

## Overcoming Barriers to Mental Health Care for Rural Children

In Ontario, one in five children and youth under 18 suffers from a mental health disorder, but only one in six children with mental health problems receives treatment. There are access problems in children's mental health care, stemming partly from a mismatch between available services and clients' needs.

Decision makers need more evidence-based research to help them improve services. In rural areas, where those in the children's mental health care system have often had to rely on anecdotal evidence, the need for evidence derived from research is even greater.

Help for rural children with mental health problems can be even more difficult to obtain because of scarce resources, distance to services (children from rural areas are often placed in residential care outside their community), and possibly lack of information. One rural mother stated, "Mental illness in children and youth is often neglected until a tragedy occurs."

This study was designed to examine access to mental health care for children and youth in rural Ontario communities, from the perspectives of both families and service providers. Two study sites were used:

the rural catchment areas (beyond 50 kilometres) of Sudbury and of Owen Sound.

First, four focus groups were held in order to obtain an overview of the rural children's mental health care system and to identify issues faced in the delivery of services on a day-to-day basis. A broad range of stakeholders participated in these discussions, including parents, government and child welfare workers, pediatricians, hospital administrators, teachers and school board members, self-help group members, clinicians, and community outreach workers.

Aided by the focus groups' identification of themes, the researchers developed an interview guide and then conducted 60 face-to-face in-depth interviews. Half were with parents (77% mothers) who had a child aged 3 to 17 years with a formal diagnosis of emotional or behavioural disorders. Sixty-three percent of the children were male. The remaining interviews were with service providers, including children's mental health professionals, private practitioners, policy makers, teachers and police officers. Half were front-line workers, the other half managers.

This issue of Research in FOCUS on Research is based on the study *The Rural Perspective on Continuity of Care: Pathways and Barriers to Care for Children with Emotional and Behavioural Disorders* conducted jointly by the Hospital for Sick Children in Toronto and the Centre for Rural and Northern Health Research, Laurentian University. The authors are Katherine M. Boydell, Raymond W. Pong, Tiziana Volpe, Kate Tilleczek, Elizabeth Wilson and Sandy Lemieux.

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## Personal Issues

### Barriers to care

Family members felt that there is a lack of confidentiality in a small community, that everyone knows when a child is taken to mental health services. The perceived stigma delayed access for many.

Despite the work done by service providers to promote mental health services, lack of awareness of the availability of these services was frequently mentioned.

Unique to rural communities is the need to travel great distances to access care. This often means having to take time off work, and the costs of gas, wear and tear on the car, parking, public transportation (if available), meals and sometimes hotels. Many simply cannot afford these expenses and there is the added stress of travel and unfamiliar location.

Family issues raised include lack of support from a spouse, the needs of other children (childcare can be especially difficult to find in more remote areas), and the difficulty of juggling work and care.

### Aids to access

The small size of a community can also foster a positive and close-knit feeling. Both family members and service providers stressed the importance of “word of mouth” and the supportiveness of the community as aids to mental health care.

Family members frequently stated that the way to gain access to mental health care is to be a “squeaky wheel” – to be demanding, even rude, write letters, complain, go to the top.

## The System

### Barriers to care

Long wait lists and out-of-town referrals are common in rural communities because of an acute shortage of children’s mental health specialists and specialized services. Families are looking for any help, not necessarily a psychiatrist. Even when they get help, it often does not seem to be enough to be effective. Queue jumping is possible in times of crisis.

### Family members identify barriers

- ▶ *“My supervisors were good at giving me time off, but it meant no pay. Then my record would not be that good ... So I was giving up any opportunities, in order to be able to get help for my children.”*
- ▶ *“We were very vocal [about getting help for our child] and people have hated me in that school from day one, I have no doubt.”*
- ▶ *“We are limited to a select few physicians who are horribly overloaded.”*
- ▶ *“The counsellor thought the staff had told us. The staff thought the counsellor had told us. We had a heck of a time getting information from the out-of-town agency back to our doctor.”*
- ▶ *“There is no central place to go and say, ‘Where do we get help?’”*
- ▶ *“I know other moms with kids who are between 16 and 18. They can’t get any help. None. It’s really maddening living out here for this reason.”*
- ▶ *“I don’t want to open my local paper and find out that some mother has gone off and gassed herself and her kids because there is nothing available in this area ... I don’t know how much stress some of these families can take.”*
- ▶ *“It’s probably been six months now and I am still waiting for someone to say, ‘Okay, this kid’s got some issues. Let’s give this lady some kind of support.’”*
- ▶ *“If you are labelled by a teacher as being a problem in grade 1, you are still a problem in grade 12. You can never leave that behind you like in the larger centres.”*
- ▶ *Sometimes they expect you to go in the winter. I have to tell them, ‘Sorry, I’m not a winter driver, I can’t do it.’*
- ▶ *“You’re exhausted taking a child to see someone on a two-hour drive. They’re either exhausted or they’re all wound up. It’s not their normal.”*

A pervasive theme in the narratives of both families and service providers was the challenge of maintaining continuity of care in rural communities given the gaps in service, the turf wars, and lack of integration.

Government policies were found to hinder access to mental health care. Criteria for acceptance into programs are often strict, thus limiting the availability of care. Many of the problems come down to issues of funding.

### Service providers identify barriers

- ▶ *“You’re anonymous in the city, so I think people are more comfortable. They know they’re never going to see their doctor at the restaurant or the grocery store.”*
- ▶ *“People wait too long... they don’t think there is any help out there.”*
- ▶ *“The ultimate conundrum for a lot of our clients is financial – they can’t afford to take their kids to Owen Sound for testing, much less London or Toronto ... We can’t pay for these tests until the kid comes into care, which is the last option.”*
- ▶ *“We’re in a rural area that has a lot of poverty. They may not have that as a priority ... or, they see it as a priority but other things get in the way – housing issues, food, their basic needs.”*
- ▶ *“Staff changes all the time. A lot of programs are not that stable. Sometimes staff are not that qualified.”*
- ▶ *“There is a tremendous failure of communication in the system.”*
- ▶ *“There’s not much testing available up here. The psychological services within the school are minimal ... and this is where you see the problems.”*
- ▶ *“I spend so much time in my vehicle! It’s beautiful scenery, yet very isolated. I feel disenfranchised many times from the urban agency that hires me and the rest of the people I work with.”*

Many suggested there is a need for greater partnership between the mental health system and the schools, including providing counselling in the schools and professional development for school staff. Some parents found, however, that the school aided them: after seeking help in vain for their preschooler’s problems, they could gain access to care once the problem was noticed by a teacher or principal.

Some families have encountered difficulties in accessing help because mental health problems are not readily visible.

### Aids to access

Rural service providers were described by some families as “going above and beyond,” “a real God

send.” Their flexibility helps to reduce many of the barriers. They are willing to accommodate the needs of parents and children by offering home visits, evening and weekend services, transportation. They also show cultural sensitivity in adapting services to meet the needs of First Nation communities. In addition, they advocate on behalf of clients to secure services and are willing to challenge the system.

To get around shortages of services in rural areas, service providers often bring in outside expertise, such as consultants. Visiting specialists offer professional development in mental health, provide professional backup, and advocate for local services, reduced wait times, etc. Service providers expressed the need for more professional development.

“Creative rule breaking” allows service providers to reduce wait times and deliver services to children in need. They might offer group instead of individual services, play with timeframes, accept clients outside the agency’s catchment area, deal with problems outside their area of expertise, and so on.

Offering services locally helps to reduce many barriers and allows for more appropriate services and better care.

### Suggestions from family members

- ▶ *“You have to find it yourself. I learned about Dr. X from a lady I work with who has two kids with disabilities.”*
- ▶ *“Because it’s invisible, it’s hard for it to be looked at as a disability ... I wish there were more information for the public to understand.”*
- ▶ *“In one sense local service is wonderful because it’s more personalized. The counsellor will drive down and pick up your kid at school and take her out for lunch for her counselling.”*
- ▶ *“They need to have some service that is streamlined, that you’re not doing all this piecemeal service.”*
- ▶ *“If the money doesn’t get spent when they’re little, then when they still don’t fit into society at 14 or 15, they’ll go to jail and the money is going to get spent then.”*
- ▶ *“I’ve been seeing someone for myself, and if I talk more about it I find it’s easier. Somebody is listening to me.”*

### Suggestions from service providers

- ▶ *“Word of mouth is the number one thing. It’s invaluable, indispensable.”*
- ▶ *“What we really need are more bodies in the field.”*
- ▶ *“I would like to see somebody come into the school instead of having people going into that office over there because of the stigma that’s attached to it.”*
- ▶ *“We’re lucky that we have Dr. X who comes to our community. We made it his business to know how our community ticks and what we’re like.”*
- ▶ *“We’ve been very creative with the money that we have ... we make the rules a little more flexible to support as many families as we can.”*
- ▶ *“Whatever they don’t have, we fill in with home visits and transportation ... If they can’t get here, we’ll get there.”*
- ▶ *“There’s often more acceptance if service is delivered locally.”*
- ▶ *“To separate a child from their family when they’re in crisis is the last resort.”*
- ▶ *“We chose to get rid of the rent money for a central office rather than reduce staff.”*
- ▶ *“I would really love to see satellite centres ... If groups could come up here for a couple of days, it would aid a lot.”*
- ▶ *I feel that substance abuse and mental health with youth should be much more joined in this province.”*
- ▶ *“It could be more coordinated between a lot of the agencies.”*
- ▶ *“We need tele-psych, somewhere they can call and talk to someone and find out where to go.”*

## Observations and Recommendations

- ▶ The route to mental health care for children in rural communities is complex, non-static and non-linear, with many roadblocks and twists and turns, more like a labyrinth than a pathway.
- ▶ Service providers and family members are constantly negotiating a web of tensions, struggles and contradictions.
- ▶ Many factors identified as barriers were also, under different circumstances, considered to be facilitators to care.
- ▶ Children’s mental health services should be provided locally, if at all possible.
- ▶ An integrated service delivery model is required, with strong communication and collaboration between service providers.
- ▶ Early intervention with children is important for assessment and treatment, as well as prevention.
- ▶ Education about mental health disorders is critical for reducing the stigma and helping parents detect problems in their children. Promotion of available services and means to access them is necessary.
- ▶ The school system and daycare are essential components of the mental health system and closer partnerships need to be forged.
- ▶ Parents need support and respite.
- ▶ Rural communities require a model of service delivery that suits their particular needs.

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