MENTAL HEALTH RESPITE SERVICES: A GROUNDED SERVICE DELIVERY MODEL

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ABSTRACT

A needs assessment for mental health respite services was undertaken at Waterloo Regional Homes for Mental Health in Kitchener, Ontario. Twenty-seven participants (consumers, carers, and service providers) were asked about their perceptions of the need for mental health respite services, and about their preferences for a model of respite in their community. A convergent analysis of participants' responses leads to one possible model of respite, while a divergent analysis considers program and value dilemmas for potential planners of programs directed at multiple stakeholders. Participants' frustrations with current services remind mental health programs of the importance of consulting with all stakeholders as they evaluate and develop programs.

Mental Health programs in Ontario reflect a history of haphazard, unplanned policy decisions based on little forethought and little consideration of available resources (Simmons, 1990). Many people with mental health issues have moved out of institutional care without adequate supports in place (Carling, 1995; Simmons, 1990). Families, who are often the primary carers, have little support available to them (Karp, 2001). The resulting stress placed on the family system can have negative physical and mental health consequences for the individual with mental health issues and for their carers (Cowley & Ordell, 1999; Karp, 2001).

Consumers often require increased support at times when it is most difficult for members of their natural support networks to be around them. Horwitz and Reinhard (1992) summarize this dynamic when they tell us that "[a]t the same time as the availability of formal control has declined the structural capacity of informal social networks to care for the seriously mentally ill has weakened" (p. 113).

A review of Ontario's mental health policy demonstrates that respite services are consistent with the mandate of the Ministry of Health and Long Term Care. *Making it happen: Implementation plan for mental health reform* (Government of Ontario, 1999) advocates a "comprehensive continuum of supports and services," including respite as one possible support service (p. 9). Further, it mandates that "crisis programs are in place to divert people from inpatient hospitalization . . ." (p. 29).

Waterloo Regional Homes for Mental Health

Waterloo Regional Homes for Mental Health (WRHMH) is a non-profit organization located in Kitchener, Ontario. It is funded by the Ministry of Health and Long Term Care to provide and facilitate access for adults with serious mental health issues, and their families, to a wide range of affordable housing and/or individualized, flexible community support services. WRHMH operates four group homes with levels of staffing varying from 20 hours a week to 24 hours a day. They also provide subsidized supported housing to adults with mental health issues in four bungalows with three residents in each; two apartment buildings with a total of 25 residents; and in head lease arrangements (where the agency is the tenant, subletting at a subsidized rate to consumers) with various landlords in the region (72 apartment units). In total, including consumers living in market rent apartments, with families, in WRHMH housing and in other circumstances, the organization provides support and/or housing to approximately 220 individuals annually with serious mental health issues.

From hearing about the lives of people served by the agency, the board of directors of WRHMH recognized that there might be a need for respite services for families managing mental health issues within the Region. They were particularly concerned about the need for respite for aging parents who provide care to adult children with mental health issues, and were interested in discovering alternatives to medical interventions which usually involve institutionalization at times of crisis. A working committee was struck, and the first author worked with them to explore the need for respite services for mental health in Waterloo Region. The committee included the executive director and assistant executive director of WRHMH, one parent of an individual with serious mental health issues, one consumer of mental health services, two other members of the Board of Directors, both professionals in social services, and the first author. In addition to gaining some perspective on the need for respite services, the group decided to ask research participants about their preferred respite service, and about any suggestions they had about this preferred service. From the outset, the committee adopted a broad perspective of the definition of respite, and recognized the importance of considering the consumer and the carer in any future program.

THE RESPITE LITERATURE

A respite service, in its broadest sense, is any service that provides a break (Newton, 2000). The service may be directed to the carer or to the individual with a serious mental health issue. "A unique feature of respite care is its emphasis on meeting the physical and mental health needs of both the caregiver and the care recipient" (Friss Feinberg & Kelly, 1995, p. 701).

Respite services are very common in developmental services, and are beginning to grow in the field of Alzheimer's disease and among service providers focusing on an aging population (Braithwaite, 1990; Brody, Saperstein, & Powell, 1989; Opie, 1992). In some cases, these are specialized services for people dually diagnosed with mental health issues and developmental disabilities (Kwok, 2001) or aging and mental health issues (Farran, Horton-Deutsch, Loukissa, & Johnson, 1998). They are less common in community mental health in Canada, but there are examples of mental health services involving respite and crisis stabilization emerging in western Canada (e.g. Vancouver Island Health Authority, 2003). In addition, the New Brunswick government has recognized the need to expand respite services (Health services review, n.d.). In Ontario, one mental health respite service was identified: the

Gerstein Centre in Toronto (www.gersteincentre.org). Safe houses, usually managed by consumer-survivors, are available in some communities for crisis stabilization (W.Czarny, personal communication, October, 2002), but attempts to locate literature about them were unsuccessful. Because of the paucity of literature regarding mental health respite, much of the following discussion has been drawn from respite literature in the developmental, aging, and Alzheimer's fields.

Some examples of established respite services include: matching and brokerage programs (where an agency matches those offering respite to those in need and often provides financial support for families to use as they decide); respite care cooperatives (where families trade services); volunteer family homes (where other families voluntarily provide respite in their home); buddy programs (volunteers for recreation); overnight camps; group day programs (structured programming offered by an organization); group respite facilities (overnight accommodation specifically for respite); drop in (unstructured location for socializing); community residences with one or two crisis/respite beds; and institutions (Canadian Association for Community Care, 1996). Some authors have recognized the need for multi-faceted approaches to providing respite service (e.g., Brody et al., 1989; Green, Vukovic, & Firemark, 2002; Montgomery, 1995), but note that lack of funding often limits the ability of organizations to do this.

What Do We Know about Respite Service Preferences?

Studies of families, and the people they support, report that respite services are underused for a variety of reasons: lack of flexibility in geographical location, type of respite offered and hours of service (Cowley & Ordell, 1999; Herman & Hazel, 1991; Newton, 2000; Opie, 1992; Salisbury, 1990); feelings of responsibility on the part of carers (Cowley & Ordell, 1999; Opie, 1992); lack of trust (Cowley & Ordell, 1999; Dossetor, Nicol, & Stretch, 1993; Newton, 2000; Salisbury, 1990); cost (Cowley & Ordell, 1999; Herman & Hazel, 1991); cost of transportation (Cowley & Ordell, 1999; Newton, 2000); lack of awareness of services (Cowley & Ordell, 1999; Opie, 1992; Sholl, Saunders, & Radburn, 1991); the tendency to wait for a crisis to use services (Dossetor et al., 1993; Opie, 1992); and feelings of guilt for needing support (Cowley & Ordell, 1999; Opie, 1992). Sholl et al. (1991), for example, found, in a study of respite for families caring for an individual with developmental challenges, that only 47% of carers knew that respite services were available in their home.

Respite services must be flexible in service, time, and location (Canadian Association for Community Care, 1996; Cotterill, Hayes, Flynn, & Sloper, 1997; Friss Feinberg, & Kelly, 1995; Green et al., 2002; Intagliata, 1986; Opie, 1992). Green et al. (2002), from interviews with consumers served by a Health Maintenance Organization in Washington and Oregon, found that the need for increased support at times of crisis could be partially met by offering respite services. They underlined the importance of these services being available as needed, without the need to plan ahead.

Intagliata (1986) suggests that programs have clear goals, and be sure services are directed toward those goals. Grant and McGrath (1990), reporting on surveys of families caring for those with developmental delays in the United Kingdom, suggest that respite services need to be part of a broader spectrum of services, and the Canadian Association for Community Care (1996), in its Best Practices manual, supports this. This broader spectrum of service should include help to build systems of support, problem solving, and education to carers about self-care. Grant and

McGrath (1990) suggest that this will help prolong the benefits of respite past the actual respite time, and decrease dependency on outside services.

There is a notable gap in the literature regarding staffing in the provision of respite services. Perhaps because services in the developmental and Alzheimer's fields are professionalized, there is no discussion of who should be providing respite service and no discussion about the possibility of peer service providers. This is an important issue in mental health respite as authors are recognizing the benefits of peer-provided service (e.g. Moxley &. Mowbray, 1997).

Benefits of Respite Services

Other authors have acknowledged the variation and lack of clarity in reports of the benefits and particular outcomes of respite services (e.g., Canadian Association for Community Care, 1996; Intagliata, 1986; McNally, Ben-Shlomo, & Newman, 1999; Zarit, Stephens, Townsend, & Greene, 1998). Respite may help people to maintain independent living, extend the period of time caregivers are able to provide care, and help people to build more positive relationships. It may also help users increase their independence and broaden their range of activities (Cotterill et al., 1997). However, as Intagliata (1986) suggests, it is difficult to assess the benefits of respite without adequate outcome studies.

Respite has been shown to be more cost-effective than other forms of intervention. Sledge, Tebes, Wolff, and Helminak (1996) found that a combination day hospital/crisis respite program was found to be 20% less expensive than in-hospital treatment for consumers assessed as needing hospitalization for safety of self or others. Standardized measures of symptoms, functioning, social adjustment, quality of life and satisfaction with services demonstrated essentially identical outcomes for the two programs (Sledge, Tebes, Rakfeldt, Davidson,& Lyons, 1996). According to the ARCH National Resource Center for Respite and Crisis Care Services (2001), the cost of one year of nursing home care could pay for 4,590 hours of respite. In comparison, if an individual in a nursing home could stay in her/his own home with respite provided for weekends, this would represent only 960 hours of respite.

THE RESEARCH PROJECT

This research project sought to determine if there was a need for respite services in Waterloo Region, so the research team designed a needs assessment. If participants felt there was a need, ideas about their preferred model were also sought. A needs assessment explores a perceived need for certain services and is the beginning stage of program development (McKillip, 1987; Neuber, 1980; Posavac & Carey, 2003). In addition, because the committee wished to consider respite from a broad perspective, considering the needs of both consumers and carers, people from both these groups participated in the project, along with service providers who were considered key informants. Participants were asked to respond to questions based on their experiences with both consumers and carers. Involving all stakeholders is a unique approach to exploring respite needs and to developing related programming. Other needs assessments of respite in developmental, physical health, aging, and Alzheimer's fields have been carried out with carers and care-receivers, or with carers and professionals (Clarke & Finucane, 1995; Hazell, Tarren-Sweeney, Vimpani, Keatinge, & Callan, 2002; Lutzer DeFilippo, & Brubaker, 1988; Michallet, Le Dorze, & Tetrault, 2001; Segall & Wykle, 1989). No needs assessments, though, were identified that included all three stakeholders. In mental health, two examples of respite needs assessment

were found, one interviewing carers (MacCarthy, Lesage, Brewin, & Brugha, 1989), and one interviewing carers and nurses (Farran et al., 1998).

The Researchers

The first author approached this project with a variety of life experiences related to mental health services: as a user of mental health services, as the former partner (and primary carer) of a consumer of mental health services, and as a community support coordinator with WRHMH. The second author has worked as a mental health educator with the Canadian Mental Health Association and conducted research on children's mental health issues for many years. Our privileged status as white women and as members of the middle class is also present in the study. This status may have affected our ability to adequately recognize cultural issues in mental health and, given that most mental health service providers in Waterloo Region are also white females, consumers and carers may have associated us with service providers, increasing the already present power differential. Being female may have affected our abilities to recognize aspects of the male experience; however, it may also have made us more attuned to issues of gender.

METHOD

Because research on mental health programs is relatively new, using a grounded theory approach is appropriate (Creswell, 1998; Strauss & Corbin, 1998). The use of grounded theory allows for the model to be built honouring the voices of participants, as opposed to approaching the research with preconceived ideas about the nature of a possible model (Creswell, 1998; Strauss & Corbin, 1998). Qualitative methods were used because the research questions focused on understanding individual experiences, specifically perceptions of need for respite and the reasons behind these perceptions. Using open-ended, semi-structured interviews, data were collected through focus groups and individual interviews. Interviews were conducted with service providers (individual interviews), carers (focus groups), and three consumers (individual interviews). Three other consumers requested to be interviewed as a group, and a peer consumer co-facilitated this focus group. The interviews lasted between 45 minutes and two hours. The authors and the members of the working committee developed the interview guides. Questions used for all interviews were similar and included the following: "What are the challenges facing individuals with mental health issues?"; "How do they face those challenges?"; "What are the challenges facing carers?"; "How do they face those challenges?"; "Do you think there is a need for respite services for mental health in our community?" (Prompts: Why?; What needs would it fill?); and "What would be the most helpful type of respite service?" (prompts: Where would it be?; What kind of philosophy would it have?; What particular services would it provide?; How should it be funded?)

Participants

Six consumers, 12 carers and nine service providers were interviewed for this project. Participants were selected using purposive sampling, as they were recruited through organizations that provide services for those affected by mental health issues (Royse, 1991). Participants signed a consent form that outlined the purposes of the study and the possible uses of the information. All participants also agreed to be audio taped, and were informed of the methods used to store and destroy the data.

Refreshments and reimbursement for transportation costs were provided but participants were not compensated for their time.

All participants except one consumer were white; however, some of the cultural diversity in Waterloo Region was represented through carers and consumers of German, Italian and Portuguese heritage. There were four male and two female consumers, ranging in age from 25 to 64, with the majority between the ages of 45 and 54. The most common source of income for consumers was the Ontario Disability Support Program and all but one of them lived in subsidized housing, including one individual who lived in a WRHMH bungalow. All consumers lived independently from the person(s) they identified as their primary support.

Reflecting the demographic make up of carers in general (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Biegel, Sales, & Schulz, 1991), all but one carer were female. They ranged in age from mid-30s to 80s, and most carers identified themselves as the parent of the consumer. Four carers were employed full-time, two part-time, and the rest received pensions. In two instances carers indicated that the person with mental health issues they supported lived with them; the rest lived separately. The consumers and carers interviewed were not related to one another.

Service providers represented a broad array of organizations that provide support to consumers and carers, including shelters, self-help organizations, hospitals, supported housing, mental health education, and consumer and family support services.

Limitations to Sample

All consumers interviewed were attached to service. This means that the viewpoints of those not receiving service are absent from the study, and their needs for respite may be quite different. The experience of male carers is not well represented in this study either, as all carers except one were female.

Data Analysis

Audiotapes from interviews and focus groups were transcribed and analyzed, first for categories of response. Using the constant comparison method (Strauss & Corbin, 1998), categories were revised throughout the study. Starting data analysis after the first interview, the researchers formulated tentative categories. These categories were either supported or modified by information from subsequent interviews. The authors were responsible for the data analysis, although the committee provided feedback and made suggestions for changes throughout. Saturation was reached for all categories (Kirby & McKenna, 1989; Strauss & Corbin, 1998). Categories were then analyzed for similarities. Those that shared characteristics were combined to form concepts. For example, the in-vivo categories (Strauss & Corbin, 1998) *over-involved* and *treat like a child* were combined to form the concept *maintaining boundaries* under carer challenges; this was further refined by adding it to other similar issues to form the concept *family relationship issues* . By examining the relationships among concepts, themes were identified (Tutty, Rothery, & Grinnell, 1996). For example, when interpreting the model requested by participants, we noted that carers seemed to be telling us that they wanted to have more involvement in their loved one's care, while consumers articulated their desire to make their own decisions. At first, these appeared to be purely conflicting desires, but on further analysis, we combined the concepts of carer involvement and consumer empowerment to note the need for empowerment of both stakeholder groups. Participants in

the project were sent the results of the data analysis for input and were invited to a stakeholder meeting to discuss the results. No suggestions were made for revisions. Concepts, with examples of categories, and themes are presented in the *Results* section, while one suggested respite program is presented in the *Discussion* section.

RESULTS: CONCEPTS

The results are separated into two sections. In this first section, the *concepts* noted in the data are described (Tutty et al., 1996). These are organized under the headings "Challenges facing carers and consumers" and "Participants' visions of respite." Following this discussion, the *themes* are presented (Tutty et al., 1996). In both sections, the similarities and differences among groups of participants are examined.

Challenges Facing Carers and Consumers

Participants were asked to reflect on challenges for themselves and for others affected by mental health issues. This means that consumers sometimes commented on their understanding of the experiences of carers, and vice versa, or that service providers offered their understanding of the experiences of carers and consumers. All participants identified challenges with family relationship issues and the inadequacy of mental health services. Consumers and service providers also identified attitudes of others as creating challenges for consumers. For participants quoted, we identify from which group they come, with S.P. signifying Service Provider.

Carer challenges. Participants mentioned many challenges faced by carers; these have been conceptualized as family relationship issues, emotional responses, and inadequacy of mental health services.

Family relationship issues. Carer #5, speaking of her challenge to avoid over-protection or creating dependency, said "Sometimes I feel like she's a kid and she's not. She's my [adult-aged relative]." Participants mentioned that family routines are interrupted and that they face practical strains due to the supports often required of them (time taken by shopping, medication management and cleaning, as well as financial stress).

Emotional responses. Carers spoke of fear of the future and of the unpredictability of mental health symptoms. Carer #3 said, "It's hard because you don't know when they're going to hit rock bottom again." Carers also spoke of being angry (also mentioned by consumers as an experience of their carer), frustrated, exhausted, worried, and resentful. Loss was a major theme among carers; best described by Carer #4, who stated, "You don't know them anymore." The family's stress was emphasized; as S.P. #1 said: "When the individual is in crisis, the whole family is in crisis."

Inadequacy of mental health services. Carer #8 linked the stress on the family to inadequate services, saying, "The government is simply increasing illness in the family. We are taking the place of a hospital ward and we can't." The primarily identified carer challenge related to frustration with inadequate mental health services in Waterloo Region. In the words of S.P. #1, "People are always walking into walls," which summed up several concerns about mental health services in Waterloo Region, including *accessibility*, *communication*, and *responsiveness* . Accessibility referred to the presence of long waiting lists, the fact that local services are not linked and, in fact, "They often operate in competition with each other," stated S.P. #3. It also

included the fact that certain types of service, particularly alternatives to hospitalization, do not exist in Waterloo Region. Communication referred to both communication with loved ones about a consumer's health and communication between services. Carer #2 highlighted both of these issues when she asked, "Why doesn't anyone talk to me? It's like it's all a big secret . . . Well, they [services] don't talk to each other either, so I guess I shouldn't be surprised." Services, according to participants in this project, are not responsive to the needs of people using them. Participants spoke of a 'one size fits all' approach to service delivery. Carer #6 asked: "Whatever happened to individualized supports? [The service her son uses] say they provide individualized support, but as soon as he gets challenging, or doesn't fit with what they want to do, they want to send him somewhere else."

Consumer challenges. Many of the challenges faced by carers were shared by consumers. The most frequently mentioned challenges for consumers included family relationship issues, attitudes of others, and inadequate mental health services.

Family relationship issues. Unclear boundaries in family relationships were highlighted by several consumers. Consumer #4, for example, said, "I know it's hard for them [supports] to watch me when I am ill. But they make things worse when they try to get too involved." Consumers did not mention the practical strains as noted by carers.

Attitudes of others. Repercussions from attitudes of others were described as loss of employment, friendships and family due to the difficulties others face in maintaining relationships with consumers through periods of active symptoms: "I have lost many jobs and really don't have a lot of people in my life. There's a lot of loss with mental illness," shared Consumer #5. Consumers elaborated on this loss, discussing the inability of others to understand that their symptoms are going to pass and are not to be feared. "It's getting better," said Consumer #6, "but people are afraid of mental health issues. They treat you like a little kid or, for some people, like a monster." Service providers highlighted similar concerns, and several mentioned challenges faced by consumers when their carers are skeptical of their progress, or have unrealistic expectations of them. All service providers lamented that most consumers lack informal supports.

Inadequacy of mental health services. Consumers spoke of the lack of choice in the mental health services they receive. Consumer #1 suggested, "It should be what you want, not what they want to give you."

Participants' Visions of Respite

Among the participants, there was almost unanimous support for the need for mental health respite services. When questioned about the preferred way to provide respite, the importance of offering a range of services was emphasized by all categories of participants, as was the need for respite to provide education and support, along with the break, in order to address the possibility that respite may become an end unto itself. The importance of not creating dependency on the service was presented by carers, consumers and service providers alike. Consumer #4 identified this quandary when she said, "One thing to be careful of is that consumers can become dependent on staff. I see this in the hospital. People think the nurses are their friends and then they feel alone when they aren't in the hospital." The responses received to the question, "What would be the most helpful type of respite service(s)?" are organized below by two broader concepts: *preferred services* and *philosophy of service.*

Preferred services. Consumers, carers, and service providers all commented on their preferred services, but there were similarities and differences among responses. All participants outlined the need for a range of services. The specific services requested included an emergency phone line, support and education, links to other services, and, most commonly suggested, an overnight respite facility for consumers. Service providers also suggested the possibility of someone stopping by when a carer is away. Carers had many concerns about the lack of opportunities for consumers to socialize and thus suggested a day program that would provide respite and socializing opportunities. For context, it is important to note that at the time of this research project, Waterloo Region had recently lost a high profile consumer self-help program which provided both social and employment opportunities.

An interesting source of divergence between groups of respondents was the potential location of an overnight respite service. Service providers maintained the importance of a downtown location, for geographical accessibility. Consumers and carers both preferred that it not be downtown, although for different reasons. Consumers envisioned a quieter, more relaxing environment, conducive to their perception of healing. Carers' requests that the service not be downtown related to their fear of consumers being exposed to drugs and crime at a time of vulnerability, a possibility they considered to be especially salient to the downtown area. Both consumers and carers suggested instead a neighbourhood accessible to the downtown.

Philosophy of service. There was general agreement among consumers, carers, and service providers on four aspects of service philosophy, or service principles: accessibility, well-trained and supported staff, clear communication about services and procedures, and increased service choices. Within some areas of these aspects, however, there were differences in detail. These concepts are elaborated below.

Accessibility. Carer #1, in describing the inaccessibility of services complained, "It seems like something major, a disaster, has to happen before we get any help." Accessibility of service, then, refers to the ability to access it proactively, rather than simply reactively. Accessibility also refers to financial affordability. Typical of social services, the question of financing a new initiative became important in the discussions with all participants. Suggestions from service providers included fee for service and various forms of government funding. When questioned about fees, some participants thought that a fee based on income would be fair while others felt that the program should be fully funded. Not surprisingly, no participant thought that a fee for service based on the actual cost of service was feasible. As Carer #4 said, "If we could afford that, we'd do it ourselves."

Staffing. Staffing considerations drew a great deal of comment from all three groups of participants, specifically related to a possible overnight respite program. Consumer #3 represented the opinions shared by most participants when he said, "You'd need a special kind of staff used to working in the trenches." Many participants used the same phrase, "a special kind of staff," and two service providers pointed out that an overnight facility breeds the potential for abuse of power. Others spoke of the need for well-trained and supervised staff to have opportunities to debrief and be supported, and all but one participant thought that if an overnight facility were offered, twenty-four hour staffing would be necessary. Two consumers suggested that these staff have a nursing background, and two also mentioned that a psychiatrist as consultant would be helpful. Service providers and consumers expressed a desire for both professional social support staff and consumer staff, while carers only spoke of professional social support staff.

Clear communication about services and procedures. Consumer #1 warned of the potential that "[t]his thing could become huge," and according to the need expressed by participants, his words are important to respect. One way to address this issue, according to participants, is to be clear about the services offered and about the procedures. Clarity could also help to build trust, a key concern, especially of carers. Carer #8 stated, "If my son is going away somewhere I better know what kind of people and program it is." Clarity of procedures was also mentioned as a way to avoid dependency or overuse of the service. Some service providers suggested that for an overnight respite program, participants sign a contract regarding length of stay and procedures (in times of crisis, this may not be practical, but it stresses the importance of resolving discrepancies between expectations of service and limitations of service). Other suggestions related to clarity included planning ahead for the point at which communication about the participant would happen with others, and a clear intake and referral process.

Increased service choices. All participants noted the importance of choice in a service. Considering consumer and carer grievances about inflexibility this is an essential consideration. Consumer #2, describing the services he is accustomed to, said, "They won't listen to you. They just do what they think is best, without asking what you want. It makes you feel like you're sick and not strong."

Choice for carers meant a range of service options available and the possibility of being involved in their loved one's care, while service providers and consumers, but not carers, emphasized the need for an atmosphere of freedom and choice, where consumer preferences are given full recognition, requesting the least intrusive means of support. Specific examples of choice for consumers were focused particularly on choosing whether or not to take medication, and on consumer control of their length of stay and of their activities. Consumer #2 suggested, "Let people make their own decisions 'cause they're gonna have to when they leave again."

RESULTS: THEMES

The broad themes identified in the data were *need for respite*, *consumer and carer empowerment as a primary value*, and *safety*. In order to recommend a possible respite service for WRHMH, convergences in responses needed to be highlighted. To do this, a convergent analysis was undertaken, where patterns and areas of agreement between groups of participants were identified (Royse, Thyer, Padgett, & Logan, 2001). In order to highlight potential challenges in planning a respite program, and to help other communities considering the development of a respite program, it also became important to uncover the divergences in responses. The themes encountered in this study, then, are also examined for differences between groups.

Need for Respite

Similarities across groups. All consumers, all carers and most service providers stated that there was a definite need for respite services. Most of the respondents said that the need was immense, with S.P. #6 stating, "Big time. How big can I say that word big?" Some of the reasons for needing respite included: increased symptoms, post-hospitalization support, a break for carers, increased support for consumers, and a break for consumers from room mates or family members. The clarity with which participants described their preferences for such a service as well as their enthusiastic reactions to the study provides evidence of the depth of this perceived need.

Differences between groups. Three service providers gave qualified affirmative responses about the need for respite, one with the opinion that respite services directed at carers would perpetuate the myth that a person with mental health issues needs a great deal of care, and two others with the concern that certain consumers would overuse the service.

Empowerment as a Primary Value

Similarities across groups. All participants suggested a respite service able to accommodate the various needs of its stakeholders, creating a context of choice and responsiveness that encourages the empowerment of service users. Participants also underlined the need for respite to help build informal connections, to provide education, and to assist in the development of problem-solving skills. As stated earlier, the literature supports the need for flexibility and accessibility (Dossetor et al., 1993; Herman & Hazel, 1991; Montgomery, 1995; Newton, 2000; Opie, 1992, Salisbury, 1990; Sholl et al., 1991), and for respite to be part of a broader spectrum of services (Canadian Association for Community Care, 1996; Grant & McGrath, 1990). The literature tells us that a respite service in isolation may breed dependency and may not achieve the desired result of helping people to cope better in the future (Canadian Association for Community Care, 1996; Grant & McGrath, 1990). This calls for an educational, supportive aspect to respite.

Differences between groups. The theme of empowerment was further explicated by participants. Consumers and service providers focused on the empowerment of consumers, whereas for carers empowerment represented more involvement in the support of their loved one, and increased communication about the state of their loved one's mental health. "In the hospital," said Carer # 9, "they expect you to just trust that they know best. Well, I'm his mother, for God's sake. Don't you think I should have something to say about that?"

Safety

Similarities across groups. All participants highlighted the importance of safe-ty in planning an overnight respite service. This idea of safety was commonly communicated in two ways: clearly communicated procedures, purpose and limits, and well-trained staff.

Intagliata (1986) states that respite services should have clear goals at which services are directed. Participants in this study told us the same, emphasizing that one of the ways to gain service-users' trust is to clearly explain the services that can be provided, and to be honest about any limitations of the service.

Intagliata (1986), Montgomery (1995) and Opie (1992) assert that respite staff must be well trained. Service providers, consumers and carers all expressed the importance of this. However, they also expanded on this understanding to say that staff need to be well supported and experienced. Staff managing those in crisis or close to crisis require emotional outlets to take care of themselves so as to be at their best in their job.

Differences between groups. The most important safety consideration for consumers was that users of a respite service be screened, in particular for drug and alcohol use. Safety from the perspective of carers included the provision of service only by *non-consumer* social support staff, while consumers indicated that the presence of medical staff would increase safety.

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DISCUSSION

Respite Program

One possible service delivery program model of respite, based on the similarities in responses from participants, is illustrated below. It is important to note that this program model comes directly from participant responses as is consistent with a grounded theory approach (Creswell, 1998; Strauss & Corbin, 1998). It also demonstrates that we respect participants' ability to identify their needs. Although not the only possible program emerging from this research project, Figure 1 below presents one approach to providing respite service.

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FIGURE 1
Respite Program
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At the intake process, consumers and carers could be made aware of the choices available for respite service, and helped to access them. This assumes there would be time available to complete an in-depth assessment. However, there is also need for respite in a crisis situation. This model allows for those in crisis to access respite, with a brief intake and immediate overnight service followed by a more extensive assessment after the situation is stabilized. In the diagram, this is reflected by arrows in both directions, from intake to respite and from respite to intake.

Limitations of the Proposed Respite Service Delivery Program Model

By attempting to meet as many of the preferences of participants as possible, the program suggested is quite complex and it could be expensive to implement. Few agencies would have the resources to immediately implement such an expansive program. However, perhaps there are aspects of existing services that could be expanded or modified to meet the needs expressed by participants. According to participants in this project, the most important service to implement is the overnight respite service. A way to start in a less comprehensive way could be to set aside beds at an existing residence, or to locate families willing to provide room in their homes. The Florida Respite Coalition provides a matching service for those looking for respite service with those willing to offer it in their homes (www.FloridaRespite.org).

Implications for Implementation

Carrying out a needs assessment that includes various groups of stakeholders may create complications for program planners because there may be tensions between the preferences of the different groups, as this study demonstrates. In any program that includes stakeholders in its development, choices will need to be made about whose needs and goals are privileged. Program planners, then, are often in a position of prioritizing goals (York, 1982). It is at this point that the values of the organization or the particular program become paramount, as the choices made will ideally reflect these values (York, 1982), and the philosophy of the organization (Gilbert & Terrell, 2002).

Using the results from this research project, one of the tasks facing program planners will be to decide whose needs are prioritized. They will need to consider differences in the meaning of empowerment since consumers and service providers asked for consumers to have more control over their support, while carers wanted to be more involved in decision-making. If an organization decides to honour both of these requests in a program, one can foresee the potential for conflicts between carer and consumer control. When deciding whose voice to honour, an organization ought to consider its values and the ways in which these values will be represented in the choices it makes.

CONCLUSION

The participants in this study offered important considerations for planning a respite service for mental health. Similarities in their views of a preferred service were noted, as were the differences in meaning of their preferences. The preferred respite program in this study was an overnight facility for consumers also providing opportunities for links to other services. Acting on these preferences, Waterloo Regional Homes for Mental Health is currently working as part of a regional crisis-response committee to investigate funding opportunities that would support establishing such a respite service in their community. They have also very recently received funding to establish crisis beds in existing supported residences.

Participants' frustrations with current services remind mental health programs of the importance of consulting with stakeholders as they evaluate and develop programs. By consulting with all three groups—carers, consumers, and service providers—this research provided a unique way to include the voices of diverse groups in program planning. It also raised some of the dilemmas in decision making posed when diverse groups are consulted.

RÉSUMÉ

Une évaluation de besoin des services de répit en santé mentale a été conduite à Waterloo Regional Homes for Mental Health à Kitchener en Ontario. On a questionné 27 participants et participantes (clients et clientes, aidantes et aidants familiaux et intervenants et intervenantes) quant à leur avis du besoin des services de répit en santé mentale et leurs préférences d'un mode de répit dans leur communauté. Une analyse convergente mène à un mode possible d'offrir le répit, tandis qu'une analyse divergente considère les dilemmes de programmes et de valeurs pour ceux et celles qui planifieront des programmes dont les récipients et récipientes viendront de divers milieux. Les frustrations des participants et participantes envers les services actuelles rappellent aux organismes de santé

mentale l'importance de consulter avec divers groupes lorsqu'ils évaluent et développent leurs programmes.

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