Family Involvement

Strategies to develop family-driven mental health services

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This report was commissioned in 2007 by Mary Heiserman, former Director of Wilder's Mental Health and Education Division, as part of a series of literature reviews. Other reports in this series examine dual diagnosis services and the mental health needs of immigrant children.

Executive summary

In 2001, the Report of the Surgeon Generals' Conference on Children's Mental Health first identified family involvement as a guiding principle to improve children's mental health services across the nation. Although momentum behind family involvement has grown among parents, policymakers, and providers, mental health agencies and other systems serving children continue to struggle to effectively put these policies and principles into practice.

This report describes effective family involvement strategies and identifies common barriers to collaboration. It also provides the Wilder Foundation with a recommended process to assess their current level of family involvement and develop new strategies to meaningfully engage families in services and decision-making.

Family involvement cannot be summarized in a single sentence. Instead, a set of guiding principles has been developed by the Federation of Families for Children's Mental Health to describe the values and characteristics evident when families are involved in mental health services. A few key characteristics of family-driven services include:

- Family and youth experiences, goals, and perceptions are used to steer decision making in all aspects of service and system design, operation, and evaluation
- Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued
- Administrators and staff activity demonstrate partnership with all families and youth by sharing power, resources, authority, responsibility, and control
- Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise when making decisions about treatment and services

Family involvement initiatives can take a variety of forms, including peer support groups, parents employed as providers of care coordination or mentoring services, or independent family-run organizations. When developing local initiatives, it may be useful to consider opportunities to collaborate with other services and enhance the capacity of existing parent groups to meet the broad needs of youth and families.

Benefits of family involvement

There are a growing number of consumer- and family-driven groups, agencies, and organizations focused on providing peer supports and services. Although there is limited research demonstrating the effectiveness of these programs in improving youth mental health outcomes, early studies have shown that family involvement programs help parents develop more positive feelings about their child's treatment and improved parenting skills. Some research also suggests that parent involvement can lead to shorter stays in residential placements.

There is also evidence that family involvement can change the way in which services are delivered. When family members are hired as service providers, they often spend more time with clients, demonstrate greater sensitivity to the individuals served by the agency, and help other professionals focus on recovery instead of possibilities of poor mental health outcomes.

Existing research methods that focus primarily on alleviation of mental health symptoms as evidence of program effectiveness may not fully capture the benefits of family involvement initiatives. Similarly, traditional research approaches that emphasize the use of randomized controlled trials and fidelity to standard programming do not easily allow for flexibility and individualized services, principles that are essential to family-driven care. New research strategies and outcome measures must also be explored with families to determine better ways to examine the effectiveness of these services.

Challenges to family involvement

Agencies interested in developing initiatives to increase family involvement face a number of common barriers, such as tokenism, role ambiguity, staff tension, and lack of long term vision. Some of the strategies agencies can use to address these challenges include:

- Create meaningful positions for family members that include appropriate professional development, training, and mentoring opportunities
- Increase the number of family representatives participating on advisory boards and other decision-making bodies at all levels of the organization
- Develop a vision of family involvement that is shared by all agency staff
- Encourage processes that allow family members and professionals to participate in multi-disciplinary teams and collaborate on projects
- Establish sustainable funding streams to support new staff positions or other family involvement initiatives

Opportunities for increased family involvement at Wilder

To varying degrees, parents and family members have been involved in the mental health programs offered through the Wilder Foundation. At the individual treatment level, family and youth involvement has become a standard part of practice. Input from parents, youth, and families is essential to the development of individual treatment goals and strategies. Although the Foundation does not currently offer peer support groups for parents and families, program staff do help some parents become connected to groups available through other community-based agencies.

To a lesser extent, parents and family members also have opportunities to provide program-level feedback or input into program decision-making. As new programs have been developed, parents have served on temporary advisory boards. Less formally, parents have opportunities to provide feedback through direct discussions with staff, comment cards, and annual satisfaction surveys. Although there are opportunities for parents to give input about the services they receive, parents and family members do not have strong decision-making roles within the organization.

There is a growing body of literature supporting family involvement as a key component of effective mental health services. However, national policies and recommendations intended to support family involvement are often difficult to adopt in practice. Although programs that have developed successful family involvement strategies can serve as models, in order to truly adopt the philosophy of family-driven care, agencies must work with families to develop the most appropriate supports and services. In order to begin a thoughtful process to examine possible approaches to increase family involvement throughout Wilder Foundation programs, Wilder Research recommends adopting the following six steps:

- Examine current strategies used to engage youth and families, and existing needs of participating youth and parents
- Convene an advisory group, comprised of administrators, program staff, and parents
- Consider a variety of peer mentoring and peer support models that could be adapted and supported by the Wilder Foundation to meet the needs of local family members
- Consider strategies to recruit family members into existing staff roles
- Based on the expressed needs of youth and families, consider developing new staff positions that would be filled by parents/family members
- Consider reimbursement mechanisms that could be utilized to create sustainable family support positions

Project background

The Wilder Foundation provides mental health services to youth and families through a variety of programs, previously referred to as the Mental Health and Education Division. Although these services incorporate a variety of strategies to engage youth and families in individual services, there have not been broad initiatives to increase family involvement in service planning, delivery, and decision-making. This report was written to describe the principles of family involvement, identify barriers organizations often face when initiating policies to increase family involvement, and highlight strategies the Wilder Foundation may use to effectively increase youth and family involvement in mental health services.

Methodology

The information presented in this report was collected primarily through a literature review and key informant interviews with representatives from family-run service organizations and mental health advocacy organizations. Although the information gathered through a review of the literature focuses primarily on steps taken to involve parents and families in children's mental health services, it also incorporates examples and lessons learned from consumer-run organizations within the adult mental health system. To examine current family involvement strategies within existing children's mental health programs, key informant interviews were conducted with two Wilder Foundation staff. The recommendations included in this report provide the Wilder Foundation with a process to increase and expand family involvement and ultimately provide more effective services.

Introduction

Over the past 25 years, there has been growing demand for increased consumer involvement in the planning, delivery, and evaluation of mental health services. On a national level, the recommendations from the 1999 Surgeon General's Report on Mental Heath, the Veteran Administration's New Action Agenda, and the Institute of Medicine's *Crossing the Quality Chasm* report, all identify shortcomings in the current mental health system and a need for increased consumer and family involvement.

An example of this policy shift can be found in the 2003 New Freedom Commission on Mental Health's report:

> *…the Commission is convinced of the need to increase opportunities for consumers and family members to share their knowledge, skills, and experience of recovery…Consumers and families with children with serious emotional disturbances have a key role in expanding the mental health care delivery workforce and creating a system that focuses on recovery.*

These policies and recommendations are beginning to be reflected at the practice level, as well. For example, a number of grants funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) require consumers and family members to be involved in project planning, delivery, and evaluation. A growing number of local, state, and national policies encourage consumers and family members to be involved in all aspects of mental health service planning, delivery, and evaluation. This policy shift is, in part, a response to years of grassroots advocacy work and recognition of the value and necessity of the consumer perspective by policy makers and mental health professionals. However, despite these well-intentioned policies and requirements, most mental health agencies fall short of fully implementing these concepts into practice.

The Recovery Movement

To better understand the concept of consumer involvement, it must be considered within the larger recovery movement. Traditionally, within a medical model of mental health care, recovery was defined as an absence of symptoms. Proponents of the recovery movement describe an alternative perspective where true recovery is reached when individuals with mental illness take control of their lives, make their own decisions, and find fulfillment in their societal role (Fisher & Chamberlin, 2004). This broad definition of recovery is also reflected in the report of the Subcommittee on Consumer Issues to the New Freedom Commission (2003):

Mental health research shows that people can and do fully recover, even from the most severe forms of mental illness. Most fundamentally, recovery means having hope for the future, living a self-determined life, maintaining self-esteem, and achieving meaningful roles in society. Most consumers report they want the same things other people want: a sense of belonging, an adequate income, a way to get around, and a decent place to live. They aspire to build an acceptable identity for themselves and in the community at large. These are the essential ingredients of recovery from mental illness.

When recovery is defined in this manner, full consumer involvement must be recognized as an essential component of the development, delivery, and evaluation of mental health services. For individuals with mental illness to find meaning in their recovery, they must not only choose whether or not to participate in services, but to also determine the type of services that are available in the community.

The consumer involvement movement has grown substantially during the past three decades. As a result, there is a great deal of published literature describing the underlying principles of consumer-driven services and effective models, as well as a growing body of literature examining the effectiveness of these programs. The values and principles first verbalized through the consumer involvement movement are shared by families who are interested in becoming stronger advocates for improved children's mental health services.

Family involvement

When children are the recipients of mental health services, primary caregivers are often responsible for making decisions that support their child's recovery. Family involvement is a key element of a child's success, especially for children in residential treatment (Anglin, 1986). Although it is essential to involve parents in treatment decisions and progress meetings, these activities alone do not constitute full family involvement in services.

Family involvement was first incorporated into national policy in 1984 when the Child and Adolescent Service System Program (CASSP) principles were adopted. More recently, family involvement has been included as a guiding principle in the 2001 Report of the Surgeon Generals' Conference on Children's Mental Health and the President's New Commission on Mental Health in 2003. These policies not only call for an integration of family and youth services in the children's mental health system, but also encourage mental health agencies to engage families and youth in the planning, development, and provision of mental health services (U.S. Public Health Service, 2000).

The Federation of Families for Children's Mental Health has developed a working definition family-driven system (see Appendix A). This set of guiding principles describes the experiences youth and families should have when they are fully engaged in family-driven mental health services. A few of these shared characteristics include:

- Family and youth experiences, goals, and perceptions are used to steer decision making in all aspects of service and system design, operation, and evaluation
- Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued
- Administrators and staff actively demonstrate partnership with all families and youth by sharing power, resources, authority, responsibility, and control
- Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise when making decisions about treatment and services

Although these policies provide a conceptual framework, they provide little practical advice to agencies wanting to implement these values into practice. Agencies who successfully engage youth and families in mental health services and shift their focus to family-driven services do adopt these values, but in very different ways. There is no single best-practice model that will meet the needs of all youth and families while also being feasible in all agencies. However, agencies that have developed successful strategies have a shared understanding of the philosophy underlying family-driven services and a commitment to finding creating ways to support these initiatives.

Levels of involvement

In order to fully examine opportunities for family involvement in mental health services, it is important to recognize that youth and families benefit from having access to a range of clinical services and non-clinical supports. This philosophy not only encourages families to identify needs that may fall outside the scope of any single provider agency, but provides opportunities for families to be involved at many different levels of the larger mental health system.

Involvement within service agencies

Although it has become standard practice for families to play an active role in the specific treatment and service decisions that impact their child, family involvement should also be a component of agency-level policy development. When parents play an active role on agency boards, they offer a unique perspective that can guide funding decisions and strategic planning. As board members, parents can also help determine the types of services offered by the agency and help shape the ways in which services are delivered.

Parents and family members also fill staff roles at many mental health service agencies. Although parents and families may choose to work in the mental health field without any type of additional incentive or encouragement, agencies whose staff predominately consists of professionals may want to consider ways to recruit family members into a variety of positions. Parents can be recruited to fill existing staff roles, such as behavioral aides, or new roles created specifically for parents, such as parent mentors or advocates.

Involvement supported by service agencies

Family involvement may be attained through ancillary services that are typically not available within a traditional mental health agency. These services are found in both adult and children's mental health services systems. For example, many adults use consumer-directed services to complement and fill gaps left by traditional psychiatric care. Although the reduction or alleviation of symptoms is an important part of recovery, many consumers also want to engage in services and supports that focus on aspects of daily life, such as their relationships with friends and families, employment, and independence (Horsfall, 2003). For example, when asked to identify helpful qualities of consumer-directed services, many individuals describe having a safe environment to meet peers and connections to a larger community (Ochocka, et al., 2006). These opportunities for peer support, although important to recovery, have not been a strong component of traditional mental health services.

Similarly, although parents want their child to receive effective mental health services, many also want to experience the benefits that come through being part of a larger community of peers. By meeting parents who are working through similar situations, parents realize that their personal experiences offer valuable insight and that they are not alone (Anglin, 1986). Peer-led parent and family initiatives can also provide opportunities for family members to lead the development of new projects and discuss the many important issues that are less likely to be addressed by the mental health professionals providing services to their child.

A framework of services

Family-driven or consumer-led services take many different forms, but all offer opportunities for increased decision-making control and greater involvement in service delivery. The figure below, adopted from Mowbray et al. (1997), provides a basic framework that can be used to describe four categories of family-driven services.

		Level of Consumer Control	
		High	**Low**
Type of service	Service delivery	Family-Run Organizations	Family members as providers, Parent representatives
	Mutual support	Parent/family support groups	Family initiatives

Service categories

Family-run organizations

Within these types of programs, family members control all decisions about the organization, including its management and service options. Although non-family member staff may be employed by the organization, all service and service-delivery decisions are made by family members and youth. Some of the most commonly identified activities of state-wide family-run organizations include: training; individual advocacy/support; information and referral; support groups; community outreach; program oversight; and evaluation (Statewide Family Networks Technical Assistance Center, 2004).

Family-members as providers/parent representatives

Using this organizational framework, this category describes family members that are hired as employees of organizations that are not consumer-run, such as mental health clinics or human services offices. These roles may include positions that are designed especially for family members, such as peer support specialists or family advocates, or other positions that do not require an individual to identify as a parent or family-member, such as case managers or therapists.

It is also increasingly common for consumers and family members to be members of advisory boards, strategic planning committees, and other types of administrative groups. In this role, parents and family members may work with other community members, agency administrators, representatives of state agencies, and mental health providers to determine which services are available and shape how these will be delivered. As representatives or advisors, families are able to participate in discussions, but the scope of their involvement is often defined by the agency.

Self help groups

Self-help groups are one of the most common types of consumer-directed services found throughout the county (Goldstrom et al., 2006). These groups are facilitated by peers, and there is little distinction between facilitator and group members. Self-help groups offer support to individuals with mental illness and their families, helping them find effective ways to overcome stigma, understand the illness, and better cope with symptoms.

Family initiatives

These types of programs are often an informal component of a formal mental health organization illness (Mowbray et al., 1997). These activities may include volunteer groups, such as parent leadership or mentoring programs, which involve family members as both providers and recipients of support. Although these groups may be family-led, the group may lack independence because it falls under the umbrella of a larger, formal organization.

Benefits of family involvement

The growing number of family- and consumer-run organizations demonstrates that peer services are valued by parents and family members. In 2002, the most comprehensive national survey to date estimated nearly 7,500 groups, organizations, and services run by and for individuals with mental illness and their families were present in the United States (Goldstrom, et al., 2006). When combined, it is estimated that these services outnumber traditional, non-consumer run mental health organizations by a 2 to 1 ratio (Davidson, et al., 2006).

Despite the large number of family-directed service organizations that are found throughout the United States, there is little research available to demonstrate the effectiveness and importance of family advocacy and support provided through these types of agencies (Dababnah & Cooper, 2006). Studies examining the impact of family involvement in services are often case studies or observational studies. Although these approaches can be effective, published research in peer-reviewed journals often focus on using validated measures that can indicate significant changes over time. To increase the research base, a variety of evaluation approaches should be used to examine the impact of family involvement initiatives.

Benefits of involvement in treatment

By offering services that address the needs of the family, provide caregivers with new skills, and encourage positive relationships, agencies can successfully engage families in treatment. However, these treatment options only fall within the framework of family-driven services when families are perceived as partners, not simply recipients of care.

In the education field, there is evidence that parent involvement is associated with improved academic achievement (Duchnowski & Kutash, 2007). The greatest predictor of change was not the presence of parents in the classroom, but changes in parent expectations and how often those values were shared with the child.

Similarly, parents involved in mental health services are believed to develop new advocacy and parenting skills that support their child's healthy social-emotional development. For example, parents who are involved in their child's treatment can have an increased sense of self-efficacy and self-esteem (Worthington et al., 2001). These characteristics may help parents feel more optimistic about their child's treatment and become positive role models for their children. Parent involvement can also lead to shorter residential treatment placements (Friesen et al, 1992). When parents are involved in their child's treatment, they can develop new skills to incorporate in the home and may also pursue community-based services that support their child's treatment. Another model, using family consultants to supplement the services offered in a center-based preschool program, found that most parents felt the program helped their child, but that this was an indirect effect of their improved parenting skills or ability to advocate (Kaczmarek, 2004).

There are a number of evidence-based practices that incorporate family skill-building and the development of individualized services that meet the needs of the youth and family. For example, Multisystemic Therapy (MST) has been shown to reduce youth alcohol and marijuana use, as well as recidivism in the juvenile justice system (Cox, 2005). Wraparound, a practice strategy which utilizes a process to identify the needs of youth and family and develop individualized support, has also been shown to lead to improvements in child functioning and reductions in out-of-home placements (Burns, et al., 2000).

Benefits of social support

Parents of children with a variety of disabilities, including behavioral problems, may experience high levels of stress and anxiety. Although informal social networks can play an important role in mediating familial and youth stress, there are few studies that examine the benefits of social support for youth and families (Cox, 2005).

Despite limited research addressing this topic, evaluation of peer support programs suggest a range of potential benefits. Evaluations of the Parent-to-Parent Program, a national program matching trained parents to new parents needing assistance, have found that this peer support model may reduce anxiety among parents of young children with chronic illnesses (Ireys et al., 2001). Other benefits identified through evaluation include: feeling better able to cope with problem; feeling better able to view their situation positively; and helping other parents make progress on their goals (Singer et al., 1999).

Benefits of family members providing services

Currently, there is limited research demonstrating possible differences between services provided by traditional staff and family-member staff. Studies suggest that consumer-providers spend more face-to-face time with clients, more time doing outreach, and less time doing telephone or office work (Simpson & House, 2002). The same review article also concluded that consumer-providers had higher turnover rates than traditional staff and less distinct professional boundaries. These differences may be, in part, a result of inadequate support or training. Although these findings suggest that services provided by family members may have unique benefits and challenges, additional research is necessary.

Family members may also directly benefit by providing services to others. The Helper-Therapy Principle describes that, when providing services to others, individuals: 1) gain a sense of competence; 2) develop a sense of equality when giving and receiving support; 3) increase their own knowledge; and 4) receive approval from the individual they are supporting (Salzer, 2002). Additional research is needed to demonstrate these effects among family-member service providers.

The improved relationship between parent-providers and traditional (non-parent) staff is also an area of potential benefit. Studies of consumer and family involvement initiatives have demonstrated that traditional (non-consumer) staff may develop a more positive attitude or greater sensitivity towards the individuals served by the agency (Dixon et al., 1997; Kaczmarek, 2004; Mowbray et al., 1996). Increased empathy by professionals not only leads to greater sensitivity to the needs of clients, but may impact treatment expectations. A recent study found that the hiring of consumer staff encouraged non-consumer professionals to focus on recovery instead of the possibilities of poor outcomes (Carlson & McDiarmid, 1999).

Reconsidering evaluation methods

Other potential benefits that may result from increased consumer and family involvement have not been widely documented, primarily because evaluations of mental health services tend to focus on the alleviation of symptoms and level of client functioning instead of other potential benefits. Although these symptom-focused outcomes are important, many consumers have questioned the use of these measures as the primary indication of program effectiveness (Salzer & Shear, 2002). There is growing support for consumers and family members to be involved in all aspects of evaluation in order to shape how services are defined and measured (Nerney, 2004). Family involvement advocates feel more time must be invested into ensuring the research questions and measures of program effectiveness truly reflect the outcomes most desirable to families (Slaton, 2003).

In addition to this ongoing discussion regarding meaningful outcomes, there is also growing recognition that traditional research designs that focus on randomized controlled studies often run counter to the principles of consumer/family involvement (Davidson, et al., 1999). As collaborative evaluation models, such as Participatory Action Research, are used, it is likely that evaluation methods and measures will evolve. For example, articles describing recent collaborative or consumer-driven evaluations show that alleviation of symptoms is not the primary measure of improved outcomes. Instead, strong emphasis is often placed on quality of life, client well-being, and recovery. Instead of using formal assessments, progress is often measured through informal monitoring by consumer staff (Campbell, 2004; Salzer, 2002). As agencies consider how to increase family involvement, it is important to consider how this effort will be maintained into evaluation.

Finally, as family members and consumers become increasingly involved as service providers, it will be important to examine how family-driven values shape various evidence-based practices. There is concern that the rigidity of many evidence-based practices do not allow adjustments to be made in order to meet the true needs of the youth and family. Fidelity measures, which examine how well a program adheres to its theory, may need to be modified to ensure high-quality services are provided while allowing new family-driven values and service delivery strategies to be incorporated (Davidson, et al., 2006). Although these treatment models provide opportunities for family involvement, it is important to remember that the process used to identify needs and consider possible treatment options should follow the same principles and values of family-driven care.

Family involvement challenges

Family and consumer involvement is encouraged through a variety of state, local, and federal policies describing effective mental health services. For example, the federal government encouraged consumer and family involvement in its 2003 New Freedom Commission on Mental Health report:

> *Local, State, and Federal authorities must encourage consumers and families to participate in planning and evaluating treatment and support services. The direct participation of consumer and family in developing a range of community-based, recovery-oriented and support services is a priority.*

Funding agencies, including SAMHSA, also require potential grantees to incorporate elements of family-driven or consumer-directed care. As a result, some agencies feel pressured to adopt consumer and family involvement policies quickly, and may not consider how these philosophical changes may conflict with standard agency practice. By simply hiring family members into traditional positions without making other changes to the program's structure, agencies may run the risk of reproducing services that are not effective (McLean, 1995). Similarly, when family members and agency providers begin working together without a shared understanding of consumer involvement goals, they may have very different policy expectations (Hopton & Nolan, 2003).

There are four common concerns that providers, family members, and consumers struggle with when implementing new consumer- or family-involvement services: tokenism, role ambiguity, staff tension, and lack of long-term vision. Although these issues can create immense barriers to family involvement, there are a number of effective strategies that agencies have used to address these concerns.

Tokenism

Tokenism occurs when consumers or family members are involved in an agency, but do not receive support in their roles (Middleton et al., 2004). This can occur when family members and agency staff have different expectations of the decision-making power that will be associated with various staff roles. For example, an agency that expands their governance board to include additional family members may simply want additional parent input, but be unwilling to have family members vote or hold higher level committee positions. If these expectations are not clearly articulated to participating family members, they are likely to feel dissatisfied (Rutter, et al., 2004).

Agencies can use the following strategies to avoid tokenism:

- Create meaningful job roles for family members. If family members are only hired in part-time, low-paid, and low-status positions, the agency will not be perceived as making a meaningful commitment to increasing family involvement (Middleton et al, 2004). By developing high-quality positions, the agency will be able to effectively recruit and retain new staff.

- Provide family members with the information and training they need to meaningfully participate (Linhorst et al., 2005). In order for family members to actively voice their opinions and participate in decision making, they may need additional information about the agency, including its mission, staff qualifications, and funding sources. It may also be helpful for family members to learn about the decision-making process that the agency uses prior to becoming involved in a committee or advisory board.

- Consider increasing the level and size of parental involvement in the organization. Although research suggests that 25 to 50 percent of advisory board members should be consumers or family members, this percentage is likely much smaller at many organizations (National Technical Assistance Center for Children's Mental Health, 1998).

- Create opportunities for family members to discuss options with a larger parent group. As families and consumers are invited to participate in agency decisions, there is often concern that one person's perspective cannot represent the views of all families being served (Crawford, et al., 2003). Although there is some validity to this statement, this argument was often used to discredit the input of consumers. By involving multiple families in committees or allowing opportunities for parents to elicit feedback from a larger parent group, this concern can be minimized.

Role ambiguity

When consumers or family members are hired as staff, there is often a lack of clarity about their new role. Consumers who have been hired in traditional professional roles have described feeling conflicted about whether to project themselves as a peer or professional (Carlson, et al., 2001). This is especially true when family members are hired by the agency that has provided, or continues to provide, services to their child.

Agencies can use the following strategies to reduce feelings of role ambiguity:

- Provide comprehensive training to all staff. All employees should have a clear understanding of their job roles and expectations. In addition, training is an important way to discuss and clarify concerns over confidentially, professional boundaries, and interagency collaboration policies (Carlson & McDiarmid, 1999).

- Develop strategies to provide ongoing supervision and/or mentoring to new staff. If new positions are developed by the agency to increase family involvement, additional supervision may be necessary to identify training needs, adjust job duties, and address unforeseen issues that arise. Although increased supervision may initially place greater demands on agency staff, it is likely this need will diminish with time (Mowbray et al., 1996).

Staff tension

Although families and staff members should share a common goal of ensuring the child receives appropriate and effective mental health services, there can be tension when there is sharing of roles or decision-making power. Consumers and family members have identified the attitudes of mental health providers as a main barrier to their participation in services (Gordon, 2005; Kaas, et al., 2003). Staff members, who are recognized by their professional degree or licensure, may not recognize the valuable knowledge families have to offer through their personal experiences. Similarly, agencies that hire staff based on credentials may not have considered ways to fully recognize and value the skills and experiences during the hiring process.

The following strategies can be used to alleviate tension between staff and family members:

- Create shared vision among all agency staff. In order to effectively implement new services and avoid staff tension, it may be helpful to utilize an organizational change model (Chinman et al., 2006). In brief, this process would include gaining support from staff at all levels of the agency, developing an implementation plan, and securing necessary resources and supports.

- Develop strategies to overcome conflicts that result from new power-sharing policies. Mental health professionals typically hold inherent organizational power because of the authority held through their position, as a service provider, or knowledge, as demonstrated through their academic achievements (National Technical Assistance Center for Children's Mental Health, 1998). Some providers may resist sharing their power, believing that this undermines their traditional role. Agencies may need to develop new policies that value the strengths of employees beyond education and practice credentials (Mowbray et al., 1996).

- Consider using processes that require interagency collaboration and consultation. In order to promote collaboration between traditional staff and family members, it may be helpful to develop multi-disciplinary teams and processes that require all staff to work together. Agencies can support collaboration by evaluating indicators of collaboration during regular performance reviews and developing training activities that utilize the different strengths of all staff (Lloyd & King, 2003).

Lack of long-term vision

Too often, family involvement initiatives are funded by short-term grants instead of sustainable funding sources. Agencies that develop a plan to involve family members through new or existing roles may not have taken the time to consider how these positions will be supported through long-term agency plans. Therefore, an agency considering a new family involvement initiative should consider the following questions:

- How does this initiative fit with our agency's mission and values?
- How will we recruit family members to employ at the agency?
- What types of information or formal professional development activities will we need to offer? How does this fit with our current policies?
- How much decision-making power will family members have?
- How do we change our decision-making process to fully involve family members?
- How will we support these changes and/or develop long-term funding to support new positions?

Family involvement at Wilder

To varying degrees, parents and family members have been involved in mental health programs offered through the Wilder Foundation. At the individual treatment level, family and youth involvement has become a standard part of practice. Input from parents, youth, and families is essential to the development of individual treatment plans. Youth and family members are encouraged to work with Wilder staff to develop treatment goals, and develop strategies to reach them.

Parents and family members have also been encouraged to give feedback as program advisors or service recipients. For example, as new programs have been developed, parents participated on temporary advisory boards. Less formally, parents provide feedback through direct discussions with staff, comment cards, and annual satisfaction surveys. Although there are opportunities for parents to give input about the services they receive, parents and family members do not have strong decision-making roles within the organization.

Parents who want additional peer support are often referred to a variety of community advocacy organizations, including the National Alliance on Mental Illness (NAMI-MN), Minnesota Association of Children's Mental Health (MACMH), and PACER Center. However, at this point, Wilder does not have a formal partnership with other community-based organizations to develop any supplemental services for parents, youth, or family members. Although Wilder had housed a local Parent-to-Parent program, this peer support and mentoring program is now available through MACMH. Peer support groups have been used as components of Cambodian Family Connect and other programs, but not as a service available to parents of all participating clients.

Although Wilder programs encourage parent and family involvement at an individual service level, there are far fewer opportunities for parents and families to participate in program-level decision making or as service providers.

Potential family involvement models

In contrast to the heavy emphasis on evidence-based practices in mental health treatment, the family involvement literature focuses far more on the process that should be used to develop meaningful strategies to increase family involvement. Although there is growing interest in evaluating a variety of supports and services provided by family members, well-defined best practice models are not evident in the literature.

In order to learn about family involvement models that have been successful in other agencies and communities, information was gathered through recently published literature and interviews with a variety of local and national consumer advocates, family resource specialists, and members of family service organizations.

Parent advisory representatives

Although Wilder has periodically convened parent advisory boards, there is not a permanent structure in place to ensure that parent perspectives are represented during regular administrative or program meetings. Similarly, although parents can offer feedback through satisfaction surveys and comment cards, there isn't an ongoing process for parents to influence program-level decisions. Parents could be included in a variety of decisions at Wilder, including staffing, new program development, or modifications/ expansions of existing programs.

This type of initiative can be successful if Wilder addresses the challenges to family involvement described earlier in this report. Although parent representatives would not need to be hired as employees, funding may be necessary to offer stipends, provide childcare, or reimburse parents for transportation expenses. Additional costs may result from the time Wilder staff use to provide parent representatives with additional information about the program, build professionals relationships with parents, or respond to additional questions and concerns parents may have.

Parent support groups

Within the Twin Cities Metro region, there are a number of organizations that provide support and advocacy for children with mental health needs and their families. In these organizations, parents can access support groups and educational classes, as well as individual support and advocacy. Other parent-led organizations, such as the Minnesota Parent Leadership Network (MPLN), also support family members who want to become more active mental health advocates and community leaders.

It may not be beneficial for Wilder to develop parent groups that duplicate the services already provided through these, and other, community organizations. Parents of children who participate in Wilder programs may benefit from parent education classes and support groups offered by the National Alliance on Mental Illness (NAMI-MN) or the Minnesota Association for Children's Mental Health (MACMH). By developing a partnership with these agencies, Wilder may be able to host classes in a location convenient for parents or find other ways to help parents attend classes and workshops.

Parents of children served by Wilder programs may want other types of support that are not offered through these organizations. For example, social events, such as picnics or family potlucks, may be desirable to some parents who simply want to socialize with other families. Similarly, parents who have found it challenging to find community or school-based recreational activities for their child may appreciate opportunities for their child to participate in games and other activities with higher levels of staff supervision.

Although support groups and social activities can be run by parent volunteers, it may be necessary to hire an individual to coordinate activities, encourage parent participation, address barriers to participation, and respond to the changing needs of parents and families. For this type of initiative to be successful, groups must not only be convenient for parents, but be responsive to their needs.

Peer mentoring

Parents who are interested in developing a peer-to-peer relationship with other parents may benefit from the Parent-to-Parent program that is currently hosted by MACMH. However, parental mentoring can also be encouraged informally by Wilder staff or through a planned volunteer mentoring program. Parents who share similar experiences may connect through social activities or classes offered through various Wilder programs. By providing a setting where parents can interact with one another, some informal mentoring and support may develop. A more formal program could also be organized by Wilder staff. Although peer mentoring is often a volunteer activity, stipends for parent participation, training for new mentors, and some administrative or organizational oversight may be necessary to help the initiative run smoothly.

Reimbursable paraprofessional roles

Among the most innovative family- and consumer-involvement strategies has been the development of sustainable paraprofessional positions in Georgia and Arizona. These significant changes in policy and practice have been the result of strong partnerships between the state, consumer- or family-run organizations, and mental health providers. Although it may not be feasible for Wilder to pursue such a broad initiative, these examples demonstrate types of reimbursable roles that have been successful and the strategies pursued to develop sustainable employment positions.

In Georgia, Certified Peer Specialists (CPS) are mental health consumers who are ready to share their personal recovery story and help other consumers work towards their recovery. CPS become certified after attending an intensive 2-week training program and passing an exam. They are trained to help consumers move towards recovery in a variety of ways, including: identifying their personal recovery goals, developing problem solving skills, building new social skills, and overcoming negative self-talk. Certified Peer Specialists fill a variety of roles, including peer specialists of ACT teams, in-home service providers, peer mentors for consumers transitioning from residential programs to living independently, and peer advocates.

Georgia's CPS model is gaining momentum. Florida and Virginia are currently developing a similar training curriculum and reimbursable certification program for peer consumers, and SAMHSA is expected to release a resource kit to help other states develop similar reimbursable services. In Georgia, there is also growing interest in developing a similar training and certification process for parents.

Similar reimbursable family positions have been developed through the Family Involvement Center, a non-profit family-run organization in Arizona. Through the work of this organization, parents have been employed in a variety of positions in agencies across the state. The center provides a four-day training and monthly refresher course to parents who want to work as employees of mental health agencies. When a community provider wants to employ a trained family member, the Family Involvement Center (FIC) assesses whether the parent is ready for employment and serves as the hiring agency.

Two of the positions developed by FIC, Family Support Partners and Parent Partners, seem most relevant to the types of roles parents could hold at Wilder. Family Support Partners are hired to work with case managers, helping build relationships between the family and service provider. They help family members feel comfortable sharing their experiences and needs with the case manager. Parent Partners provide direct services to families by helping them learn specific parenting skills developed through the wraparound process.

The Family Involvement Center utilizes a broad range of funding to provide ongoing training, support, and employment options for parents, and the direct services that parent-professionals provide are reimbursable through Medicaid. Other funding has come through state and county grants, as well as training and consultation contracts through local behavioral health managed care organizations.

Although Minnesota has not established a statewide reimbursement mechanism exclusively for parent paraprofessional roles, there is flexibility in the certified Mental Health Behavioral Aide (MHBA) position that Children's Therapeutic Supports and Services (CTSS) certified agencies can employ. Current training and supervision requirements may make it difficult for mental health providers to employ these paraprofessionals as full-time employees. Instead, it may be more financially feasible to hire parents as part-time employees or subcontractors.

The organizations highlighted in this report have been successful by making a commitment to increasing family involvement, engaging family members and consumers in the development of new services, and using creative, diversified funding strategies to sustain program and staffing changes. There is no single model that works in all programs to meet the needs of families. To determine how to best address the needs of families participating in Wilder programs, it is essential that parents and families are fully engaged throughout the planning process and have decision-making power.

A process to increase family involvement at Wilder

Current state and national policy reflects the growing expectation that consumer and family members are involved in all areas of mental health service planning, delivery, and evaluation. Although there is limited research demonstrating the effectiveness of these programs in terms of outcome improvements and overall service quality, there is growing recognition of the importance of engaging families in order to provide high-quality services that meet the needs of children and families.

Although the models described in this report do not clearly identify a single strategy to increase family involvement, they demonstrate approaches that may be feasible within agencies that provide direct services to children and families. There is not a single model that can be used to increase family involvement in every agency, but lessons from other organizations can be used to guide new initiatives and develop unconventional staff roles.

Based on the current literature and discussions with a number of family service organizations, Wilder Research recommends the Wilder Foundation consider using the following recommendations to guide the development of family involvement initiatives in all youth and family-focused mental health programs:

- **Examine current strategies used to engage youth and families, and existing needs of participating youth and parents.** To assess current levels of family involvement, it will be useful to review current program mission statements, policies, and strategies. This may occur through discussions with program staff or a review of written materials. Appendix B includes a number of questions that agencies may use to examine their current policies and practices.

  Before any strategies for family involvement are developed, the needs of youth, parents, and family members must also be identified. Wilder Research recommends convening a series of focus groups that allow parents to openly discuss their satisfaction with the services their child receives and additional support or services that would help their child and family. This discussion should allow family members to discuss formal services that they would like to access, as well as ways that informal support or staff empathy can be increased.

- **Convene an advisory group, comprised of administrators, program staff, and parents.** It is essential that family members be involved in the exploration and development of family involvement strategies early in the process. Wilder Research recommends that program administrators use a thoughtful approach to engage parents an community members as members of a Family Involvement Advisory Group, encouraging diversity and developing strategies that would minimize barriers to participation (such as providing transportation and child care, or accommodating the schedules of parents).

  This advisory group could take on a variety of tasks, such as identifying how Wilder currently encourages parent involvement, examining the unmet needs of parents and families who currently receive services, and developing new strategies to become an increasingly family-driven organization. Prior to an advisory group being established, a commitment must be made to support this initiative with staff time, resources, and openness to new ideas.

- **Consider a variety of peer mentoring and support models that could be adapted and supported by the Wilder Foundation to meet the needs of local family members.** As described previously, there are a number of peer support and peer mentoring models that the Foundation could consider adapting to meet the needs of parents. Although this report identifies some possible models, it is likely that any family involvement initiative will need to be modified to meet the needs of family members and complement the services already offered through Wilder.

  If family members of Wilder program participants are interested in peer support, advocacy or mentoring programs that cannot be offered internally, Wilder Research recommends establishing formal partnerships with existing community-based programs. Possible community partners may include the National Alliance on Mental Illness (NAMI-MN), the Children’s Mental Health Network (Minnesota Statewide Family Network), PACER, the Minnesota Association for Children’s Mental Health (MACMH), the Minnesota Parent Leadership Network (MPLN), or Minnesota’s Parent-to-Parent program.

- **Consider strategies to recruit family members into existing staff roles.** Although many staff positions at Wilder require specific training or credentials, parents and family members can be encouraged to apply for a variety of existing positions. Job openings could be revised to value the knowledge of parents who have considerable personal experience, but fewer academic or professional accomplishments.

  There are indirect benefits to employing parents and family members. For example, employees who have experienced the mental health system may have a greater level of understanding and empathy for the children and parents they encounter at Wilder. In addition, parents who are employed by the organization can offer insight on how to improve services or offer information in ways that are most helpful to parents and families. By putting value on the skills and attributes parents gain through personal experience, parents and family members will considered as stronger applicants for a variety of staff positions.

- **Based on the expressed needs of youth and families, consider developing new staff positions that would be filled by parents or family members.** Through discussion with youth and parents, Wilder staff may learn that the needs of families will be best addressed by developing new staff roles. These positions could focus on a variety of needs, such as support, education, or advocacy. In addition to developing new staff positions and duties that meet the needs of families who are involved in Wilder programs, it will be essential to consider how to make these positions desirable to family members.

- **Consider reimbursement mechanisms that could be utilized to create sustainable family support positions.** Although there are certainly rules and regulations that dictate which services are reimbursable through Medicaid, the example of Georgia's Certified Peer Specialist program demonstrates that there is some federal support for developing family- and consumer-provided services. For a similar initiative to begin in Minnesota, it will necessitate the full support and involvement of the Minnesota Department of Human Services. If state-led change is not realistic, the flexibility of the MHBA position could be used to fund at least a portion of new parent paraprofessional positions.

Appendix A

Definition of family-driven care

Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- Choosing supports, services, and providers;
- Setting goals;
- Designing and implementing programs;
- Monitoring outcomes;
- Partnering in funding decisions; and
- Determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

Guiding principles of family-driven care

1. Families and youth are given accurate, understandable, and complete information necessary to set goals and to make choices for improved planning for individual children and their families.
2. Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes with providers.
3. Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports.
6. Providers take the initiative to change practice from provider-driven to family-driven.
7. Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.

8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9. Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.
10. Everyone who connects with children, youth, and families continually advances his or her own cultural and linguistic responsiveness as the population served changes.

Characteristics of family-driven care

1. Family and youth experiences, their visions and goals, their perceptions of strengths and needs, and their guidance about what will make them comfortable steer decision making about all aspects of service and system design, operation, and evaluation.
2. Family-run organizations receive resources and funds to support and sustain the infrastructure that is essential to insure an independent family voice in their communities, states, tribes, territories, and the nation.
3. Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued, everyone is respected and trusted, and it is safe for everyone to speak honestly.
4. Administrators and staff actively demonstrate their partnerships with all families and youth by sharing power, resources, authority, responsibility, and control with them.
5. Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise so they have good information to make decisions.
6. Funding mechanisms allow families and youth to have choices.
7. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf.

- Federation of Families for Children's Mental Health

Appendix B

Assessing family involvement in mental health settings

Adapted from the Centre for Community Change through Housing and Support, Trinity College: Berlington, Vermont

The following questions ask about the degree of family involvement in your agency activities, and can be used to help identify areas where family involvement can be increased. It is not intended to be an exhaustive list, and should be expanded collaboratively with family members and agency staff.

Policy:

1. Does your agency have an explicit policy on family participation in planning, decision making, and service provision?
2. Is this a written policy?
3. Are all staff and families aware of this policy?

Agency Board Participation:

1. How many family members are board members? How many family members are voting board members? How many family members participate in board committees and advisory groups?
2. How do you recruit new family members to participate on your board?
3. What accommodations for board participation are in place (such as orientation, training, transportation, daycare, or other supports)?

Employment Opportunities:

1. When recruiting for new staff, do you advertise in a way that attracts family members?
2. Do you provide reasonable accommodation policies and practices to support family members employed in staff roles?
3. Do family members hired as staff have the same roles and access to information as non-family member staff?

Services:

1. Does the agency regularly solicit family input into service planning and service provision? Is this input used to alter service provision practices?
2. Are the services you offer based, even in part, on the stated needs and preferences of the youth and families you serve?
3. Are family members involved in evaluating agency services?
4. Are family members involved in hiring decisions?
5. Do you have systems in place for family members to file and resolve grievances, or review treatment decisions? Are all staff and family members understand this procedure?

Training and activities:

1. Are family members invited to participate in agency training events?
2. Do family members act as trainers at agency training events?
3. Do family members participate in training and orienting new staff?
4. Does your agency co-sponsor events with local advocacy groups?

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