary, Calgary, Alberta

<sup>2</sup> City of Hamilton Public Health Services, Family Health Division, Hamilton, Ontario

<sup>3</sup> Department of Nursing, Faculty of Health Sciences, McMaster University, Hamilton, Ontario

Corresponding email: [jmclenna@ucalgary.ca](mailto:jmclenna@ucalgary.ca)

Submitted: July 27, 2007; Accepted: November 16, 2007

## Background

Mental health and developmental problems in young children are common. A United States (US) study reported that 3.3% of infants and preschoolers had functional delays (Simpson, Colpe, & Greenspan, 2003). Mental health disorders were estimated to occur in 9.1% of preschoolers in a large US primary care paediatric population (Lavigne et al., 1996). Using a more inclusive measure and data from the National Longitudinal Survey of Children and Youth, 26% to 31% of Canadian children under six years of age are developmentally or behaviourally "vulnerable" (Willms, 2002). Unfortunately, many of these children may not receive the specialty services necessary to assess and treat their mental and developmental difficulties.

Primary care is a crucial component of the

system for the identification, treatment and referral of young children with mental health and developmental problems. Most Canadian children are seen by a primary care physician (family physician or community paediatrician) in the early years. These physicians are therefore often the first person to whom parents identify concerns regarding their child. Early identification in primary care may lead to earlier entry into interventions which may result in improved outcomes. However, only 17% of children identified as delayed in the US study referred to above were receiving specialty services (Simpson et al., 2003). In a large study of primary care providers, only 16% of children (aged four to 15 years of age) with psychosocial problems were referred for specialty care at their initial primary care visit (Rushton, Bruckman, & Kelleher, 2002). A recent

Canadian study of general and family practitioners identified significant variation in their comfort and skill managing children in their practices with behavioral and emotional concerns (Miller, Johnston, Klassen, Fine, & Papsdorf, 2005). Unfortunately, there is little research regarding primary care management of young children with mental health and developmental concerns in Canada (Kates et al., 1997). The objective of this pilot study was to explore the role primary care physicians played for a group of young children seen in specialty care.

## Methods

*Sample:* Four specialty centres participated in the study: two in Alberta (Glenrose Rehabilitation Hospital and Child and Adolescent Services Association (CASA)) and two in Ontario (Chedoke Child and Family Centre and Resource, Education and Counselling Help [R.E.A.C.H]). These centres are major mental health and developmental providers for children in their regions. They were chosen as they were already participating in a larger exploratory study of the integration of health and social services for young children (Integrating Child and Youth Services, 2004).

Eligibility criteria included the child (i) was less than six years of age at the time of recruitment, (ii) attended one of the four study specialty centers, (iii) had their first contact with the specialty centres between Oct 1, 2000 and Oct 1, 2002 (inclusive), and (iv) had parents able to read and write English. Each centre extracted a list of families meeting inclusion criteria from their clinical databases and sent out the survey along with a stamped return envelope. A total of 1,196 survey questionnaires were sent out. The research team did not have access to the list of families nor was information available as to the characteristics of the full sample. Only one mailing of the survey was done due to funding limitations.

*Measures:* Items for the pilot survey were constructed from three sources: (i) a review of other survey instruments used with parents of children with mental health and developmental difficulties; (ii) issues identified from preceding qualitative interviews with families, service providers and administrators; and (iii) requested questions from decision-making partners. The

instrument was reviewed by administrators and providers from each site and then piloted with ten families and the final survey instrument was revised based on this feedback. The survey instrument included questions regarding service use, referral patterns, and problems experienced in obtaining services. Relevant to this report, parents were asked (i) what professional they saw first with regards to their concern about their child (check box or write in response), (ii) the role of their primary care physician (check boxes), (iii) and types of referral made (write in responses).

*Analysis:* Variables analyzed for this report included information about the first professional seen, whether a child had seen a family physician and/or a community paediatrician, and the role of these two professionals. Chi-square tests with continuity correction were used to compare groups.

## Results

Two-hundred and thirty-three (20%) parents/caregivers returned completed surveys. The majority of children were boys (67%). Eighty-three percent of the respondents were mothers, 88% of the sample had graduated from high school and 82% lived in dual-parent families.

Table 1 provides the frequency distribution of diagnoses reported by caregivers. Pervasive developmental disorders were the most commonly reported group of diagnoses (27%). Twenty-five percent of caregivers reported more than one diagnosis.

Caregivers reported that family physicians and paediatricians were the professionals most commonly seen first with regard to their concern about their child's development (Table 2). However, other professionals were also accessed including speech and language pathologists, nurses and psychologists. Families from rural or urban areas in Ontario and rural Alberta most often were seen first by family physicians compared to community paediatricians. In contrast, those from urban Alberta were more often seen by community paediatricians first compared to family physicians.

Eighty percent indicated having seen a community paediatrician prior to coming to the specialty center. Eighty-five percent indicated having a family physician. Sixty-five percent indicated having both. All children had one

**Table 1: Frequency distribution of caregiver-reported childhood diagnoses**

DIAGNOSIS	FREQUENCY % (n)	GENDER	
		BOYS % (n)	GIRLS % (n)
Pervasive developmental disorders	27.2 (64)	90.6 (58)	9.4 (6)
Other mental health disorders*	16.6 (39)	48.7 (19)	51.3 (20)
Communication disorders	14.5 (34)	58.8 (20)	41.2 (14)
Developmental disorders	12.8 (30)	56.7 (17)	43.3 (13)
Other neurological disorders*	12.3 (29)	65.5 (19)	34.5 (10)
Attention deficit/hyperactivity disorder	7.2 (17)	76.5 (13)	23.5 (4)
Genetic syndromes	6.0 (14)	42.9 (6)	57.1 (8)
Fetal alcohol spectrum disorder	5.1 (12)	66.7 (8)	33.3 (4)
Other physical problems*	4.3 (10)	40.0 (4)	60.0 (6)
Seizure disorders	3.4 (8)	25.0 (2)	75.0 (6)
Reactive attachment disorder	3.0 (7)	28.6 (2)	71.4 (5)
Miscellaneous**	6.0 (14)	71.4 (10)	28.6 (4)

\* "other" categories include disorders with a frequency of less than 3% (examples included anxiety and behaviour disorder [under other mental health disorders], blindness and agenesis of the corpus callosum [under other neurological disorders], and asthma and cleft palate [under other physical problems])

\*\* "Miscellaneous" included issues such as prematurity

and/or the other. Six percent indicated their family physician diagnosed their child, while 24% indicated the community paediatrician had done so.

Caregivers were also asked about the role of these primary care physicians in making referrals for their child. The number and types of referrals are presented in Table 3. Ninety percent received at least one referral from the family physician and/or community paediatrician. Specialty centre (79%) and paediatrician (57%) referrals were the most common types received by families from their primary care

physicians. Referrals to participating specialty centres were more likely to have come from a community paediatrician than a family physician (76% vs. 36%,  $\chi^2 = 61.7$ ,  $p < 0.0001$ ). Families reported that their family physician frequently referred them to a paediatrician (56%). Twenty-one percent of the parents indicated that no primary care physician referred their child to the participating specialty centers. As all children were recruited from these specialty centers, they must have accessed these centers through other pathways.

One pathway of service delivery is from

**Table 2: First health professional seen for caregiver's concern about their child**

LOCATION	PROVIDER TYPE				TOTAL % (n)
	FAMILY PHYSICIAN % (n)	PAEDIATRICIAN % (n)	OTHER* % (n)	MISSING % (n)	
Large urban Alberta (AB)	25.0 (22)	47.7 (42)	23.9 (21)	3.4 (3)	100 (88)
Large urban Ontario (ON)	46.3 (31)	35.8 (24)	13.4 (9)	4.5 (3)	100 (67)
Small urban/rural AB	53.3 (24)	31.1 (14)	11.1 (5)	4.4 (2)	100 (45)
Small urban/rural ON	55.0 (11)	15.0 (3)	30.0 (6)	0.0 (0)	100 (20)
Missing location	53.8 (7)	38.5 (5)	7.7 (1)	0.0 (0)	100 (13)
All areas	40.8 (95)	37.8 (88)	18.0 (42)	3.4 (8)	100 (233)

\* "Other" includes professionals such as speech and language pathologists, nurses, psychologists

**Table 3: Pattern of referral receipt from family physicians and community paediatricians**

NUMBER OF REFERRALS	FAMILY PHYSICIAN % (n)	COMMUNITY PEDIATRICIAN % (n)	EITHER PHYSICIAN % (n)
No referrals	24.9 (49)	17.1 (32)	10.3 (24)
One referral	31.0 (61)	29.9 (56)	23.2 (54)
Two or more referrals	44.2 (87)	52.9 (99)	66.5 (155)
Total	100 (197)	100 (187)	100 (233)
REFERRAL TYPE*			
Specialty centers**	35.5 (70)	75.9 (142)	79.4 (185)
Paediatricians	55.8 (110)	28.3 (53)	57.1 (133)
Other professionals***	35.5 (70)	46.0 (86)	56.7 (132)
Other special services†	19.8 (39)	32.1 (60)	36.9 (86)

\* Multiple responses allowed

\*\* restricted to the four specialty centers from which children were recruited

\*\*\* most common other professionals included speech and language pathologists, occupational therapists, neurologists

† other services included early language/intervention programs, social/government services, audiology

family physician to community paediatrician to specialty center. We examined to what extent children in our sample may have taken this pathway. Sixty-six children with a family physician received a paediatric referral from the family physician but not a referral to a specialty centre. Fifty-one of these children received a referral to the specialty center via the community paediatrician. This represents 22% of the overall sample. However, this may be an overestimate of the use of this pathway as we made assumptions about the sequencing given that timing of referrals and specific identities of the paediatricians were not collected.

Ninety-two percent of caregivers indicated they were the coordinator for their child's services. Twenty-nine percent and 17% indicated their paediatrician or family physician, respectively, also assumed some of the coordination role. Other professionals identified as assuming some service coordination included early childhood educators (22%), social workers (16%), and case managers (14%).

## Discussion

All families indicated having at least one type of primary care physician involved with their child with a mental health or developmental problem. These primary care providers played at least some role in the care for the majority of these children at least through a referral process. The primary care providers infrequently provided a service coordinator or diagnostic role

for this sample of complex children according to the parents. It is important to note that this is parents' perspective of the role of the primary care physicians which may differ from the physicians' perception of her or his role.

Though diagnosing of these complex problems may in some cases be beyond the mandate and expertise of the primary care physician, one recommendation for improving earlier identification is the increased use of screening tools in primary care to detect developmental and mental health problems. The Psychosocial Paediatrics Committee, Canadian Paediatric Society (2000) notes the importance of using standardized instruments to assess developmental delays. Various screening strategies and tools have been proposed for use by primary care clinicians (Weitzman & Leventhal, 2006). The American Academy of Pediatrics has proposed a comprehensive algorithm for screening and surveillance to help in the early identification of children with possible developmental problems (Council on Children with Disabilities, 2006). However, it has been estimated that less than 20% of primary care physicians use such tools because of concerns with excessive length, minimal training in how to screen, and lack of confidence in the results (Filipek et al., 1999; Glascoe, 2000). The province of Ontario is moving towards a universal developmental screening process at 18 months of age.

Increased screening, however, does not

guarantee increased access to specialty services. There are several additional barriers that would need to be considered in order to ensure a more efficient early intervention track for young children demonstrating early problems. For example, to what extent can primary care physicians obtain timely access to specialty assessments and treatments for young children they identify in their practices? Unfortunately, there is a lack of information in Canada with regard to these critical questions. However, the long wait periods to access mental health specialists was identified as a frequent barrier by community paediatricians in the United States for the diagnosis and treatment of children in their care, as was their own lack of time (Horowitz et al., 2007).

Explicit support to primary care physicians in managing aspects of care for young children with special needs is another important strategy. For example, the provision of referral support materials increased the rate of referrals from primary care to Head Start programs in the United States (Silverstein et al., 2004). Shared care strategies in which specialists work directly with primary care offices is another strategy that may benefit young children with mental health problems (Kelleher, Campo, & Gardner, 2006). There is a particular need to consider how child psychiatrists could best support primary care physicians in early identification, assessment and judicious use of referrals for young children presenting with mental health problems.

Children with complex problems often have needs across multiple domains and require resources from a variety of providers and agencies. Although primary care physicians play a vital role in initial assessment and subsequent referral, it is unclear the extent to which they should also take on the role of service coordinator for these patients. In our study, all children saw additional service providers other than primary care physicians, with 25% seeing more than 12 (mean 8.9; median 9). Coordinating this number of providers may be a formidable task, one for which physicians may not have adequate time, resources or expertise.

Results and interpretations of data from this pilot study are limited. First, this study is based on a select sample of children with mental health and developmental problems who were

seen at four specialty centers. A particular concern was the low (20%) response rate and the use of a single mail out only. It is unknown whether a systematic bias exists that would challenge the generalizability of these findings to these and other specialty centres. We suspect that caregivers with higher education and those from dual parented households were over-represented. A second limitation is the reliance on parent retrospective recall. However, focusing on young children with relatively short treatment and service histories should limit recall bias (Pless & Pless, 1995).

Further inquiry is required to determine the timeliness and appropriateness of young child referrals to specialty centres. This will require a prospective study of a representative sample of children seen within primary care. An additional avenue for future research is to employ measures that examine parents' experience with the quality of primary care (e.g., Seid et al, 2001).

#### **Acknowledgements/Conflict of Interest**

Canadian Health Services Research Foundation, Alberta Heritage Foundation for Medical Research (AHFMR), and the Ontario Ministry of Health and Long-Term Care provided funding for this study. The Canadian Institutes of Health Research and AHFMR have provided salary support for the first author. The authors would like to thank the other members of the research team and, in particular, the late Dr. D.R. Offord. Thanks also to Michelle Caza with help in earlier drafts of this paper.

#### **References**

- Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*, *118*(1), 405-420.
- Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Dawson, G., Gordon, B., et al. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *29*(2), 439-484.
- Glascow, F. P. (2000). Evidence-based approach to developmental and behavioural surveillance using parents' concerns. *Child: Care, Health, and Development*, *26*(2), 137-149.
- Horwitz, S., Kelleher, K., Stein, R., Storfer-Isser, A., Youngstrom, E., Park, E. R., et al. (2007). Barriers to the identification and management of psychosocial issues in children and maternal depression. *Pediatrics*, *119*(1), e208-218.
- Integrating Child and Youth Services (2004). Available at <http://www.offordcentre.com/integration/index.html>.

- Kates, N., Craven, M., Bishop, J., Clinton, T., Kraftcheck, D., LeClair, K., et al. (1997). Shared mental health care in Canada. *Canadian Journal of Psychiatry, 8* (Suppl 42), 12.
- Kelleher, K., Campo, J. & Gardner, W. (2006). Management of pediatric mental disorders in primary care: where are we now and where are we going? *Current Opinion in Pediatrics, 18*(6), 649-653.
- Lavigne, J. V., Gibbons, R. D., Rosenbaum, D., Binns, H. J., Dawson, N., Sobel, H., et al. (1996). Prevalence rates and correlates of psychiatric disorders among preschool children. *Journal of the American Academy of Child and Adolescent Psychiatry, 35* (2), 204-214.
- Miller, A., Johnston, C., Klassen, A., Fine, S. & Papsdorf, M. (2005). Family physicians' involvement and self-reported comfort and skill in care of children with behavioral and emotional problems: a population-based survey. *BMC Family Practice, 6* (12).
- Pless, C. E. & Pless, I. B. (1995). How well they remember: The accuracy of parent reports. *Archives of Pediatrics & Adolescent Medicine, 149* (5), 553-558.
- Psychosocial Paediatrics Committee, Canadian Paediatric Society. (2000). The child with multiple impairments. *Paediatrics & Child Health, 5*(7), 397-402.
- Rushton, J., Bruckman, D. & Kelleher, K. (2002). Primary care referral of children with psychosocial problems. *Archives of Pediatrics & Adolescent Medicine, 156*(6), 592-598.
- Seid, M., Varni, J., Olson Bermudez, L., Zivkovic, M., Davodi Far, M., Nelson, M. & Kurtin, P. (2001) Parents' perception of primary care: measuring parents' experiences of pediatric primary care quality. *Pediatrics, 108*: 264-270.
- Silverstein, M., Mack, C., Reavis, N., Koepsell, T., Gross, G., & Grossman, D. (2004). Effect of a clinic-based referral system to head start: a randomized controlled trial. *Journal of the American Medical Association, 292*(8), 968-971.
- Simpson, G., Colpe, L. & Greenspan, S. (2003). Measuring functional developmental delay in infants and young children: Prevalence rates from the NHIS-D. *Paediatric and Perinatal Epidemiology, 17*(1), 68-80.
- Weitzman C. & Leventhal J. (2006). Screening for behavioral health problems in primary care. *Current Opinion in Pediatrics, 18*(6), 641-648.
- Willms, J. (2002). The prevalence of vulnerable children. In J. Willms (ed.), *Vulnerable children: Findings from Canada's National Longitudinal Survey of Children and Youth* (pp. 45-69). Edmonton, AB: The University of Alberta Press.

## Academic Position in Psychiatry



The Department of Psychiatry, University of Saskatchewan in Saskatoon, Canada invites applications from qualified academic psychiatrists in Child & Adolescent Psychiatry. This fulltime appointment will be at the rank of Assistant Professor or above.

The successful candidate will have a demonstrated interest in Child & Adolescent Psychiatry, and be an active participant in research, clinical practice and undergraduate and/or postgraduate training programs.

The incumbent will practice at one of the facilities of the Mental Health and Addictions Services of the Saskatoon Health Region. The Department collaborates in a full range of in and outpatient psychiatric services, including all of the core subspecialties of Psychiatry.

The University of Saskatchewan is committed to the principles of employment equity and welcomes applications from all qualified candidates. Women, people of aboriginal descent, members of visible minorities and people with disabilities are invited to identify themselves as members of these designated groups on their application. Applications are invited from qualified individuals regardless of their immigration status in Canada. The rank, salary, and benefits will be commensurate with qualifications and experience.

Please call (306) 966-8223, fax (306) 966 8761, email [raymond.tempier@usask.ca](mailto:raymond.tempier@usask.ca) or write to: Dr. Raymond Tempier, Professor and Head, Department of Psychiatry, 103 Hospital Drive, University of Saskatchewan, Saskatoon, SK, S7N 0W8, Canada.

Websites to visit: [www.usask.ca](http://www.usask.ca), [www.saskatoonhealthregion.ca](http://www.saskatoonhealthregion.ca), [www.sreda.com](http://www.sreda.com), [www.tourismsaskatoon.com](http://www.tourismsaskatoon.com), [www.sma.sk.ca](http://www.sma.sk.ca).