The Rural Perspective on Continuity of Care: Pathways to Care for Children with Emotional and Behavioural Disorders

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Key Implications for Decision Makers

- Pathways to children’s mental healthcare are non-linear, complex, and dynamic. The concept of a single point of access to children’s mental health services needs further investigation.

- Rural communities differ from urban communities. What works in facilitating access to children’s mental health in urban centres may not work in rural communities. There is a need to address alternate or more flexible funding mechanisms and/or service delivery models for rural areas.

- There are multiple challenges to accessing mental healthcare for children and youth in rural communities. Within each community, these challenges coexist with unique advantages and strengths. There is no one homogenous rural reality; therefore, decision-making for these areas should be tailored to the specific strengths and needs of each community.

- Family self-help and advocacy groups facilitate access to and utilization of children’s mental health services. Financial support is required for these groups to form and flourish.

- Several mental health service programs were identified as facilitators to successful treatment access. Evidence-based programs that are working well in rural communities need to be promoted and expanded upon.

- Skilled, local service providers could be trained to act as support to more specialized practitioners. They require financial support, as well as acceptance and recognition by other professionals, both inside and outside the community.

- Locating mental health professionals in school settings requires further consideration in order to address issues of access. For example, building local capacity in school settings to conduct risk assessments could lead to earlier intervention and prevention.
Executive Summary

Decision makers indicate the need for evidence-based research to advocate for improved or different services and support (CHSRF, 1999). They have identified the lack of an evidence base in the children’s mental health system. In rural areas, the situation is even more pronounced (Pitblado & Pong, 2000). Decision makers have had to rely on anecdotal evidence about the pathways and barriers to care and have noted that recent calls to strengthen the evidence base of policy development have become more pronounced in response to pressures for greater transparency and accountability in decision-making.

Currently, there are as many as 10 million Canadians who can be considered rural residents — one-third of all Canadians (Pong, 2000). Children and their families in rural and northern areas may face more obstacles to obtaining health services and supports than those in urban areas (Cutrona, Halvorson & Russell, 1996; Starr, Campbell & Herrick, 2002). The problems of service access often result from geographic, economic, and cultural factors (Kelleher, Taylor & Rickert, 1992; Letvak, 2002).

The objective of this study is to examine access to mental healthcare for children and youth in rural Ontario communities, from the perspectives of service providers and families. Participants were asked to identify the challenges and facilitators to accessing and delivering services to children with emotional and behavioural disorders and their families. Qualitative methods were used to obtain the voice of families and service providers regarding access issues in the children’s mental health service system in rural areas.
Four focus groups were held with a broad range of community stakeholders in the children’s mental health system to obtain a comprehensive overview of the system and identify issues faced in the delivery of services on a daily basis. Qualitative in-depth interviews were conducted with 30 parents who live in the rural catchment areas of our two study sites (Sudbury and Owen Sound) who had a child, three to 17 years of age, with a formal diagnosis of an emotional or behavioural disorder. In addition, 30 service providers were interviewed in both study sites, including children’s mental health professionals, private practitioners, policy makers, and providers of related services such as teachers and police officers.

Pathways to mental healthcare for children in rural communities are complicated, dynamic, and non-linear. Although faced with multiple roadblocks, there are also several factors to help minimize these barriers. The interview data show three overall thematic areas that describe the main barriers and facilitators to care for children and youth with mental health problems in rural Ontario. These are personal, systemic, and environmental factors. More importantly, our analysis reveals that service providers and family members are constantly negotiating ongoing tension, struggle, and contradiction vis-à-vis their attempts to access and provide mental healthcare for children. Most factors identified as barriers are also, under different circumstances, facilitators. Our analysis clustered around the contrasts, contradictions, and paradoxes present throughout the interviews. For example, the small size of communities was often mentioned as a reason for ease of access to care through word of mouth in a close-knit community. This notion of a more supportive rural community has been noted previously (Philo, Parr & Burns, 2003). On the other hand, the small size of the community contributes to the lack of anonymity and stigma associated with mental illness. This “glare of rural familiarity”
(Voss, 1996) can contribute to the reluctance of some people to use mental health services. The fear of being seen is frequently an important issue related to the decision to avoid seeking mental health services (Bachrach, 1983).

The assumption of a rural homogeneous reality masks the diversity and uniqueness of rural communities. While emphasizing the common themes prevalent in service providers’ and family members’ narratives, we have attempted to highlight the unique perspectives and experiences that each participant shared with us. Consequently, recommendations made by the parents and service providers participating in this study were varied, but several common themes emerged: i) accessibility; ii) integration; iii) early intervention; iv) education and promotion; v) school and child care; vi) parental support; and vii) rural approach to service delivery.

This research was based on an approach designed to have decision makers participate in all aspects of the study from implementation to dissemination. Information from this study will be used to inform the strategic planning activities of the agencies and organizations serving these rural communities. Thus, project results have important implications for the organization and delivery of mental health services for children in rural areas. It offers information to support the development and evaluation of policies and procedures to overcome some of the barriers to care for children and youth with emotional and/or behavioural disorders.
Context

*Emotional and Behavioural Disorder in Children and Youth*

Twenty percent of Ontario’s children and youth (younger than 18) suffer from a mental health disorder, but only one in six receives treatment (Offord, Boyle, Fleming, et al., 1989; John, Offord, Boyle, et al., 1995). There is considerable agreement that there are problems regarding access to mental health services and support provided to children and youth. It is typically at least two years before parents obtain appropriate help, and many families drop out of treatment (Lazear, 2001). Part of the problem stems from a mismatch between what service providers feel they can offer and what potential clients perceive as their needs and the resources available to meet those needs.

Decision makers indicate the need for evidence-based research to advocate for improved or different services and support (CHSRF, 1999). They have identified the lack of an evidence base in the children’s mental health system. In rural areas, the situation is even more pronounced (Pitblado & Pong, 2000). Decision makers have had to rely on anecdotal evidence about the pathways and barriers to care and have noted that recent calls to strengthen the evidence base of policy development have become more pronounced in response to pressures for greater transparency and accountability in decision-making.

This issue is also of prime importance to families whose children suffer from emotional and/or behavioural disorders. An article in the *Ottawa Citizen* (Oberoi, M., March 9, 2001) highlighted the enormous cracks in the system, particularly the difficulties many families encounter in obtaining mental healthcare for their children. This situation is exacerbated in rural and remote communities where help is not easily accessible due to scarcity of resources, distance to service centres, and possibly lack of information. One mother stated that “mental illness in children and youth is often neglected until a tragedy occurs.” Family caregivers would like children’s mental health issues to be a higher priority on the government’s agenda.
The Rural Reality

As many as 10 million Canadians can be considered rural residents — one-third of all Canadians (Pong, 2000). Children and their families in rural and northern areas may face more obstacles obtaining health services and supports than those in urban areas (Cutrona, Halvorson & Russell, 1996; Starr, Campbell & Herrick, 2002). The problems of service access often result from geographic, economic, and cultural factors (Kelleher, Taylor & Rickert, 1992; Letvak 2002). In sparsely populated areas, travel expenses increase the costs of providing and obtaining care. In addition, children from rural areas often must be placed in residential care outside of their community because of the lack of resources (Sheldon-Keller, Koch, Watts & Leaf, 1996). Geographic and professional isolation make rural communities less attractive to mental health workers. It is difficult to recruit and retain specialists, who tend to concentrate in larger urban areas (McCabe & Macnee, 2002). Most rural communities are too small to sustain highly specialized personnel. Moreover, within the health research community, rural issues are often overlooked or dealt with generically. When rural perspectives are examined, it is frequently within the context of urban-rural differences, rather than as the sole focus of attention (Pong, Atkinson, Irvine, et al., 2000). When mental health is the focus, there is little literature documenting the mental health experiences and needs of rural and remote communities, and a lack of focus on children in particular (Fuller, Edwards, Procter, et al., 2000).

Definition of Rural

There is no universal definition of rural (Gregoire & Thornicroft, 1998). In addition, administrative or academic definitions of rural may have little relevance to grounded “human realities,” as “census definitions fail to take into account the sociological dimensions between rural and non-rural populations” (Voss, 1996, p.216). We must remain sensitive to the quite different historical and geographical contexts within different rural places. Rural areas cannot be treated as homogenous. It has been suggested that the method of defining rurality be appropriate to the study being conducted (Philo, Parr, & Burns, 2003). The definition of rural used in the current study is based on the Statistics Canada definition, which refers to people living outside the commuting zones of larger urban centres, especially outside census metropolitan areas (pop. 100,000 or more) and census agglomerations (pop.10,000-99,999) (du Plessis, Valerie, Beshiri &
For the purposes of this study, a distance of at least 50 kilometres from census metropolitan areas and agglomerations was utilized.

**Study Objective**

The objective of this study is to examine access to mental healthcare for children and youth in rural Ontario communities, from the perspectives of service providers and families. Participants were asked to identify the challenges and facilitators in relation to accessing and delivering services to children with emotional and behavioural disorders and their families.

**Approach**

*Qualitative Method*

This study used qualitative methods to obtain the voice of families and service providers regarding access issues in the children’s mental health service system in rural areas. The growing role played by qualitative methods in health services research has been recently recognized (Shortell, 1999). This evolution is consistent with developments in the social and policy sciences, which reflect the need for a more in-depth understanding of naturalistic settings, the importance of understanding context, and the complexity of introducing change. Qualitative methodology allows constructs and theory to be grounded in participants’ cultural experiences and facilitates an in-depth understanding of the context (Devers, 1999). Qualitative methods allow people to speak in their own voice rather than conforming to categories and terms imposed on them by others and allows for an in-depth and richly textured understanding of the phenomena under study.

*Participants*

Four focus groups were held with community stakeholders in the children’s mental health system to obtain a comprehensive overview of the system and identify issues faced in the delivery of services on a daily basis. A broad range of stakeholders representing a variety of service sectors participated, including government, child welfare, pediatricians, hospital administration, teachers, school board personnel, family self-help groups, mental health clinicians, community outreach workers, and parents. Qualitative in-depth interviews were conducted with 30 parents.
who live in the rural catchment areas of our two study sites (Sudbury and Owen Sound) who had a child, three to 17 years of age, with a formal diagnosis of an emotional or behavioural disorder. In addition, 30 service providers were interviewed in both study sites, including children’s mental health professionals, private practitioners, policy makers, and providers of related services such as teachers and police officers. A purposive maximum variation sampling strategy (Lincoln & Guba, 1985) was used to ensure a diversified sample (that is, a range in the children’s gender, age, and diagnosis [internalizing/externalizing], regional locales, and front-line and managerial providers).

**Data Collection: Focus Groups and Individual Interviews**

Extensive field notes were taken during the focus group discussions and were used in conjunction with the interview transcripts. In-depth interviewing, described by Charmaz (1991) as a “directional conversation that elicits inner views of respondents’ lives as they portray their worlds, experiences and observations” (p.385) was used. A semi-structured interview guide was developed, which included a cover sheet for basic demographic data for both participant groups. Experienced field researchers were recruited to conduct the face-to-face interviews. All interviews were audio taped, transcribed verbatim, and converted into the format required for use with the Ethnograph, a computer-assisted program for the analysis of text-based data (Seidel & Clark, 1984).

**Analysis**

SPSS was used to produce basic descriptive statistics regarding demographics of our participant group. The qualitative analysis process involved a seven-step method for analysis of qualitative data (Diekelmann, 1992). Each member of our multidisciplinary team examined all transcripts. Themes were identified and discussed, and a coding scheme was developed to reflect these themes. The team used the codebook developed as a result of the aforementioned processes to systematically review the textual data. This process was facilitated by the categories of interest generated from the focus groups, which provided a framework for the individual interview guide.
Results

Study Participants

Family members were primarily mothers (77 percent). Most family respondents were married (74 percent) and 58 percent were employed. The mean age of the children was 11.6 years, 63 percent were male, and mood disorders, anxiety-related disorders, and oppositional-defiant disorders were experienced by one-half of the children. Service provider interviewees were evenly split between front-line and administrative/managerial staff with an average of 14 years of service. They represented all service sectors, including education, health, social services, and criminal justice.

Complexity of Pathways to Mental Healthcare

The notion of a “pathway” to care is misleading, as it implies a linear process. The route to mental healthcare for children in rural communities is complex, dynamic, and non-linear, with multiple roadblocks. It is more like a labyrinth or tangled web than a pathway. Analysis of interview data indicated three overall thematic areas that describe the main barriers and facilitators in relation to care for children and youth with mental health problems in rural and remote Ontario. These are personal, systemic, and environmental factors.

Our analysis revealed that service providers and family members are constantly negotiating a web of ongoing tension, struggle, and contradiction that permeates their attempts to access mental healthcare for children. We found Montgomery and Baxter’s (1998) notion of dialectic tension useful when examining the competing thematic categories. Many factors identified as barriers were also, under different circumstances, facilitators. Our analysis clustered around the contrasts, contradictions, and paradoxes present throughout the interviews.

Personal Factors: Barriers to Access and Utilization

The key personal-level barriers to accessing mental healthcare for children and youth included the stigma of mental illness; lack of information; economic challenges; and family factors such as lack of support from spouse, other children, and work responsibilities.
**Stigma**

Families identified perceived stigma and lack of confidentiality as barriers to care for children with emotional or behavioural disorders. Stigma delayed access for many participants, and it likely acts to prevent access in other cases. Family members seeking services indicated that, due to the small size of rural communities, everybody knows when a child uses mental health services. Consequently, they felt that it was safer to make visits to healthcare professionals at night. The stigma includes being “labelled” or “pegged,” and families feel that, once the label is conferred, it remains.

*You’re anonymous in the city, so I think people are more comfortable. They’ll go to their doctor. They know they’re never going to see their doctor at the restaurant or the grocery store.* [service provider]

Although the small size of the community and the tendency for most individuals to be on a first-name basis contributes to difficulties in maintaining anonymity, it also plays a role in the positive, intimate, and close-knit feel of the community. The importance of word of mouth and the supportiveness of the community emerged as a facilitator to mental healthcare (see small size and word of mouth sections below).

**Lack of Information**

Lack of awareness of the availability of mental health services was frequently mentioned as posing a service barrier. This occurred despite the work done by service providers to promote such awareness.

*People really and truly don’t understand. They wait too long, you know? Part of it is I think that they don’t think there is anything out there.* [service provider]

*It would be awful handy to have a place where somebody could actually open up a book and get their kid help from there… actually steer me to where I can go. There isn’t that… [It] leaves parents like myself wondering where do we go? What do we do? If there was somebody to give you a helping hand to walk you through it.* [family member]
**Economic Challenges**

Accessing mental healthcare for children was clearly affected by monetary issues on a number of levels. Unique to rural communities is the need to travel great distances to access care, which often entails having to take time off work, costs of gas, wear and tear on the car, parking, meals, and sometimes hotel accommodation.

*They were very good at giving me time off, but it meant no pay. And then if I ever wanted to apply for full-time there, my record would not be that good. I was concerned about my work record, so I was giving up any opportunities to be able to get help for them [my children]. [family member]*

*The ultimate conundrum for a lot of our clients is financial — lack of resources, so they can’t afford to take their kids to Owen Sound for testing, much less London or Toronto. So the burden comes back to our agencies because they have to say we can’t pay for these tests... until the kid comes into care, which is the last option. [service provider]*

**Family Factors**

Family factors included lack of support from spouse, the needs of other children, and work responsibilities. For several families, there was disagreement between parents as to the need to seek formal help for the emotional and behavioural difficulties of the child.

*I also ran into difficulties... just my husband kind of fighting me on it. He didn’t want him [our son] being diagnosed. He didn’t want him being tested. He didn’t want him on medication. [family member]*

*We’re in a rural area that has a lot of poverty. So families have a lot of other issues on the table and 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. I know one family who was evicted from the place they were living in. These things take priority. [service provider]*
The fact that there were other children in the family who had needs often posed difficulties. Child care was often hard to obtain, particularly for those families living in more remote communities. Because of the typical hours of operation of mental health services, family members often had difficulties juggling work and care. In addition, the behaviour of the child with the emotional or behavioural disorder might be upsetting to other children in the family.

*One agency has long been concerned about those younger kids. Either they’re affected by the child [with the emotional or behavioural disorder] or by the depletion of energy of the parents.* [service provider]

**Personal Factors: Facilitators to Access and Utilization**

Family members living in rural communities detailed the circumstances that enabled them to access the system. Two themes that emerged repeatedly throughout the interviews with service provider and family members were the importance of word of mouth in finding out where to go and how to obtain services, and the critical role of individual advocacy.

**Word of Mouth**

The role of the informal network in facilitating access to mental healthcare was apparent. It was often in a serendipitous manner that families found out about ways to access services for their children.

*Word of mouth is like wildfire. It’s the number one thing, it’s word of mouth. Word of mouth is valuable, invaluable. Indispensable.* [service provider]

*You have to find it yourself. I learned about Dr. L. from a lady I work with who has two kids with disabilities. She got me going to Dr. L.* [family member]

**Advocacy**

Analysis of transcripts revealed that being a “squeaky wheel” resulted in greater attention and facilitated entry to service. Some of the words used to describe this advocacy work by family
members were: demanding, very vocal, fighting tooth and nail, convincing, getting angry, yelling and screaming, knocking down doors, raising Cain, being rude, persisting, bugging, go-getting, pushing, calling around, researching it, writing letters, following up, complaining, and going to the top. Family members faced the inherent tension between advocating to obtain help for their child and being thought of as a “pain in the butt.” The latter was seen as possibly making things worse.

*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. [family member]*

*Because they are overworked or overloaded or whatever; so if you don’t make a noise, you don’t get [help] ... The squeaky wheel gets the oil, you know. [family member]*

Parents acknowledged that they frequently did not get services because they did not push hard enough. This lack of advocacy was often the result of many factors including personal style, lack of education, and lack of time due to work obligations and parenting other children.

**Systemic Factors: Barriers to Access and Utilization**

Study participants identified multiple barriers to accessing services at the systemic level. They included the lack of human resources in rural communities; linkage and territoriality; policy and funding issues; waiting lists; and the role of the school.

**Human Resources**

A frequently cited systemic barrier to accessing children’s mental healthcare in rural communities is shortages of human resources. Recruitment and retention of children’s mental health specialists and the shortage of specialized services such as psychometric testing were identified as contributors to long waiting lists and out-of-town referrals. It is important to note that family members indicated that “*any help at all would have been acceptable.*” They are not necessarily looking for a psychiatrist.

*What we really need are more bodies in the field. [service provider]*
Although we have services, they tend to be constantly changing. Staff changes all the time. A lot of programs are not that stable. Sometimes staff are not that qualified. It’s pretty much a mish-mash. [service provider]

We are limited to a select few physicians who are horribly overloaded, overworked. [family member]

Children were seen by a wide variety of practitioners. These visits were “brief encounters” of just one, two, or three sessions, and practitioners frequently conclude “everything is fine.” This was very frustrating for family members, because they know that their child is not fine. The practitioners did not see the child on a daily basis, and family members often felt that their expertise and experience were ignored or undervalued.

**Linkage and Territoriality**

A pervasive theme in the narratives of service providers and family members was the challenge of maintaining continuity of care in rural communities, given the gaps in service, lack of integration, and territoriality or turf wars. This theme is balanced by the many formal and informal relationships that existed or that were cultivated in these communities.

There is a tremendous failure of communication in the system. [service provider]

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. They did not correspond back and forth. There is no central place to go and say, “where do we get help?” [family member]

**Policy and Funding Issues**

Study participants indicated that federal, provincial, and local policies interfered with their ability to easily access services. Service programs often adhered to rigid policies regarding criteria for program acceptance. For example, the issue of age was often raised as a problem in service access.
Once she hit the magic age of 16, there’s nothing... [She’s] too young for adult service, too old for kid’s services. [family member]

If you are between 16 and 18, there is not a single soul who will help you. [family member]

I know other moms with kids who are between 16 and 18 and who are pulling their hair out. These kids are totally depressed, they are not going to school, and they’re addicted to drugs. They can’t get any help. None, you know? So, it’s really, really maddening living out here for this reason and I was thinking of moving for that sole reason. [family member]

Inherent in these rigid policies was the practice of bending the rules to accommodate individuals not otherwise served. Not surprisingly, a great deal of the identified problems regarding access to care came down to issues of funding and the lack thereof.

I don’t want to open my local paper and find out that some mother has gone off the deep end and gassed herself and her kids because there is nothing available in this area... The government has cut back and they closed institutions... but they better pass some dollars along to these families, because I don’t know how much stress some of these families can take. [family member]

**Waiting Time**

Waiting lists for children’s mental health services and supports are pervasive in rural communities. All regions in the current study had waiting lists. The length of time spent on a waiting list varied from a few months to one to two years.

For someone working in the field, a month just flies by. But for me, as a parent, dealing with a child every day who doesn’t want to live and who doesn’t want to eat and who doesn’t go to school, you know, every day is a huge challenge. [family member]

So, it’s probably been six months now and I am still waiting, still waiting for someone to say, “Okay, this kid’s got some issues. Let’s give this lady some kind of support.” [family member]
One was able to access mental healthcare more readily under certain conditions, namely, at times of crisis; for example, if the child was a harm to self or others or suicidal. In these cases, “jumping the queue” could occur.

*In Grade 2, [our child] brought a knife to school. It was probably one of the best things she did because then other people got involved. People jumped up and said “what’s going on here?”*  
*family member*

*We have a duty to respond. There’s a ministry-driven duty that if someone is in crisis, we have an obligation as an agency to do an assessment.*  
*service provider*

**School Barriers**

There was a perceived need for greater partnership between the mental health system and the school system, including the provision of counselling within schools and professional development for school staff. The lack of resources for mental health channelled into the school system was noted, particularly at the preschool and secondary levels.

*I find that the school is a marvellous place, because the kids are going to school, so this way there would be no travelling and this way there would always be somebody there for the kids when they need it.*  
*family member*

*I think what I would like to see, myself, personally, is somebody to come into the school instead of having people going into that office over there, because of the stigma that’s attached to it.*  
*service provider*

*It’s a lot easier to treat the child in the school than drag them off to the mental health building.*  
*service provider*

*There’s not much testing available up here. The psychological services within the school are minimal… and this is where you see the mental health and the substance abuse problems, in the school… I mean, this is where kids live.*  
*service provider*
Paradoxically, the school was also a facilitator of access to mental healthcare. Family caregivers repeatedly attempted to seek help for their child’s problems only to be told that it was “just a phase” or “he’ll grow out of it.” Understandably, physicians were often reluctant to medicalize behavioural problems despite family intuition that something was definitely “not right” with their child. It was only when the child became school age and teachers and/or principals notice that there is a problem that help is both sought and obtained.

**Invisibility**

Many interviewees addressed the difficulty of dealing with mental health issues in children and youth. These problems are not physical; hence they are often not readily visible. Consequently, it is difficult to get help for something that is hidden, that cannot be seen. The importance of obtaining a diagnosis cannot be undermined. However, paradoxically, once labelled, there is the problem of lack of resources and stigma.

*People have more sympathy for people when they have a physical impairment and you can identify it when you look at them.* [family member]

*Because it’s invisible, it’s hard for it to be looked at as a disability... I wish there was more information for the public to understand.* [family member]

**Systemic Factors: Facilitators to Access and Utilization**

Many systemic facilitators to accessing mental healthcare for children were identified. They included delivery of personalized services, engaging outside expertise, breaking the rules, and offering services locally.

**Delivery of Personalized Services**

The characteristics and flexibility of rural service providers reduces personal, systemic, and environmental barriers such as stigma, cultural differences, travel, distance, human resource shortages, and waiting lists. Service providers were described as being *good people, good to us,*
open-minded, taking time, going above and beyond the call of duty, being there when needed, they made it easy, a real God send, and it’s not the system, it’s the people. There was a perceptible willingness to accommodate the needs of parents and children, to go where the family was located, by offering transportation to clients (personally or through volunteer drivers), home visits, and offering services on nights/weekends. This was often necessary in order to keep families engaged. For example, in one case, attempts were made to find a female counsellor for a client with a history of sexual trauma.

Rural professionals demonstrated cultural sensitivity in their adaptation of services to meet the needs of First Nations communities. They also advocated on behalf of their clients in order to secure services and showed a willingness to challenge the system and bring issues to the forefront. The notion of the squeaky wheel was apparent for service providers and for parents.

So I mean the clinic itself is phenomenal, her counsellor is very good. He’s very nice. Thursday night I called him at his own home to talk to him to get some advice on what to do and he called back later in the evening to find out how she was doing. He’s very accessible. He’s told us, actually right from the beginning, that if there were any problems after-hours that we could call him at home… He’s always been more than courteous and encouraging towards both of us. [family member]

I work late at night lots of times, late at night when nobody’s in the building... I’m still very flexible, but they get services that they feel safe and comfortable with. [service provider]

**Engaging Outside Expertise**

Service providers circumvented human resource shortages in rural areas by engaging outside expertise, such as consultants. They also participated in professional development activities. Professional development seminars were offered to professionals and parents, with communities arranging for experts to visit by paying them as outside consultants. This was described as a “creative use of money.” Travelling/visiting specialists advocated for local services, reduced
waiting lists, supported local workers, and validated their work. Outside specialists offered to work with local staff for specialized skill development in mental health and provided professional back-up.

*Yes. And we're lucky enough that like we have Dr. [Name] who comes to our community. Who's made it his business to know how our community ticks and what we're like and, you know, he just doesn't, he's not just a consultant who comes in and, you know, makes up something that's beyond our ability to reach and then walks out. You know, he works with the workers, and says, “Ok,” you know; and says, “what's achievable and what isn’t.” So we stick to what's achievable and he's supportive of that. [service provider]*

Unfortunately, professional development and the lack thereof were also mentioned by many mental health providers as a drawback of the current system. Quite clearly, many rural service providers did not see professional development as adequate.

**Rule Breaking**

Creative rule breaking allowed service providers to reduce waiting times and deliver services to children in need. Front-line workers referred to working “around the system” and using the “back door” to access services. This often entailed a great deal of collaboration and communication. Some strategies for reducing waiting lists and servicing families more quickly included offering group instead of individual services; playing with time frames (such as breaking protocol by postponing the initial psychosocial assessment if the client just wants to talk); accepting clients outside the agency’s catchment area; bridging the gap until a child is connected to services; dealing with problems or issues outside their area of expertise (“it is not their job but they are treating families because there is no one else”); and creative use of funds by physicians, for example, by hiring a staff person out of OHIP billing.

*And we have this network of services... I can’t give you concrete examples of what they might do, but my suspicion would be that they would bend a rule or do something in whatever way they can in order to care for their children. [service provider]*
And [the GP is] just saying, “show up at emerg because if we try to refer you, they won’t take you in.” Or going to other urban centres with the notion that you might be able to get more immediate help if you just show up at emerg. [service provider]

And we’ve been very creative with the dollars and the pots of money that we have had to not try and bend the rules, make them a little more flexible to support as many families as we can. [service provider]

One problem associated with breaking the rules is the fact that, in doing so, the true impact of the lack of resources in these communities is attenuated.

**Offering Services in Local Communities**

Services offered locally mitigate personal, systemic, and environmental barriers. In terms of personal barriers, it is less disruptive to families, more convenient, and there is greater acceptance of programs offered locally. Hiring locally is also more culturally acceptable and retention rates tend to be higher. Most importantly, local programs allow children to remain with their parents in the community. Furthermore, it is easier for a service provider to visit a number of families in their local community rather than have families go to a central office. It is helpful for service providers to see families in their natural environment. Home visits develop relationships between families and service providers, building trust and rapport. Local services allow for more intense delivery of services and deliver better care since one is accountable to local citizens, resulting in an increased commitment to the community. Finally, local service delivery decreases barriers to service (for example, by reducing long-distance travelling) and encourages program participation, particularly programs offered in the schools. In our study communities, there were examples of effective, integrated programs such as Integrated Services for Northern Children and Working to Reinforce all Partners.

Yeah, well whatever they don’t have, we fill in with home visits and transportation. They get it because we offer it. Like, I mean, I will go do out-of-the-way home visits to those who don’t have any transportation. If they can’t get there, we’ll get there. They get it in one way or another. [service provider]
And I think the reason why people are trying to work with them [families] locally is because of the distance. It’s so hard on families and so disruptive... There’s recognition that to disrupt, to separate a child from their family when they’re in crisis, is the last resort. [service provider]

We needed to save rent money. Really. Either we had to save rent money or reduce staff. And we chose to get rid of the rent money, you know, the money we had to pay for rent for an office, rather than reduce staff. We did a little evaluation of that. And the feedback we got from the community, the families served in the community was as good or better than the satisfaction of the people who were served out of the [central] office. [service provider]

My experience in rural communities is that there’s often more acceptance if it’s delivered locally. And it becomes part of the community than if people have to drive an hour and a half to get to where the service is... uh, they don’t even really look seriously at being able to use it. [service provider]

**Environmental Factors: Barriers to Access and Utilization**

**Distance**

Family participants identified difficulties in accessing needed services that were located at great distances from their home communities. Access to out-of-town services was further hindered by adverse weather conditions in winter, travel costs, lost wages, and the lack of public or private transportation. The additional implications of distance include the assumption that families have a car, the added stress of travel, and the negative effect of an unfamiliar location on the child or parent(s).

*Travelling is a barrier. You can pretty much do it only in the summer. Sometimes, they expect you to go in the winter, and I have to tell them “sorry, I’m not a winter driver, I can’t do it.”* [family member]

*You’re exhausted taking a child to see someone on a two-hour drive. Well, they’re either exhausted by the time they get there or they’re all wound up. Like, it’s not their normal.* [family member]
Service providers also faced these same barriers in terms of accessing their clients. Many providers spent as much as half of their time on the road, travelling to see a client. The impact of this often lonely and isolating work remains relatively unacknowledged. In many cases, service providers could not access their cell phones because of the lack of transmission in more remote communities.

We’re usually on the road three and a half days per week. [service provider]

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 because we’re so busy doing our own little thing all over these hundreds of square miles. [service provider]

**Environmental Factors: Facilitators to Access and Utilization**

**Small Size**

Living in a small town can assist parents in their efforts to seek help for their children. An active community presence and long-established relationships with service providers lent credibility to parental claims that something was wrong with their child.

In one sense, it’s 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. [family member]

We’re really a team instead of three separate agencies. [service provider]

There is a very positive culture within the community. Service agencies work together. [service provider]

There was also frequent mention of being on a first-name basis with other community residents. The natural emotional and practical support system in such communities was clearly critical to sustaining good mental health.
Discussions and Recommendations

Pathways to mental healthcare for children in rural communities are complicated, dynamic, and non-linear. Although faced with multiple roadblocks, there are also several factors that help to minimize these barriers. The interview data show three overall thematic areas that describe the main barriers and facilitators to care for children and youth with mental health problems in rural Ontario. These are personal, systemic, and environmental factors. More importantly, our analysis reveals that service providers and family members are constantly negotiating ongoing tension, struggle, and contradiction vis-à-vis their attempts to access and provide mental healthcare for children. Most factors identified as barriers are also, under different circumstances, facilitators. Our analysis clustered around the contrasts, contradictions, and paradoxes present throughout the interviews. For example, the small size of communities was often mentioned as a reason for ease of access to care through word of mouth in a close-knit community. This notion of a more supportive rural community has been noted previously (Philo, Parr & Burns, 2003). On the other hand, the small size of the community contributes to the lack of anonymity and stigma associated with mental illness. This “glare of rural familiarity” (Voss, 1996) can contribute to the reluctance of some people to use mental health services. The fear of being seen is frequently an important issue related to the decision to avoid seeking mental health services (Bachrach, 1983).

The assumption of a rural homogeneous reality masks the diversity and uniqueness of rural communities. While emphasizing the common themes prevalent in service providers’ and family members’ narratives, we have attempted to highlight the unique perspectives and experiences that each participant shared with us. Consequently, recommendations made by the parents and service providers participating in this study were varied, but several common themes emerged: i) accessibility; ii) integration; iii) early intervention; iv) education and promotion; v) school and child care; vi) parental support; and vii) rural approach to service delivery.

i) Accessibility: Mental health services should be provided locally to reduce the effects of environmental barriers (transportation, weather, and distance) that families face when attempting to access the children’s mental health system. Access can be improved either through
professionals coming to rural communities as travelling teams or permanently located within the community. In-home services can also be beneficial as they allow professionals to observe the home environment.

*I’m not going to drive two hours a week for three hours intervention and home again, it’s an impossibility.* [family member]

*I really and totally believe in in-home services for intensive, particularly with high-needs kids and families.* [service provider]

There is also a need for a more widely available single point of access into the system that allows a parent to access a broad range of services.

*It would be awful handy to have a place where somebody could actually open up the phone book and go, “I can get my kid help from here.”* [family member]

*They need to have some that is streamlined, that you’re not doing all this piecemeal service.* [family member]

ii) **Integration:** There is a need to link children not only into the mental health system but also to other related services such as addiction services or the correctional system. An integrated service delivery model is required, including a flow of information between service providers.

*The primary care community clinics, it’s a group of physicians that practice in collaboration in a rural part of the district, have employed someone to assist them in making referrals, appropriate referrals to a range of agencies for children.* [service provider]

*I really feel with my experience that I’ve had, that substance abuse and mental health with youth should be really much more joined in this province.* [service provider]
We need to look at a model of service delivery that goes, extends beyond a specific sector so that you can try to get the best utilization of your resources. [service provider]

High staff turnover in rural communities reduces service continuity. Therefore, there is a need to have more permanency in staffing. People in rural areas need access to specialized services, such as vocational training, services for 16 and 17 year olds, and behavioural therapy. Specialized training is required for rural workers to meet the needs of their clientele.

iii) Early intervention: Early intervention with children is important for assessment and treatment, as well as a preventive measure. As a preventive measure, early intervention can support the mental health of young children by providing a positive and stimulating environment that, for example, a day-care program can provide. Parental and family support was also perceived as an important preventive measure. Many children in rural areas do not receive any help for their mental health problems until they enter the school system. Early intervention can facilitate assessment and treatment of mental health disorders for young children and prevent more serious mental health problems as the child grows. The Early Years Centres are up and running in these communities and, in fact, act as system facilitators.

I feel the money should be spent when they’re small on speech and language and all the things that will fit them into the mainstream of society. [family member]

If the money doesn’t get spent when they’re little, when they are 14 and 15, and they don’t, still don’t fit into society, they’re going to jail and the money is going to get spent then. [service provider]

iv) Education and Promotion: Education regarding mental health disorders was viewed as critical in order to reduce the stigma associated with mental health disorders and to help parents detect mental health problems in their own children. Rural residents need to be educated in ways that suit their particular needs. In addition, education and training should be provided to healthcare practitioners to help them identify and treat mental health disorders
Promotion of available services and supports was seen as necessary to improve access to mental health services. Methods of promotion include booklets, pamphlets, and a central telephone number. The school system would be an important vehicle for distributing information. Although pediatric telepsychiatry services were mentioned by several interviewees as an intervention that facilitated system access, the majority of participants did not mention using this service. Better promotion of telepsychiatry in rural areas has been identified as a priority (Boydell, Greenberg & Volpe, 2004).

*We need tele-psych. Somewhere they’re, even if there’s a phone, you know, where they call them and they talk to someone and they give them some suggestions. You know, give them some kind of, well this is where you go.* [service provider]

v) School and Child Care System: The school system and daycare were viewed as essential components of the mental health system. There was a clear need to forge closer partnerships between these systems. The school system was recognized as an important vehicle to distribute information.

vi) Parental Support: There is a need for respite for parents and in particular for respite within the family home. Parent support workers were identified to help parents cope with the stresses associated with dealing with a child with mental health issues. A parent hotline to discuss children’s mental health issues was suggested as a means of avoiding stigma and maintaining confidentiality. Efforts should be made to use the existing platforms of rural communities to generate local support groups as a substitute for absent mental health services, or as adjunct to current services.

*Get them into a room where other parents can talk and you know, give suggestions.* [service provider]

*I’ve been seeing someone for myself and I find that if I talk more about it I find it’s easier. Like if somebody is listening to me about it.* [family member]
vii) **Rural Approach to Service Delivery**: Rural communities differ from urban communities and may need a different model of service delivery that suits their particular needs. A rural model of mental healthcare would need to address the key concerns identified in this report. Although the barriers to accessing children’s mental health services and supports in rural communities are formidable, there are also unique facilitators that are important factors in service delivery.

**Knowledge Translation**

This research was based on an approach designed to have decision makers participate in all aspects of the study from implementation to dissemination. Our advisory committee played a critical role in terms of acting as ambassadors for the study from beginning to end. Information from this study will be used to inform the strategic planning activities of the agencies and organizations serving these rural communities. Thus, project results have important implications for the organization and delivery of mental health services for children in rural areas. It offers information to support the development and evaluation of policies and procedures to overcome some of the barriers to care for children and youth with emotional and/or behavioural disorders.

The knowledge dissemination strategy involves not only peer-reviewed publications and conference presentations but also a series of fact sheets distributed to key stakeholders in the study communities, articles in their local newspapers, and informal face-to-face meetings with multi-sectoral service providers and family members. In addition, in collaboration with the Film Studies Program at Laurentian University, a documentary based on our study results is being produced.
References

1 The term “emotional and behavioural disorders” reflects the continuum of disorder, from mild to serious. The interest here is in exploring the landscape rather than focusing only on serious disorders. The term includes one or more of the anxiety-related disorders, affective and mood disorders, attention deficit hyperactivity disorder, conduct disorder, and oppositional defiant disorder.

2 For instance, the Northeast Mental Health Centre recently announced curtailment in services, including counselling and treatment services due to budget deficits (Sudbury Star, April 17, 2004).

- Devers, K.J. (1999). How will we know “good” qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research.* 34(5):1153-1189.


