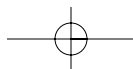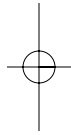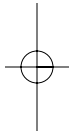# Best Practices in Mental Health

AN INTERNATIONAL JOURNAL

Family and Youth Voice in Children's Mental Health

Best Practices in Mental Health

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Best Practices in Mental Health: An International Journal is a refereed publication intended primarily for mental health scholars and practitioners. The journal publishes original articles that promote best practices in mental health. By having an international scope, the journal is able to publish the best mental health practices and research from around the world. The journal is in keeping with National Institute of Mental Health's priority to replicate and improve promising practices and to promote the transfer of technology.

Manuscripts are solicited from the entire mental health community and also invited from other educators, researchers, and practitioners who focus on strengthening mental health practices. The journal's space is reserved for original contributors. A manuscript or any substantial part of a manuscript must not have been published previously, accepted for publications, or be currently submitted for publication elsewhere.

Submission requirements. Submissions by e-mail (as attached Microsoft Word or Corel WordPerfect) are required. Send to wsrowe@usf.edu (The editors may request that you send up to five clearly printed hard copies of the complete manuscript.) The entire manuscript should be submitted, without author identification, along with a cover letter to identify the corresponding author(s) and stating that the paper is not being submitted to another journal for review.

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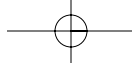
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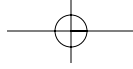
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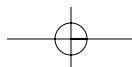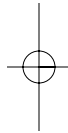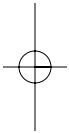
Introduction to the Special Issue

Harold E. Briggs, Nancy M. Koroloff, Janet S. Walker, and
Barbara J. Friesen

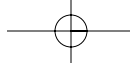This special issue of *Best Practices in Mental Health: An International Journal* focuses on the field of children's mental health and how, over the last quarter-century, the field has been profoundly changed by the increasing influence and advocacy of family members who care for children with serious mental health disorders. The papers in this issue explore the mechanisms that have served to enhance family members' influence and power and describe how the field has evolved as a result of families' increasing impact on areas from individual services to national policy. At the same time, the articles in this special issue describe how the Research and Training Center on Family Support and Children's Mental Health (RTC) has contributed to this remaking of the field through its research about how family voice is developed and supported. The six articles in this issue report on research about family and youth participation in a variety of roles and venues, and illustrate how these new forms of participation have created opportunities for family members and youth to shape a children's mental health service system that is more responsive, culturally centered, and family-driven.

The first paper in this collection lays the conceptual groundwork for thinking about the mechanisms through which family members have gained and exerted influence within the developing field of children's mental health. The authors (Friesen, Koroloff, Walker, & Briggs) provide a framework based on the classic work on interpersonal influence by French and Raven (1959) and use it as a basis for

understanding how it is that family members—and, more recently, youth and young adults—have developed influence and become empowered. The paper then works through a series of examples using the conceptual framework to explain the dynamics that have driven the evolution of family participation and influence in practice, policy, and research.

The second article begins by describing how broad intellectual and cultural currents in the United States have created a profound change in people's perceptions regarding the nature of authority and expertise. The public has become much more skeptical of scientific authority and professional expertise, and this in turn has given greater legitimacy to other forms of knowledge. Within the field of children's mental health, this shift has supported the idea that family members have important and unique knowledge and expertise about their children and that they should therefore play a primary role in making treatment-related decisions. Walker, Bruns, Conlan, and LaForce use the example of wraparound—a team-based care-planning and delivery process—as an example of a treatment planning approach that seeks to balance family and professional expertise in order to achieve improved outcomes for children with high levels of mental health and related needs. The authors go on to describe how the inclusion of family perspectives in wraparound at the treatment level has contributed to a dynamic that reinforces family influence in the design of systems and services. Specifically, the authors focus on how collaboration between family members and professionals has been a hallmark of the work of the National Wraparound Initiative as that organization has worked to refine the practice model and build the research base for wraparound.

The third article draws attention to the importance of considering parents' perspectives when planning early childhood and primary education transition services for at-risk families with young children entering elementary school. Malsch, Green, and Kothari describe their work to prepare families whose small children have challenging behaviors for their children's entry into kindergarten. The experiences of families are examined and used to form the foundation of practice guidelines that reinforce how essential it is that staff members in early childhood settings prepare parents to know what to expect and to advocate for their children in school systems.

Rosenzweig, Malsch, Brennan, Huffstutter, Stewart, and Lieberman discuss the key communication competencies that human resource personnel need to employ as they work with employees who have children with serious emotional or behavioral disorders. The authors offer insight into ways that human resource personnel can structure the work environment and communicate with families so that the workplace is free of stigma and helps employees to balance work and family demands.

Cross, Friesen, Jivanjee, Gowen, Bandurraga, Matthew, and Maher described a culturally centered method for measuring the effectiveness of culture-specific services for Native American youth. Developed from the ground up in partnership with an urban Indian community agency and a national Native American center

that focuses on training, technical assistance, and research, the approach is grounded in principles of community-based participatory research. A series of focus groups with elders, youth, parents, staff, and community partners were used to arrive at a community-based definition of success for Native youth and to define measurable milestones and outcomes. The cultural adaptations necessary to conduct the focus groups and collaboratively analyze the results are examined. Results of this study provide support for a broader and more culturally appropriate definition of success and services in programs serving Native youth.

Jivanjee and Kruzich describe the experiences and attitudes of transition-age youth and their families as they negotiate the mental health system and strive to maintain a satisfying and productive life in the community. The results of the study illustrate the importance of having staff members with the skills and capacities to respond effectively to the unique needs of transition-age youth. The study highlights the importance of providing family and peer support, and reinforces how essential it is for providers to be able to interact with youth in a compassionate manner.

Taken together, these six articles are a reflection of the diversity of ways in which the field of children's mental health has been affected by the growing influence of family, youth, and other lay perspectives. The articles provide tangible evidence of the ways that the inclusion of these perspectives has stimulated profound changes, not just in practice but also in the policies and systems that provide structure to the children's mental health system today.

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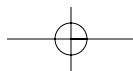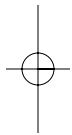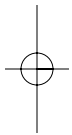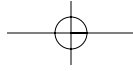
Family and Youth Voice in Systems of Care: The Evolution of Influence

Barbara J. Friesen, Nancy M. Koroloff, Janet S. Walker, and
Harold E. Briggs

*The authors of this article seek to explain the dramatic rise of family member and
youth influence in the field of children's mental health over the last twenty-five years,
using a classic framework addressing interpersonal influence. The article also describes
the contribution of the Research and Training Center on Family Support and Children's
Mental Health to these changes, largely through its research on ways to strengthen
family and youth participation, organizing, and effective advocacy. After reviewing how
and why family and youth voice has increased so dramatically, the authors present
examples of how increased family and youth voice has stimulated changes in practice,
service infrastructure, and policy to achieve a more family-driven and youth-guided sys-
tem of care. Four examples address the rise and impact of the authentic participation of
family members and youth: family advocacy organizations, families as policymakers,
family members' influence on research, and families and the wraparound process.*

Keywords: mental health; children; family support organizations; system change;
sources of influence; practice; policy

Over the past twenty-five years, there has been a dramatic acceleration in the
extent to which the voices of families and youth are heard in the children's mental

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fessor, School of Social Work, Portland State University in Portland, Oregon. This research was
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health field. Changes in practice from the early 1980s, when most families were denied authentic participation in treatment/service planning for their children, to today's "family-driven and youth-guided care" (National Federation of Families for Children's Mental Health [FFCMH], 2010; Osher, Penn, & Spencer, 2008) can be traced to forces that bolstered the empowerment and influence of family members and family organizations and more recently, youth. In turn, as the empowerment and influence of family members and youth has grown, so have their perspectives and preferences been increasingly expressed, given credence, and incorporated into decision-making and change at the practice, system, and policy levels.

This article addresses two major questions about the increase in family member and youth influence in the mental health field during the last twenty-five years: first, *how have families and youth gained power?* What explains how their roles have changed from being objects of intervention and study to operating as partners in planning their own services; participating in decision-making at the organizational and system levels; and making impressive contributions to local, state, and federal policy change? This first question calls for an explanation of the rise in influence of family organizations, family members, and youth over the last two and a half decades. The second question follows from the first, but focuses more squarely on the changes that have come about at least partially because of the increased voice, access, and influence of families and youth: *what changes in the focus of services, practice, and infrastructure have been associated with increased family and youth influence?*

Figure 1 below illustrates how these two questions intersect. The six boxes around the outer edge of the circle describe actions associated with sources of

Figure 1. Contribution of Family/Youth Voice to Change Efforts in Children's Mental Health
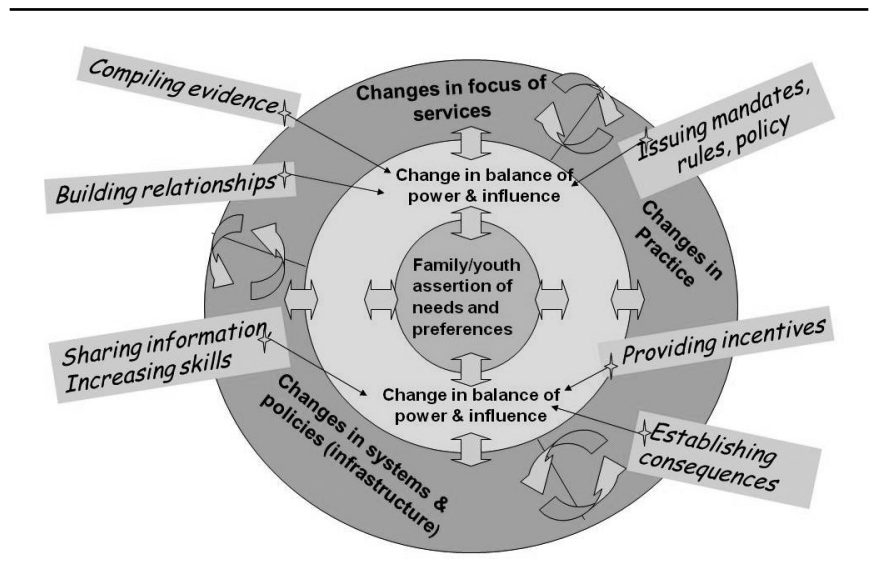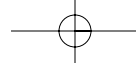
influence that roughly parallel French and Raven's (1959) five sources of inter-personal influence (reward, coercive, legitimate, referent, and expert power), along with "informational power" added in 1965 (Raven, 1965, 2008). This framework is useful in understanding how increases in family and youth influence have come about. In the central area of the circle, family/youth expression of needs and preferences occurs because of heightened courage, empowerment, and influence; the expression of family perspectives also contributes to changes in the balance of influence with other actors and groups who have a stake in the process and content of decisions. The outer ring of the circle illustrates major areas of change: changes in the focus of services, changes in practice, and changes in systems and policies (infrastructure) within which mental health services are developed and delivered.

Understanding the Rise in Influence of Family Members and Youth, Individually and within Organizations

It should be noted that this analysis of the forces that served to enhance the power and voice of individual family members, youth, and organizations is retrospective and does not reflect a systematic grand design that existed at the beginning of the children's mental health change effort in 1984. There was, though, an overall goal on the part of the federal government of developing family organizations, and of the Research and Training Center on Family Support and Children's Mental Health (RTC) to increase the extent to which family organizing occurred and was effective. It is possible to identify six areas of activity that have had the effect of increasing family and youth influence (see also fig. 1). They are: (1) providing incentives, such as special recognition or monetary rewards for behavior or practices that align with guidelines or policies that are being promoted (French & Raven's "reward power"); (2) establishing consequences for lack of adherence to principles or policies (French & Raven's "coercive power"); (3) issuing mandates, rules, and/or policies that support the desired behaviors or practices (French & Raven's "legitimate power"); (4) compiling evidence about the value or effectiveness of desired policies or practices (French & Raven's "expert power"); (5) building relationships that may increase the extent to which cooperation and collaboration will occur (French & Raven's "referent power," in which influence is thought to be connected to the ability to dispense approval or acceptance); and (6) sharing information and increasing skills (French & Raven's "informational power," which involves the control and communication of essential information). Expert power and informational power are related; influence associated with expert power is more likely to be related to the source of information, while informational power flows from the content of the information itself.

Providing Incentives, Establishing Consequences, and Issuing Mandates

Within the field of children's mental health, the first three bases of influence (providing incentives, establishing consequences, and issuing mandates) have been held and exercised primarily, but not exclusively, by governmental and other

sources of funding and policy. For example, providing incentives is associated with government programs that are sources of funding for state- and community-level programs designed to develop and sustain systems of care. Requirements attached to funding for grants and cooperative agreements have provided powerful reasons for grantees to adopt practices that increase family and youth access, participation, and influence in decision-making. These same requirements also provide a basis for establishing consequences for non-compliance, although it is difficult to meaningfully evaluate implementation, and it appears that consequences such as withholding or withdrawal of funding related to family or youth issues have rarely been exercised. The third area most clearly associated with governmental activity is that of issuing mandates, rules, and policies. Important federal legislation that helped to shape the policy and practice context for reform efforts in children's mental health include PL 94-142 (1975), the Education for All Handicapped Children Act, which required parent participation in special education planning; the Community Mental Health Center Amendments of 1975, which mandated that mental health services be provided to children in federally funded Community Mental Health Centers; and the Omnibus Budget Reconciliation Act of 1981, which set aside 10 percent of state mental health block grant funds for children's programming. Efforts at system change became more focused when Congress established the Child and Adolescent Service System Program (CASSP) in 1984. CASSP provided grants to states to improve children's mental health services and was instrumental in several pioneering efforts with regard to promoting family participation at all levels of planning and service. In 1993 the Comprehensive Community Mental Health Services for Children and Their Families Program (also called the Children's Mental Health Initiative, or CMHI) provided a major influx of funds to support the development of systems of care in communities throughout the United States. Unlike many previous federal efforts to improve children's mental health that called for better coordination or shifting of existing resources, CMHI provided new dollars to fund children's mental health services. This program has allocated over $1 billion to nearly 150 system of care grantee communities nationwide. In addition, successive program announcements related to these funds have added requirements about family partnership and the inclusion and funding of family advocacy organizations that have directly supported increased family voice and influence (Osher et al., 2008).

In addition to governmental and nongovernmental requirements attached to funding programs, family organizing and family advocacy have also contributed to changes in perceptions and practice through providing incentives (e.g., public attention and awards given to people and organizations that exemplify family- and youth-friendly leadership/practice). Family members and family organizations have also been instrumental in promoting a source of influence not directly addressed in the framework presented—that is, establishing the moral authority associated with family and youth participation and increased influence. In general, individual family members and family organizations are not in a position to directly hold or exercise influence related to either establishing consequences or issuing
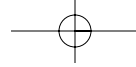
mandates, rules, and policy, although family members and family organizations have frequently been able to promote policy agendas through their advocacy work at federal, state, and local levels. For example, at the Parent Involved Network of Pennsylvania, the parent director and family members were involved in the design of a comprehensive mental health system for children and families; and in New Jersey, the Statewide Parent Association for the Children's Effort (SPACE) organized testimony from family directors and volunteers that helped pass New Jersey's Bring the Children Home Bill (Briggs, Koroloff, Richards, & Friesen, 1993).

Compiling Evidence, Building Relationships, and Sharing Information and Skills

In contrast to the three sources of influence just described, those depicted on the left side of figure 1 (compiling evidence, building relationships, and sharing information/increasing skills) are not directly tied to money, laws, or sanctions, and thus are more available for use by a variety of individuals and organizations. These sources of influence may be less powerful points of leverage for change but have the advantage of being less dependent on surveillance than reward and coercive power. Any given action or event may address multiple purposes, and changes may involve more than one point of leverage or source of influence.

The compilation of evidence about family and youth participation and influence has been complicated by a lack of shared assumptions about the value of such activity. Family members and youth, along with many like-minded professionals, often assume that the value of increasing family participation and influence is self-evident and inherently desirable. This perspective is associated with research and other activities addressing questions such as, "To what extent are family members included in professional education or evaluation?" (Jivanjee & Friesen, 1997; Osher, Van Kammen, & Zaro, 2001) or, "How can we best conceptualize and measure family empowerment?" (Koren, DeChillo, & Friesen, 1993). Other audiences, however, do not accept that moral authority exists with regard to family participation and influence, viewing the matter solely as a research issue, leading to questions such as, "What is the point or added value of family participation?" and, "Is it worth the effort?" Addressing these questions involves compiling findings of research about the relationship of family or youth participation to other outcomes, such as reductions in out-of-home placement or length of hospital stay (Jivanjee, Friesen, Kruzich, Robinson, & Pullmann, 2002) or better service planning for youth (Walker et al., 2007). Thus the first perspective leads to a focus on identifying effective strategies for increasing family and youth involvement, while the second perspective demands that such involvement and increased influence be justified.
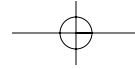
Recent examples of compiling both hard evidence and practice wisdom about developing partnerships with families and youth can be found in documents addressing family-driven care (Osher et al., 2008) and youth-guided services (Matarese, Carpenter, Huffine, Lane, & Paulson, 2008).

Efforts related to building relationships, especially between family members and youth on the one hand and service providers, administrators, and/or policy-makers on the other, have involved a variety of activities that vary in their purpose and intensity. One example of a direct effort to increase mutual understanding and empathy across family and professional groups was training for special education teachers developed by a family organization in New Mexico, with family members serving as trainers and group facilitators (D. Roach, personal communication, May 25, 2010). Interpersonal empathy-building has been a key ingredient of a variety of efforts of RTC projects and others designed to increase understanding and promote partnerships between family members and service providers (Vosler-Hunter, 1989; Williams-Murphy, DeChillo, Koren, & Hunter, 1994; DeChillo, Koren, & Mezera, 1996; Osher et al., 2008). Increased understanding and empathy were also goals at the administrative and policy levels when family organizations held briefings, legislative breakfasts, and other events where families, professionals, administrators, and legislators could get acquainted and exchange points of view (Briggs et al., 1993; Osher et al., 2008). One aspect of such relationship-building is the formation of alliances and networks that provide access to other individuals or organizations interested in or sympathetic to one's cause, make introductions or assist in relaying information to key leaders, or garner support for change goals (Koroloff, Friesen, Reilly, & Rinkin, 1996; Osher et al., 2008).

Another widely used strategy to build relationships is convening meetings and conferences. A notable example is the Families as Allies conference that was held in every region of the U.S. in 1986 and 1987 (McManus & Friesen, 1986). These meetings were designed to promote dialogue and encourage partnerships between family members, service providers, administrators, and other professionals and resulted in the formation of family organizations and family-professional alliances in several states. Sponsored by the RTC from 1992 to 2009, the Building on Family Strengths conference brought together family members, youth, researchers, service providers, advocates, policymakers, and others to exchange information through formal and informal means, with an emphasis on opportunities for the various groups to build relationships across roles, titles, and points of view. Other opportunities to build relationships and learn about others' perspectives included federal CASSP project directors' meetings, periodic meetings of representatives from communities funded through the Children's Mental Health Initiative (CMHI), and training institutes and conferences organized by Substance Abuse and Mental Health Services Administration (SAMHSA)–funded research and technical assistance centers. These meetings often had building partnerships among families, youth, service providers, researchers, and administrators as an explicit objective.

A recent activity undertaken by the RTC and explicitly aimed at building relationships and engaging youth leaders in setting organizing and advocacy goals was a Youth Summit held in conjunction with the Building on Family Strengths conference in Portland, Oregon, in June 2009 (Strachan, 2009; Strachan, Gowen,

& Walker, 2009). Youth leaders from across the U.S. were sponsored to attend the Summit, and to present the results of their work to a conference plenary session. One result of the Youth Summit was a "youth mental health bill of rights." Participants in the youth summit included representatives of a newly formed national youth organization, Youth M.O.V.E. (Motivating Others through Voices of Experience) National. This organization has been fostered and supported by the federal government and the National Federation of Families for Children's Mental Health (FFCMH). Information about Youth M.O.V.E. is available on their Web site (www.youthmovenational.org).

Sharing information about the value of family and youth participation and strategies to enhance such involvement has been accomplished through a variety of publishing formats: journal articles, user-friendly pamphlets, and monographs (e.g., Jivanjee et al., 2002); Web-based presentations (Research & Training Center Staff and AMP Project Advisors, 2007); as well as direct presentations at meetings and conferences, Web-based materials, webinars, and other modes of communication. In addition, family organizations have developed a wide range of information-sharing and training strategies designed to promote family and youth access to decision-making opportunities and to increase the effectiveness of participation at a variety of levels (service-planning, service on advisory committees or boards, involvement in staff hiring and evaluation, family participation and influence in crafting state and local proposals and contracts) and a variety of other activities (Briggs et al., 1993; Briggs, Briggs, & Leary, 2006; National Federation of Families for Children's Mental Health [FFCMH], 2010).

Families and Youth as Participants in System Reform

As depicted in figure 1, the forces that contributed to changes in the focus of services, in practice, and in systems and policies are interactive and reciprocal. Family members' expressions of needs and preferences, often through family advocacy organizations, were instrumental in stimulating changes in practice or policy. Concurrently, these changes created a more fertile environment for further expressions of family preferences and family- and youth-driven change.

Changes in the focus of services often involved shifts from a rather narrow focus on behavior change in children to a more comprehensive view of the needs of the child and of the entire family. Although the system of care principles (Stroul & Friedman, 1986) identified "comprehensiveness" as a core aspect of the system of care, this term initially pertained more to addressing a child's needs across domains (health, mental health, education, recreation, etc.) than addressing the children's and families' needs in a more holistic way. Furthermore, attention to family and youth preferences helped to promote a change in perspective that deemphasized the child's behavior per se as problematic, instead seeing the behavior as signaling a mismatch between the needs of the child and the demands or expectations of the environment. This change in perspective led to calls for a variety of practice and policy changes.
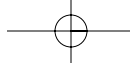
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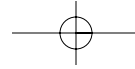
As family members expressed their vision for change (e.g., attention to the needs of the entire family, family support services defined as "whatever it takes" [National Federation of Families for Children's Mental Health [FFCMH], 1992]), expansion beyond an exclusive focus on clinical treatment began to include a variety of interventions, supports, and services, such as respite care, peer support, family recreation and wellness, behavior support, treatment for caregivers and/or siblings, and tailored interventions at home and in school. In addition to expanding the focus of intervention beyond the identified child/youth, these interventions were often focused on modifying home, classroom, and/or social environments so as to increase the opportunities for children and families to experience positive interactions and outcomes. Family members have increasingly been engaged in providing some of these expanded services in roles such as peer support workers or family advocates. They may do their work as employees of mental health agencies or as contract workers, usually through a family support and advocacy organization. Currently, the National Federation of Families for Children's Mental Health (FFCMH) is working to develop a framework for identifying, training, and certifying family support partners through its "Family-to-Family Support Initiative" (National Federation of Families for Children's Mental Health [FFCMH], 2010). There is also growing interest in peer-to-peer support among youth.

The following sections provide thematic examples that both address the question of how increased family and youth voice has come about and illustrate how this increased influence has been exercised to promote further change. The examples further illustrate how the six strategies have been used, both singly and in combination, to stimulate and reinforce change. They also demonstrate how, in many instances, families and family organizations used their growing influence to bring about changes that, directly or indirectly, intentionally or unexpectedly, contributed to further increases in their influence and their ability to bring about further transformations in practice, in the focus of services, and changes in systems and policies.

The first example focuses on family support and advocacy organizations at the local, state, and national levels. The activities of these organizations have been essential in stimulating and sustaining both family-to-family support and system- and policy-level change. Family organizations have also been the source of creative ideas and innovations for addressing the complex needs of children with mental health conditions and their families.

Next, two examples illustrate the changing roles and influence of families and youth in two areas where family and youth participation was completely absent twenty-five years ago. The involvement of family members or youth in local, state, or national policy work related to children's mental health was largely beyond the imagination of either service recipients or service providers in the early 1980s (Koroloff et al., 1996; McCammon, Spencer, & Friesen, 2001). Similarly, the active participation of family members and youth in research and evaluation processes is a recent development stimulated by both strategic intervention and coincidence (Turnbull, Friesen, & Ramirez, 1998).
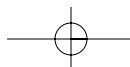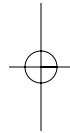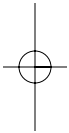
The final example addresses wraparound, a practice-level innovation that has increased family influence not just at the service level but also at higher levels, where policy and funding decisions are made.

Family Advocacy Organizations

Family advocacy organizations directed by family members who are caring for children with serious mental health conditions have been vehicles for the voices of families to influence both the focus of service and the shape of service infrastructure. The number of family advocacy organizations with a primary interest in children's mental health issues increased from nine in 1988 (Friesen, 1991) to more than thirty statewide organizations and hundreds of local groups in 1993 (Wagner, 1993). In 2010 there were more than one hundred state and local chapters of the National Federation of Families for Children's Mental Health (FFCMH). Founded in 1989 (Friesen, 1993), the FFCMH is a national advocacy voice for families that has provided both an organizing point for state and local chapters as well as a presence in national policymaking. In addition to FFCMH and its chapters, other national organizations (e.g., the National Alliance on Mental Illness and Mental Health America) have added the needs of children and families to their policy agenda (Bryant-Comstock, Huff, & VanDenBerg, 1996), and advocacy organizations for other disability groups (e.g., ARC, National Autism Association) often include emotional or behavioral problems in their missions. The rapid increase in organized family voice suggests that these groups are filling a need for families at the personal level as well as in promoting systems- and policy-change issues.

Family advocacy organization are typically governed and staffed by family members and address four objectives: (1) mutual support and sharing of information, (2) advocacy on behalf of individual families and children, (3) modification and enhancement of the service delivery system, and (4) ensuring a family-centered policy agenda (Koroloff & Briggs, 1996). An early study of the 15 SAMHSA-funded family organizations (Briggs et al., 1993) documented that family organizations provided a range of services that included: (1) personal support during a crisis at home or school; (2) community- and state-level organizing; (3) individualized peer-to-peer problem-solving assistance; (4) support networks via individual and group formats; (5) outreach to culturally diverse families and support to address the barriers that limit these families' successful therapeutic experience in mental health service systems; and (6) active involvement in legislative reform, systems change, and policy and practice development efforts in their state children's mental health service systems. Few local family advocacy organizations are able to pursue all of these activities; however, the rise in statewide and national family organizations has increased the available person power and leadership available to influence services and state and national policy.

Only nine local family organizations were identified nationwide in 1985, and there was at that time no state-level family organization focused on children's mental health. The first five statewide family organizations addressing children's

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mental health were initiated in response to the allocation of federal funds for that purpose in 1988/89, followed by three more grants to support statewide organizations the following fiscal year (Friesen, Koroloff, & Robinson, 2005). Between 1990 and 1993, fifteen statewide family organizations were successfully funded by the SAMHSA's Center for Mental Health Services (CMHS) (Briggs et al., 1993), and by 2007 the federal CMHS was funding forty-two statewide family networks and a technical assistance center (Osher et al., 2008). Many of these organizations have expanded far beyond their initial intent and beyond their capacities as fledgling mom-and-pop storefront organizational arrangements (Briggs, Briggs, & Leary, 2005).

Family advocacy organizations have played a critical role in the evolution of family influence and power, primarily by compiling evidence (e.g., document needs and gaps in services), building relationships with other organizations and with policymakers, and developing infrastructure to share information with family members and give them opportunities to increase their skills as change agents. Compiling evidence has been a strength of family advocacy organizations, although often this compilation is relatively ad hoc and consequently has had little impact outside of the local context. A good example is the Georgia Parent Support Network, which has accumulated enough evidence about families' experience of tensions and the need for changes supported by family voice and expertise to transform the service systems in that state. Although its original structure was informal and the evidence compiled was primarily anecdotal, the Georgia Parent Support Network has evolved into a major social service agency, providing family-driven supports and services, conducting studies, and compiling formal reports that are critical to the ongoing transformation of Georgia's children's mental health service system. Other arenas in which the ability to compile evidence has influenced the trajectory of services include documentation of the voices of culturally diverse families (Briggs et al., 2005), ways to provide family support to other families (Briggs, 1996), methods of influencing systems (Briggs et al., 2006), ways to sustain the self-governing capacities of family organizations (Briggs & Koroloff, 1995; Koroloff & Briggs, 1996), ways to involve families in evidence-based practice with foster youth with serious emotional disorders (Briggs, 2009), and ways to involve families in program development and program evaluation (Briggs, Koroloff, & Carrock, 1994; Briggs et al., 1993; Osher et al., 2001).

Building relationships with other groups and organizations has been an important tool for family advocacy organizations, one they have used strategically and to good advantage. From the beginning, leaders of family advocacy organizations have had to struggle to establish productive working relationships with mental health service providers and policymakers at state and national levels. Several statewide organizations have documented the process they used to get to know their state legislators and enlist their help in changing state policy to better support children and families. The Vermont Federation of Families described how they worked to develop relationships with policymakers and then provided data to support the need for respite care in their state. After a series of letter campaigns,
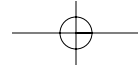
in-person testimonials, and meetings between families and state policymakers, the efforts of families resulted in the state's approving an additional $200,000 to cover respite care for families of children with mental health conditions (Briggs et al., 2006).

Sharing of information and skills about many topics, including how to work with legislators and state officials, happens regularly and can be observed by attending meetings of the Statewide Family Network grantees; the National Federation of Families for Children's Mental Health (FFCMH) Annual Meeting; the biannual Summer Training Institutes sponsored by the Georgetown National Technical Assistance Center; or other national, state, and local training events. Through these conferences, family knowledge and expertise in managing clinical, organizational, and systemic dilemmas are shared. This exchange of information and skills serves to extend the accumulated wisdom to a larger number of families and expands the leadership within family advocacy organizations. Events that share information and skills often include or are targeted at service providers and other professionals, helping to create a shared understanding of the needs and preferences of families and their children.

Although family advocacy organizations rarely have the opportunity to issue mandates, provide incentives, or establish consequences, they may employ conflict as a strategy to instigate broad systems change and transformation (Briggs et al., 2006; Netting & O'Connor, 2003). For example, the parent director for Hawaii Families as Allies sought help from professionals and lawmakers to create policy and funding for respite services. Unable to find respite care for her son while she kept an appointment with a legislator to discuss the availability of respite care, the parent director brought her son along to the meeting. During the meeting the child became agitated, disrupting the meeting and the senator's office. This combination of relationship-building and experience-sharing resulted in rapidly drafted legislation to sponsor statewide respite care in the state of Hawaii. Though this interaction did not directly benefit her son, the family organization director's willingness to risk her professional advocacy image allowed an important policymaker to directly experience the daily reality of her family. It was a defining moment for that senator, who became an advocate for transforming children's mental health programs, practices, and policies (Briggs et al., 1993).

In many states, family advocacy organizations have helped to provide incentives and establish consequences through their collaboration in class-action lawsuits or consent decrees aimed at changing the focus of mental health services and the structure of the service system. For example, lawsuits were initiated in a number of states claiming that states were failing to provide appropriate behavioral health care to children with complex behavioral health-care needs in their homes and/or communities. Class-action lawsuits, such as *Rosie D. v. Romney* in Massachusetts, *JK v. Eden* in Arizona, and *Katie A. v. Bonta* in California, resulted in settlements directing states to improve services. Family-organization involvement in policy change through class-action lawsuits is almost always exercised in collaboration with major policy organizations such as the Bazelon Center for Mental

Health Law, which count on family organizations and family members to compile information and provide testimony about their experiences.

Families as Policymakers

Recognition of the value of family-member input at the systems level began to emerge in 1985, the second year of the CASSP program (Friesen & Huff, 1996), when a goal was added to the program announcement requiring applicants to "develop family input into the planning and development of service systems" (Lourie, Katz-Leavy, & Jacobs, 1986, p. 2). The federal government thus caused states to take a first step in institutionalizing family voice by pairing a mandate— to give family members a voice in policymaking—with the incentive of receiving grant funding. In 1986 the State Mental Health Services Comprehensive Plan (PL 99-660) passed. This federal legislation mandated family participation in developing the mental health plans that states must submit in order to receive funding under the Community Mental Health Services Block Grant. Although state-level planning processes were often dominated by the family members of adult consumers in the early years, this mandate gave family members of children entrée into the planning process at the state level and, ultimately, some influence over how state mental health block grant dollars were spent. In both of these examples, the mandates were instituted after family leaders and sympathetic professionals had spent several years compiling evidence and building alliances. Using mandates as a way to institutionalize caregiver voice in policymaking appears to have been successful. By 1995 Davis, Yelton, Katz-Leavy, and Lourie (1995) reported that twenty-two states mandated the participation of parents of children and youth in state-level decision-making about children's mental health. Another example of pairing a mandate with an incentive emerged in the federal program announcement for the statewide family advocacy organizations in 1989 (Friesen, Koroloff, et al., 2005). Successful applicants for these awards had to detail strategies for involving family members in changing policy. This was accompanied by requirements that awardees provide skill training to family members and provide evidence of their actual participation in policymaking.

These and other efforts to promote family voice in policymaking were supported by work at the Research and Training Center on Family Support and Children's Mental Health (RTC) that was designed to gather evidence about the feasibility and impact of family participation in policymaking and to enable the sharing of information and skills about how family participation could be promoted and supported. Beginning in 1989 the Families in Action Project at the RTC engaged in a variety of initiatives designed to increase knowledge about family member participation at the policy level. Project staff examined literature about consumer involvement, conducted focus groups to compile ideas about family member participation in decision-making groups, conducted oral histories and documented the development of national family policy leaders, and created and evaluated the effectiveness of a skills training curriculum. This curriculum was designed to help families and policymakers advance their skills and develop
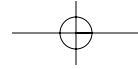
strategies for working together. Compilation of data from several demonstration sites around the country helped to establish the challenges facing family members who wished to join a policy body but also highlighted successful techniques for sharing power (Koroloff, Hunter, & Gordon, 1995).

This early effort has been followed by other examples, such as the collection of data through the National Evaluation of CMHI "systemness review" that helped funded communities focus on the level of family member participation that has been achieved in a system of care community (Vergon & Dollard, 2007).

Since it was first founded in 1989, the National Federation of Families for Children's Mental Health (FFCMH), its state chapters, and other statewide family advocacy organizations have been active in providing training and technical assistance to family members about how to most effectively advocate for family needs and preferences in the policy context. These efforts focus on helping family members learn to use various influence-building strategies. The FFCMH and other national organizations provide information to family groups in the form of policy briefs and the promotion of collaborative policy agendas. Family organizations have been, for the most part, very strategic about building relationships with family friendly legislators and other powerful decision-makers at both the state and federal levels.

These examples illustrate some of the mechanisms that have contributed to the change in family member influence and participation in the policy process, from one that was dominated by policymakers and service providers to one that includes family members as partners, although often not equal partners.

A parallel change in the balance of power is going on with regard to youth voice. Although this transformation got started much later, it also seems to be going much more quickly. This is at least partially because youth are able to build on the progress that was previously made by families, including the information developed and the knowledge gained about influence-building strategies and how to teach their use. The rapid transformation is also being enabled because of the experience and skills that professionals gained as they learned to share power with family members. In addition, the wide acceptance of the rights of families to participate in decisions that affect their children has facilitated the acceptance of a parallel right of youth to make decisions about their own service and education planning, and more broadly, to drive decisions about all aspects of their lives.

Family Members' Influence on Research

Research and evaluation efforts exist in many different forms, and it is not always easy to identify and track change over the past twenty-five years. The gold standard for research has been the randomized clinical trial, a research design and research process that is researcher-driven, historically determined, and highly prescriptive. Other kinds of research, such as consumer opinion surveys, needs assessments, and program evaluation, have been much more open to influence from families. If we focus specifically on the kind of research that examines family members' roles and relationships to the children's mental health system, the changes are subtle but worthy of discussion. There are two areas where change

can be detected: (1) the ways that non-researcher voices are able to influence the content of what will be studied, and (2) the personnel that will be involved in the actual data collection and interpretation of findings. Although the changes in these two areas are not universal, the fact that there has been any change, given the entrenched nature of research and research funding, is encouraging. Within the children's mental health field, this shift is at least partially due to a shift in the balance of power and influence away from the academic researcher and toward the consumers of services and research.

The shift toward sharing power with family members is seen most prominently with regard to decisions about what will be studied and what outcomes will be valued. In 1984 most research on children's mental health was focused narrowly on the impact of specific clinical interventions on a clearly defined set of symptoms or diagnoses or on exploring the possible impact of parent characteristics or behaviors on the development of problems in their children (Friesen, Pullmann, Koroloff, & Rea, 2005). Researchers had not yet recognized that children with serious mental health challenges often had two or more diagnoses at the same time and existed within a complex community and family environment. Studies at that time did not examine the service delivery system or the impact of system level variables on the development of children and families. Families were viewed as part of the mental health problem and were involved solely as research subjects and not as valued partners in research (for a more detailed discussion of these issues, see Friesen, Pullmann, et al., 2005).

More recently, there have been a few examples of how mandates, rules, and policies have helped to increase family voice in the research enterprise, which continues to be largely in the hands of professional researchers. One example is a requirement by the CMHI program announcement that families be involved in both national and local evaluation of the system of care implementation and outcomes. The development of family advisory groups for local evaluations and the hiring of family members as interviewers have given families an opportunity to influence the topic of the local evaluation, the way data are collected, and the interpretation of the findings. Further, this requirement has created opportunities for family members to receive training in research methods, allowing them to build skills and become even more effective voices on the evaluation team (Osher et al., 2001).

With an eye toward sharing information and building skills, the National Federation of Families for Children's Mental Health (FFCMH) in collaboration with the Research and Training Center on Family Support and Children's Mental Health developed a series of workshops titled "The World of Evaluation: How to Make it Yours" (National Federation of Families for Children's Mental Health [FFCMH], 2002). Delivered jointly by an evaluator and a family member, this training helps family members participate on evaluation teams more effectively; advanced training has the goal of preparing them to conduct their own evaluations. An evaluation of the family evaluator training found that participants were

more confident in voicing opinions about evaluation, more positive about working with researchers and evaluators, and more effective in their ability to advocate, in addition to learning more about the evaluation process (Koroloff, Jivanjee, Slaton, Schutte, & Robinson, 2004). Researchers at the Portland RTC also conducted a qualitative study of perspectives of evaluators who are working on evaluation teams with family members. The evaluators noted a number of benefits to working collaboratively with families, including more relevant research, better response rates, more detailed and possibly more honest answers, and more accurate interpretation of data. They also mentioned a number of challenges including the time and investment of resources to hire and pay family members adequately and to develop collaborative relationships, evaluators' and family members' different goals, and the tensions between research and advocacy (Jivanjee & Robinson, 2007; Koroloff et al., 2010). Strategies reported to strengthen family involvement in evaluation included recognizing family expertise, open communication about the challenges, sharing power and resources, and training for both evaluators and family members.

At the policy level, one of the best examples of family voice in the research process is described by Friesen, Giliberti, Katz-Leavy, Osher, and Pullmann (2003) in their article "Research in the Service of Policy Change: 'The Custody Problem.'" This article describes the process by which research was conducted and findings compiled to help establish the nature and extent of the problem created when families had to give up custody of their children in order to obtain residential mental health services. Family organizations and family members were one of the major forces behind this process, identifying issues and helping to collect and analyze data. In this example, professional researchers were partners with the family members, bringing their technical expertise and research experience to the joint project.

Probably most exemplary of the shift in research expertise is seen in the studies that have been conducted by families or youth with academic researchers as advisors. The National Federation of Families for Children's Mental Health (FFCMH) in collaboration with the Georgia Family Support Network was funded by SAMHSA to conduct a family-led research project with consultation from researchers at MACRO International, the research firm conducting the national CMHI evaluation. The topic, which was developed by a broad array of family members using a Delphi process, focused on family engagement in systems of care, the barriers to engagement, and the impact of engagement on outcomes for children and families (Koroloff et al., 2010). The resulting study reported that families believe that their own engagement has an impact on outcomes—particularly increased empowerment, improved care and services, and increased levels of family support (Bates, 2005). In a similar vein, several studies have emerged that were conducted by young people with mental health challenges with the help of researcher consultants (e.g., Federation of Families for Children's Mental Health [FFCMH] & Keys for Networking Inc., 2001; Sanchez, Lomeli-Loibl, & Nelson, 2009). These studies

have served to expand the field's understanding of what young people experience when they receive services and how they describe their needs and preferences for services and supports. These research and evaluation reports are valuable resources to families, service providers, funders, policymakers, and researchers alike.

Although family members have achieved some influence in the evaluation of mental health services, particularly through the requirements of the national evaluation for the CMHI, no major federal research funder has yet required consumer involvement in the development of research projects, although some program announcements have encouraged this input, and some agencies include consumers on peer review committees. Most research funders do not recognize the legitimacy of the expertise of family members or youth when it comes to mental health disorders or mental health treatment. Yet the fact that more research is being done with consideration of the needs and preference of families and more research studies are using family and youth as advisors suggests there is hope for continued development of the roles of family members and youth in research.

Families and Wraparound

Wraparound is a collaborative, team-based approach to comprehensive service/ support planning for children with serious emotional and behavioral conditions and their families. Over the last twenty-five years or so, a confluence of factors— including mandates, incentives, accumulation of research evidence, and vocal support from families and family advocacy organizations—has spurred rapid growth in the number of wraparound programs and initiatives. Since *family and youth voice and choice* is the first guiding principle of wraparound, the expansion of wraparound has stimulated and/or reinforced family/youth empowerment philosophy and practice in communities around the nation. The family-driven and family support–oriented changes that have resulted have not been limited to the practice level, however; wraparound has contributed to changes in the larger policy and funding contexts as well.

Wraparound was one among a number of person-centered planning approaches for human services that emerged in the 1980s (VanDenBerg, Bruns, & Burchard, 2008). After the resounding success of the most visible prototype wraparound program, the Alaska Youth Initiative (Burchard, Burchard, Sewell, & VanDenBerg, 1993), replications were quickly undertaken in Washington, Vermont, and a number of other states. Since those beginnings, wraparound has spread dramatically. By 2007 an estimated 98,000 families were receiving wraparound. Wraparound programs were reported to exist in at least forty-three of U.S. states and territories, and more than half of the states reported some type of statewide wraparound initiative (Bruns, Sather, & Stambaugh, 2008).

The expansion and increasing influence of the family and (more recently) youth advocacy movements has undoubtedly contributed to the rapid growth of

wraparound, as both individual advocates and advocacy organizations used their influence to promote the approach (Walker, Bruns, & Penn, 2008). The wraparound philosophy is extremely appealing to families and youth, in large part because the most fundamental goal of wraparound is one that resonates profoundly with them: keeping children out of institutions by helping them thrive in their homes and communities. What is more, wraparound aims to do this through a process that unequivocally emphasizes empowering families and youth in making care- and treatment-related decisions, and that stresses the importance of building and strengthening families' social and community ties. In this, the wraparound philosophy is entirely consistent with the ethos and goals of the family movement. Families have also been particularly concerned about ensuring that wraparound is implemented with fidelity to its principles. When research—including findings from the Teamwork in Practice project from the RTC (Walker & Schutte, 2004, 2005)—began in the late 1990s and early 2000s to document wide variability in the quality of wraparound being provided, families were among those most actively supporting efforts to clarify practice standards and to develop fidelity assessments and quality assurance tools.

Alongside family advocacy, consequences and mandates have also been instrumental in fueling wraparound's spread (Bruns et al., 2010). In a number of states, legislation has prompted wraparound expansion. California, Kansas, Colorado, Florida, and New Jersey, among other states, have passed legislation encouraging wraparound implementation either directly or indirectly (by promoting or requiring cross-agency collaboration, pooled or braided funding, or adoption of system of care principles). Lawsuits have also contributed to wraparound's growth. A number of the existing state wraparound initiatives were created in response to suits claiming that states were failing to provide appropriate behavioral health care to children with complex behavioral health-care needs in their homes and/or communities. Recent examples include class-action lawsuits such as *Rosie D. v. Romney* in Massachusetts, *JK v. Eden* in Arizona, and *Katie A. v. Bonta* in California. In each of these cases, the settlement directed states to provide individualized, team-based service coordination to thousands of children and youth who were members of the class, and the states responded by developing or increasing their capacity to provide wraparound.

Incentives have also contributed substantially to the growth of wraparound. Most notable has been the federal Comprehensive Community Mental Health Services for Children and Their Families program (also called the Children's Mental Health Initiative [CMHI]), funded by SAMHSA. Funded communities are required to provide individualized, community-based service coordination (U.S. Department of Health and Human Services, 2007), and a large majority of the communities implement wraparound to fulfill this requirement.

Finally, evidence of wraparound's impact has also been a factor in its expansion. A number of wraparound programs have been able to achieve superior outcomes while containing costs and providing wraparound in a way that reflects its

values and principles. In the last few years, wraparound has been identified in various state and national contexts as an "evidence-based," "promising," "emerging," or "best" practice (Walker & Bruns, 2006). And while there continues to be a need for high-quality research on wraparound, recent research reviews (e.g., Suter & Bruns, 2009) have contributed to wraparound's reputation as an effective practice, thus providing further impetus to the wraparound movement.

Though increasing family empowerment was not always the primary goal of the forces described above, the net result has been to spread wraparound, together with its empowerment ethos, to communities across the country. As wraparound has spread, it has also matured, particularly in its family/youth voice and family support aspects. For example, wraparound's focus on family and youth voice has been a spur to wraparound stakeholders to develop and implement methods for ensuring that family and youth perspectives are truly driving the wraparound process. One large effort of this kind has been undertaken through the National Wraparound Initiative (NWI, in part an offshoot of prior RTC work, Walker & Bruns, 2006), a nationwide stakeholder collaboration aimed at defining and improving wraparound practice and implementation. Within the NWI, a work group composed primarily of family members undertook a formal consensus-building process to clarify the role of family partners (paid peer family support workers) in wraparound (Penn & Osher, 2008). In another example of efforts to ensure consumer voice in wraparound, the Achieve My Plan (AMP) project at the RTC has developed and tested a set of practices that have been successful in increasing youth participation and engagement in the wraparound planning process. What is notable is that, in keeping with the wraparound ethos, these efforts to strengthen family and youth voice in wraparound were themselves family-driven (NWI) or youth-guided (AMP). Beyond spurring attention to ensuring family/youth voice, wraparound's focus on family support has created pressure on programs and their staff to become skilled in other areas as well. For example, wraparound's emphasis on "natural support" (i.e., interpersonal support from extended family, friends, individuals, and organizations in the community) has created pressure for practitioners to create methods for developing and integrating these allies into wraparound plans.

The impact of wraparound in communities around the nation has not been limited to the service level alone, however. Studies of wraparound implementation—including the Context of Services project at the RTC (Walker & Koroloff, 2007)—have presented evidence that empowering family perspectives at the team level creates pressures to change service systems and the service array. For example, wraparound implementation typically requires the creation of some sort of collaborative community-level body to provide oversight of the project (Walker & Sanders, 2010). There is a strong expectation that these community-level bodies will themselves adhere to wraparound principles. Thus, by promoting family and youth voice at the community system level, wraparound helps to open channels for families and youth to have influence over decisions that affect policies and
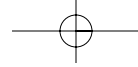
resource allocation. Wraparound implementation also typically creates pressure to make changes in the service array. For example, as wraparound is implemented, the need to fulfill family-driven wraparound plans creates system-level pressure to make the services and supports that families and youth tend to find relevant to their needs (e.g., behavior support, mentoring, and respite) much more widely available.

The example of wraparound thus illustrates a complex interweaving of activities and forces that served to promote family empowerment philosophy and practice in communities across the country. At the same time that wraparound penetrated communities and promoted change, the influence of families penetrated to the heart of the wraparound movement and further strengthened wraparound's commitment to and capacity for empowering youth and families. Beyond tangible and intentional efforts to promote wraparound and change practice and systems, what was possibly the most important force for change was the growing moral legitimacy of the expectation that family and youth would drive the wraparound planning and would partner with professionals for change at the community system level. The moral imperative for stakeholders to "walk the talk" of wraparound has turned out to be at least as important as legislation, lawsuits, evidence, and other forms of compulsion or persuasion.

Conclusion

In this article we have presented a framework for understanding the impressive changes in the roles and influence of family members and youth during twenty-five years of reform efforts in children's mental health. We have also identified some of the important changes in practice, focus of services, policy, and infrastructure that have both been stimulated by an increased family and youth voice and have served to bring about further increases in family and youth influence.

These changes in access, voice, and influence have occurred as the result of strategic initiatives promulgated by state and federal governments and a variety of efforts on the part of families and youth, some individually, but usually as members of support and advocacy organizations. Some very fruitful results have also occurred when families and system representatives (service providers, administrators) have worked together toward mutual goals.

Clearly, over the last twenty-five years family members, services providers, administrators, and other stakeholders in the children's mental health field have used the strategies and points of leverage identified in the framework we have presented here. However, our retrospective analysis suggests that the activities and actions undertaken by reformers wanting to increase their ability to stimulate and bring about change have often been intuitive and improvised, rather than planned and strategic. As efforts to promote and sustain family and youth voice move forward, it seems that the purposeful application of strategies to build and use influence would enhance the ability of families and youth, along with their professional partners, to implement the vision of family-driven and youth-guided care.

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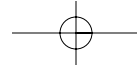
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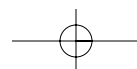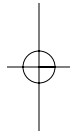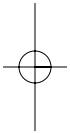
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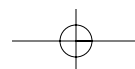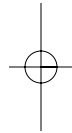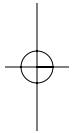
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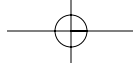
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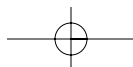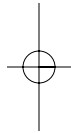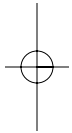
The National Wraparound Initiative:
# A Community of Practice Approach to
Building Knowledge in the Field of Children's
Mental Health

Janet S. Walker, Eric J. Bruns, Lisa Conlan, and Carol LaForce

One of the most significant recent trends in the field of children's mental health has been the shift in the conceptualization of authority and expertise. Increasingly, there are demands to recognize—and to respond to—the perspectives of people who have traditionally been seen more as passive targets of interventions and other change efforts. This has led to a variety of efforts to blend perspectives and/or build partnerships between consumers and providers or between researchers and practitioners. This article explores how a commitment to blending perspectives as a way of providing children's mental health services was a central factor in the emergence of wraparound, a widely implemented care-planning approach for children with complex needs and their families. The commitment to blending perspectives is also a central organizing principle of the collaborative work of a community of practice called the National Wraparound Initiative (NWI), which has worked to support wraparound and to generate knowledge about wraparound practice and implementation. The article goes on to describe some of the benefits, challenges, and tensions that have emerged in the work of the community of practice and to consider what the experience of the NWI may have to offer to others engaged in similar efforts.

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One of the most significant trends in the field of children's mental health in the last quarter century has been the gradual but profound shift in the conceptualization of authority and expertise. This shift has been most obvious in the evolution of ideas about the relationship between service providers and the families or other caregivers of children experiencing mental health difficulties. Traditional service delivery was built around the view of the professional as expert, with children and their caregivers seen primarily as targets for provider intervention (Malysiak, 1998; Osher, Penn, & Spencer, 2008; Rosenblatt, 1996). This view has undergone a radical shift over the past twenty-five years, with an increasing recognition of caregivers as experts about their children's conditions and about the care, support, and treatment strategies that are likely to be successful. As a result, the conceptualization of caregivers' role in treatment-related planning and decision-making has gradually evolved from "ally" to "full partner" to "driver" (Osher, Penn, & Spencer, 2008).

More recently, a similar philosophical evolution has been underway regarding the participation of the young people themselves in treatment-related planning and decision-making (Gyamfi, Keens-Douglas, & Medin, 2007; Huang et al., 2005; Stroul, Blau, & Sondheimer, 2008). A parallel shift has also occurred regarding caregiver and youth participation in other arenas within the field of children's mental health. For example, guidelines, rules, and regulations at the organizational, local, state, and national levels all increasingly encourage—or even require—caregiver and youth participation in advisory groups, governing boards, and other policymaking entities (Huang et al., 2005; Matarese, Carpenter, Huffine, Lane, & Paulson, 2008; U.S. Department of Health and Human Services, 2007).
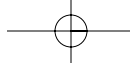
This overturning of traditional ideas about expertise and authority is of course not limited to children's mental health services. In the field of adult mental health care, a central feature of the consumer recovery movement has been the focus on self-determination and empowerment in mental health care decisions at both the service and systems levels (Anthony, 1993; Onken, Craig, Ridgway, Ralph, & Cook, 2007). More broadly, there has been a growing focus on the empowerment of consumer or client perspectives across the human services—including developmental disabilities, disability services, and child welfare.

This evolution of ideas about expertise and authority has been driven in part by philosophical arguments that highlight individuals' rights to autonomy and self-determination. But this evolution has also been driven in part by pragmatic arguments that draw on the accumulating evidence of the shortcomings of traditional approaches to care and service delivery in children's mental health. For example, large percentages of children and families who are eligible for services choose not to access them; among those who do access services, large percentages do not fully engage; and many others may engage but then leave treatment

without completing it (Kazdin, 1996; McKay & Bannon, 2004; Morrissey-Kane & Prinz, 1999). Perhaps this should not be surprising, since caregivers and youth report experiencing traditional services and service systems as stigmatizing, blaming, deficit-based, and lacking in respect for their real needs and for their economic, social, and cultural realities (Federation of Families for Children's Mental Health [FFCMH] & Keys for Networking Inc., 2001; Hinshaw, 2005; Johnson et al., 2003; Pescosolido, Perry, Martin, McLeod, & Jensen, 2007; Petr & Allen, 1997; Yeh, Hough, McCabe, Lau, & Garland, 2004). It thus seems reasonable to expect that services and systems that promote and respond to caregiver/ consumer/youth perspectives will be more relevant and responsive and will have more beneficial effects as a result (Anthony, 1993; Kurtines et al., 2008; Larson, 2000; Taub, Tighe, & Burchard, 2001).

A parallel reexamination of expertise and authority has also been underway regarding the processes for producing knowledge—and particularly knowledge about practice and intervention effectiveness—within the human services. In the traditional model of intervention development, it is researchers who are expert and who create scientific, empirical knowledge about effective practices. This knowledge is then diffused or disseminated to community practitioners (Broner, Franczak, Dye, & McAllister, 2001; Hoagwood & Olin, 2002; Huberman, 1994), who are seen primarily as targets of practice change efforts. In this context, the rethinking of expertise and authority focuses on the lack of attention typically paid to the perspectives and expertise of the professionals and providers who are supposed to implement empirically supported interventions and practices. Similar to the shift in thinking about services and service systems, this rethinking of expertise and authority has been driven in part by a philosophical commitment to empowering those who have traditionally been treated as passive targets of intervention. But pragmatic considerations probably play a larger role in this shift, given the accumulating documentation of the low level of uptake of research findings in general and of empirically supported interventions and practices in particular. Again, traditional approaches to generating and disseminating knowledge have been criticized for not creating outputs that are relevant, useful, or feasible in real-world settings. This lack of uptake by the field has been referred to as a problem with "transportability," the "science-service gap," and the "research-to-practice problem" (Hoagwood, Burns, & Weisz, 2002; Hoagwood, Hibbs, Brent, & Jensen, 1995; Huberman, 1994; New Freedom Commission on Mental Health, 2003; Schoenwald & Hoagwood, 2001; U.S. Department of Health and Human Services, 1999; Weisz & Kazdin, 2003).

It is of course not a coincidence that these developments are occurring in parallel. Each reflects a far broader intellectual and social current that has been brewing in Western thought since the nineteenth century and that emerged into mainstream culture in the United States during the social unrest of the 1960s and '70s. This broad intellectual current is based in a critique of the modern worldview, particularly its confidence that there is a single, external, objective reality that can be discovered using empirical, scientific methods (Taylor & Winquist, 2001). In
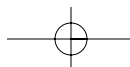
contrast, postmodern worldviews are rooted in the recognition that multiple, equally valid perspectives are possible, and that what is believed to be right or true is shaped by the social and power contexts in which knowledge is produced and used. As a corollary, postmodern thinking is generally skeptical of the notion that scientific methods are the only or even the best means of creating knowledge (Smith & Wexler, 1995; Taylor & Winquist, 2001).

At a practical level, the permeation of culture by postmodern thinking has undermined confidence in—and the legitimacy of—traditional institutions and authority. Within children's mental health, this is reflected in the undermining of the authority of the service provider (vis-à-vis service users) and of the scientist/researcher (vis-à-vis community providers). This in turn has allowed space within the field for fresh, exciting ideas to emerge. However, the field has also been challenged by the flip side of postmodern thinking, namely, the question of how to manage competing perspectives. If multiple perspectives are potentially valid, and if the scientific method—or traditional authority—is not always a reliable way of selecting among available perspectives, on what basis should people make individual and collective decisions about how to act in the world?

Within postmodernist thinking, a proposed response to this central challenge is to create knowledge by integrating divergent perspectives through dialogue (Broner, Franczak, Dye, & McAllister, 2001; Habermas, 1984). In children's mental health, this same impulse has led to a variety of efforts to blend perspectives and build partnerships between consumers and providers or between researchers and practitioners. To date, however, the rhetoric of change far exceeds the reality. While the field has acknowledged the potential value in blending perspectives to make treatment-related decisions, create system policy, or develop new interventions, typical experience is that real change has yet to be realized to a meaningful extent (FFCMH & Keys for Networking Inc., 2001; Gyamfi, Keens-Douglas, & Medin, 2007; Johnson et al., 2003; New Freedom Commission on Mental Health, 2003). Part of what keeps the field stuck is a lack of knowledge about what kinds of processes are useful for blending perspectives and a lack of skills to carry out these processes (Walker & Shutte, 2004). Furthermore, participatory decision-making processes tend to be relatively time consuming and their outcomes unpredictable.

In the remainder of this article, we describe how a commitment to blending perspectives as a way of providing children's mental health services was a central factor in the emergence of wraparound, a widely implemented care-planning approach for children with complex needs and their families (Walker & Bruns, 2006a). Because the commitment to blending perspectives is so central to wraparound practice, it was thus quite natural that a perspective-blending approach would also be attempted when wraparound stakeholders came together in a series of collaborative efforts intended to generate and share knowledge about wraparound practice and implementation (Walker & Bruns, 2006b). The article describes how this collaboration, now known as the National Wraparound Initiative (NWI), came to be and how it functions in many ways as a community of practice. The article goes on to describe some of the benefits, challenges, and tensions
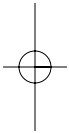
that have emerged in the work of this community of practice and to consider what the experience of the NWI may have to offer to others engaged in similar efforts within the human services and education.

Emergence of Wraparound

Wraparound emerged in the early 1980s as a collaborative, team-based planning approach to providing community-based care for children and youth with complex mental health and related challenges. A wraparound team brings together people who have a stake in seeing a struggling child and family succeed. Typically, the team includes the family members themselves, the providers of services and supports, and members of the family's social support network. Team members work together to create, implement, and monitor a plan to meet family needs.

Rather than being explicitly theory-based, wraparound is defined most fundamentally by its values (Walker & Bruns, 2006b), with its first commitment being to family voice and choice. This means that wraparound planning is to be focused on meeting the needs and reaching the goals that family members identify as most essential. It also means that the treatment and support strategies that are included in the wraparound plan must reflect family members' views of what is likely to be helpful in meeting needs and reaching goals (Burchard & Clarke, 1990; VanDen-Berg, 1993). The values of wraparound further specify that the process must be individualized, culturally competent, strength-based, and outcome-oriented.

Throughout the 1980s and '90s, more and more programs adopted practices that they called "wraparound" and described as being rooted in the wraparound philosophy. Yet while many of these programs shared features with one another, there existed no consensus about how wraparound was defined or how it could be distinguished from other planning approaches. By the late 1990s, research began to appear documenting impressive outcomes from several wraparound programs and high levels of satisfaction with wraparound among youth and families from diverse populations (Anderson, Wright, Kooreman, Mohr, & Russell, 2003; Burchard, Bruns, & Burchard, 2002; Burns, Schoenwald, Burchard, Faw, & Santos, 2000; Kamradt, 2000). However, looking across the studies, it was unclear whether the wraparound being provided in different places was even the same intervention. The lack of specification for wraparound was thus proving to be a barrier to the accumulation of research required to build evidence for the effectiveness of the approach, a growing imperative in a field increasingly focused on evidence-based practice. More troubling, other studies documented wide variation in quality among wraparound programs, with many programs apparently failing to operate in a manner that reflected the wraparound values (Bruns, Burchard, Suter, Leverentz-Brady, & Force, 2004; Burchard, Bruns, & Burchard, 2002; Walker & Schutte, 2004). Yet without a clear definition of what wraparound was—or was not—it was difficult to develop fidelity measures or quality assurance tools. As a result, by early in the new

century, perhaps 200,000 children and families were receiving some form of wraparound, yet alongside the growing enthusiasm for wraparound were growing concerns about how to ensure its integrity.

The history of wraparound clearly reflects the broader social impulse to question the legitimacy of traditional forms of authority and expertise. Wraparound's philosophy questions traditional notions about the superiority of institution-based care over community-based care, of provider views and treatment strategies over family views, and of professionally provided services over support provided by friends, family, and community members. And rather than being under the control of a single researcher/developer overseeing consistency of implementation, wraparound was continually adapted at the local level to reflect community needs and realities.

While the overturning of traditional modes of authority stimulated a flood of creativity and energy within wraparound, it also gave rise to the postmodern conundrum of how to manage competing perspectives. At the practice level, putting the wraparound principles into practice in a high-quality planning process turned out to be quite difficult. In particular, effectively blending the perspectives of professionals and families/youth proved an ongoing challenge. Teams appeared to lack skills and understanding for how to prioritize family perspectives within a collaboration that included all team members. At the program level, many wraparound flowers bloomed, but this proliferation apparently included both prize specimens and weeds, with no clear method for distinguishing between them.

Moving Wraparound Forward

In light of these concerns, a group of stakeholders from across the country came together in 2003. They met at the Research and Training Center on Family Support and Children's Mental Health (RTC) in Portland, Oregon, where staff had been engaged for some time in research on wraparound. The goal of the meeting was to develop a strategy for defining wraparound and building evidence of its effectiveness. The group's members committed to working together in a manner that reflected the wraparound philosophy and that built on the collaborative ethos that had been a central feature of wraparound's development, with individuals and programs freely sharing ideas, tools, and techniques. This meant that the work would be undertaken collaboratively, and that decision-making processes would be both consensus-based and transparent. Furthermore, members representing all stakeholder groups—particularly youth and family members—would be welcomed into the collaboration, and the expertise of each stakeholder group would be valued equally.

By the end of 2004, the group of stakeholders became known as the National Wraparound Initiative (NWI) and had grown to more than eighty members, including family members and advocates, youth consumers, service providers, and administrators and policymakers from the agency level to the state and

national levels. During that period, the NWI made significant progress on two of its top priorities: clarifying the principles of wraparound and defining a practice model (i.e., specifying the essential constituent activities that make up the wraparound process). In undertaking these and subsequent projects, the NWI has used a range of collaborative and consensus-building strategies, virtually all of which are implemented electronically, via e-mail, Web-based surveys, and other Internet-mediated processes (Walker & Bruns, 2006a, 2006b). For some projects—those for producing general resources or tools—the processes used are relatively informal and unstructured. However, a more rigorous approach is taken to other projects, particularly if the product to be developed has direct practice-related implications, as was the case in the work on both the principles and the practice model.

Typically, the more formal approach begins with the formation of a work group to collect and review background materials. The workgroup then formulates an initial version of a product that is subsequently circulated one or more times to a larger subgroup within the NWI. Feedback from this larger group is then incorporated into the product, which is ultimately circulated one or more times to the entire membership for review. The early steps in this process usually involve soliciting feedback in a relatively unstructured, open-ended manner. As the product is honed, and as the group providing feedback becomes bigger, feedback is sought using a more structured communication and consensus-building process based on the Delphi technique (Woudenberg, 1991). In these later, more structured steps of the process, people providing feedback are asked to provide numerical ratings for various specific portions or aspects of the product and to provide brief written justifications for their ratings. Feedback is aggregated, and people providing feedback in the next round have access to this information as they make ratings and provide comments on subsequent versions of the product. Final versions of products usually have full approval by 95 percent or more of participating raters (Walker & Bruns, 2006a, 2006b).

In addition to refining the principles (Bruns et al., 2004) and defining the practice model (Walker et al., 2004), the more rigorous approach has been used to create an assessment of the extent to which a community provides system-level support to wraparound, a description of the peer "family partner" role and its relation to the principles of wraparound, and a description of the role that family partners play in carrying out the phases and activities of wraparound. The same approach is currently being used to develop a series of implementation guidelines and a community readiness measure.

Less formal collaborative approaches have been used within the NWI to create a large number of supplementary resources. These include a fifty-chapter *Resource Guide to Wraparound* (covering topics such as history, practice, principles, staffing/roles, finance, quality assurance, information systems, and others); the *Wraparound Process User's Guide: A Handbook for Families* (in English and Spanish); *How and Why Does Wraparound Work: A Theory of Change*; an online, searchable
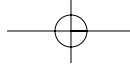
Compendium of Tools to support wraparound practice; and various research summaries and reviews.

The NWI as a Community of Practice

Participants in the NWI did not set out self-consciously to build a community of practice; nevertheless, the NWI does indeed appear in several key ways to function as one. While there are many variations on the definition of "community of practice," virtually all of them trace their origins to work by Lave and Wenger (1991) and include similar elements. Communities of practice emerge when people come together out of a shared passion for a topic and a desire to achieve change, improve existing practices, and/or identify and solve problems in a specific domain of knowledge. The community of practice provides members with opportunities for collaborative reflection, dialogue, and inquiry, allowing them to share expertise and resources, learn from each other, and solve problems. The shared solutions and insights that emerge from community members' interactions form a common store of knowledge that accumulates over time. Community members make use of this accumulated and cocreated knowledge by applying it to their own practice which, in turn, deepens the expertise that they share with the community. Through the interactions that it promotes and sustains, a community of practice creates both tangible and intangible value by creating a shared language and worldview among members; creating knowledge, solving problems, and promoting practice improvement; making tacit knowledge explicit; and creating trust-based interpersonal relationships between members (Lesser & Storck, 2001; Preece, 2004; Wenger, 1998a; Wesley & Buysse, 2001).

Definitions of "community of practice" can paint a rather idyllic picture of people working harmoniously together; however, like members of communities more generally, members of communities of practice do not always get along or collaborate, do not always feel completely satisfied with how the community is evolving, that they are sufficiently respected, or that their perspective is adequately represented in community decisions. Members may become disillusioned with the community, withdrawing to the periphery or even leaving the community altogether. Other challenges, from lack of resources to questions about who really belongs to the community to the undercutting of community norms and values by outside forces, affect communities of practice no less than communities generally. These and other challenges are recognized in the literature on communities of practice, and many have been experienced by the NWI and its members.

The manner in which the NWI began is certainly consistent with the community of practice definition: a group of people came together out of a shared passion for a topic and a desire to achieve change, improve existing practices, and identify and solve problems in a specific domain of knowledge. In the remainder of this article, we present some evidence of ways in which the NWI has served as a community of practice for its members. We follow this with a discussion of some of the

key challenges that arise for communities of practice and describe how these challenges have been experienced by the NWI. We then present a description of recent steps taken by the NWI to address some of these challenges and conclude with a brief discussion.

NWI Impacts and Functioning

In late 2008 the coordinators of the NWI created a Web-based survey as a means of at least partially documenting the Initiative's impact and its functioning as a community of practice. Members of the NWI were asked about their familiarity with the NWI's key products, and they were asked to rate the NWI's success in achieving its four priority goals (identified at its first meeting in 2003). Finally, they were also asked to provide specific examples of ways in which the NWI had had an influence on knowledge, practice, policy, implementation, or some other aspect of wraparound (Bruns, Sather, Walker, Conlan, & LaForce, 2009). About one-third of the approximately two hundred then-active NWI members responded to the survey. Respondents represented the range of wraparound stakeholders, including supervisors and managers in provider organizations (28%), administrators and policymakers (26%), wraparound trainers and consultants (20%), wraparound provider staff (11%), and researchers (9%). Across respondents and roles, 35 percent of survey respondents said they had participated in the wraparound process for themselves, a child, or a family member at some point. Of course, with only one-third of members responding, the results of the survey cannot be said to represent the perspective of the NWI membership as a whole; however, communities of practice, like other communities, comprise not just fully active members, but also those whose participation is more peripheral (Lave & Wenger, 1991). Thus findings from a substantial subset of members do legitimately speak to the issue of whether or not there is a community of practice functioning at least at the core of the group.

Information gathered through the survey offers evidence that members do indeed feel that they are part of a collaborative group that is working toward solving problems, that the group is building a foundation of shared knowledge, and that collaboration within the NWI has had an impact on members' own conceptions and practice of wraparound. For example, 50 percent of all respondents rated the NWI as having a largely positive impact—and a further 46 percent rated it as having a moderately positive impact—on bringing family members, youth, providers, trainers, researchers, and advocates together to collaboratively address key challenges facing wraparound. No respondents rated the NWI as having a negative impact in this area. Similar near unanimity was found in members' rating of the extent to which the NWI was "providing the field with a better understanding" of wraparound practice and the extent to which the NWI was helping to create and share tools, resources, and information—other key functions of communities of practice.
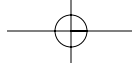
Data also indicated that respondents are familiar with the key products and resources that were produced through the collaborative processes described above and that the use of NWI-created products has had substantial impact on respondents' own conceptualization and practice of wraparound. Data showed that respondents were very familiar with the nine key products and resources that the survey asked about. All of the respondents were familiar with the description of the wraparound principles, and 97 percent were aware of the document describing the phases and activities of the wraparound process. Familiarity was around 90 percent for four more products and close to 80 percent for the remainder. This indicates that, at least for an active core of the NWI, it is true that the shared solutions and insights that have emerged from members' interactions have formed a common store of accumulated knowledge. Furthermore, the impacts described by survey respondents show that community members do make use of this accumulated and cocreated knowledge by applying it to their own practice. This is most clearly shown in respondents' descriptions of the impacts in the area of coaching and training, the most common type of impact described (25% of all examples of impact). Many of the respondents specifically described how NWI materials changed their own practice and/or their approach to coaching and training. Respondents' descriptions of impacts in other areas, such as supervision and quality assurance, also provided examples of how they applied the cocreated knowledge in their own practice.

It is worth noting that NWI impacts were not limited to members alone. A total of more than two hundred non-duplicated impacts were submitted on the survey, and the typical impact was described as having an effect either statewide or regionally. Thus, in addition to having impacts within the community of practice, the NWI's work appears to be creating substantial impact and value outside of the community of practice as well.

Opportunities for Collaboration and Reflection

Members' individual narratives provide an even clearer sense of how the NWI has brought disparate stakeholders together to collaborate and reflect, deepening their own knowledge as a result. Some of the most compelling and impassioned stories of the NWI's impact on individual members of the community of practice come from family members who are NWI members and who have increasingly used the experience to develop expertise on implementation of the wraparound process:

> Through participation in the NWI, I have been able to participate in workgroups (such as the family partner and standards workgroups), where I have been able to provide input into documents, respond to surveys and questionnaires, and learn from others. At the same time, the opportunity to participate in the NWI has definitely influenced my thinking about the implementation of wraparound in my own state, and as I provide technical assistance to

other states and communities. As a parent who directly received wraparound in the early '90s, I learned a great deal about the implementation of wraparound firsthand, while participating now in the NWI has both reinforced and influenced my thinking in what the process should look like.

Other family members have also described the dual benefits of gaining in-depth understanding of wraparound through contributing to the work of the NWI and being able to then bring these to bear locally.

In sum, though communities of practice can be unwieldy at times, the potential benefits of this kind of collective activity are apparent. Perhaps most important of all, members of the community of practice tend to not feel simply like passive targets of knowledge dissemination and utilization efforts but are instead highly motivated to use the knowledge the community creates (Huberman, 1994). This sort of practice-based-evidence approach thus represents a promising strategy for avoiding major research-to-practice/science-to-service pitfalls, such as a lack of buy-in and acceptance by those who implement and receive the intervention (Tanenbaum, 2005).

Challenges

In its efforts to formally define, support, and build evidence for a specific human service intervention, the NWI appears to be fairly unique as a community of practice. To our knowledge, few if any other human service interventions have been so directly informed by a democratic, consensus-building process with inclusion of a wide spectrum of stakeholders. McGrew and Bond (1995) surveyed experts to identify the critical ingredients of assertive community treatment, now recognized as an evidence-based practice. However, the experts surveyed were primarily researchers and did not include consumers at all. Moreover, the NWI's work to support wraparound more generally is of a qualitatively different nature, with the group making decisions about long-range priorities and working together over time.

Despite its apparent value to members, the NWI faces a number of challenges to both its legitimacy and its longer-term viability. In many ways, these are challenges that are similar to those faced by communities of practice more generally. For example, one of the most obvious challenges to the NWI relates to the funding that is needed to support the people who perform core functions. This includes salary for the people who facilitate, support, and document the NWI's knowledge-building and resource-creating activities. This work is quite effort-intensive and absolutely necessary for a community of practice to move its agenda forward. While the NWI can, and does, sell publications, the publications and other resources represent only a small part of the value that is created through the community of practice. As described in the responses from the survey quoted earlier, the NWI clearly creates intellectual and social capital among its members (Lesser & Storck, 2001; O'Donnell et al., 2003). Yet this type of value is difficult to calculate, and it is not something that can be easily sold (or withheld if someone does

not wish to buy it). What is more, because knowledge is created collaboratively, it is not clear that the intellectual capital—or even the intellectual products—are necessarily owned by the NWI, and it is therefore also not clear whether or to what extent the NWI has a right to try to profit from them, even if only to sustain its ongoing work.

In common with other communities of practice, the NWI thus faces the challenge of finding ways to leverage the intellectual and social capital into economic value that can support sustainability (O'Donnell et al., 2003; Preece, 2004). For communities of practice that exist *within* organizations—typically businesses—the recommended strategies for sustainability typically involve demonstrating value to management so that management will pick up the tab (O'Donnell et al., 2003; Wenger, McDermott, & Snyder, 2002). In the field of children's mental health, however, there is no "management," and the value produced by the NWI is not captured within any single or even any well-defined set of organizations. There may also be a tendency to underestimate the effort required to support the NWI's work, since communities of practice are seen as organic (Wenger, 1998a) and perhaps therefore self-sustaining. Typically, knowledge-creation activities in the field of children's mental health are funded by research grants; however, basic funder expectations about the process of knowledge production (i.e., that the optimal research process will be defined before the work begins and then rigidly adhered to) are not particularly compatible with a community of practice approach, which by its nature is unpredictable and uncontrollable.

Beyond the resource issues, several other challenges to sustainability arise from tensions that are inherent in a community of practice. Among these, the tension between reification and participation (Wenger, 1998b) has been most obvious in the NWI's work. In this context, *reification* is the process of turning abstract, fluid, implicit thinking into tangible form, typically as documents. *Participation* is the ongoing negotiation of meaning that drives an engaged learning process and that also drives the knowledge generation that goes on in a community of practice. The NWI's document defining the wraparound practice model offers an illustration of this tension. Creating the document was an intentional effort to make explicit members' implicit knowledge about effective wraparound practice; however, the existence of this description of practice has given rise to a very real danger—namely, that wraparound programs will use the information in the document to implement a rigid approach to practice that focuses far too much on moving through the defined process and far too little on achieving the deeper vision that is described by wraparound's principles and philosophy. This still-unresolved tension continues to be at the root of some significant discord within the NWI, though it has also created important opportunities for internal dialogue about the nature of learning and effective practice.

A related challenge has stymied attempts by some NWI members to create program standards. A substantial number of NWI members argue that the development of standards is a high-priority activity, and that standards are essential for ensuring wraparound program quality. While there is substantial agreement

about some general expectations for programs—for example, in areas such as caseloads, staffing patterns, expectations for coaching and supervision, training sequences, and so on—there is also awareness that there are legitimate reasons to make exceptions for almost any specific standard that could be created in these areas. In addition, a substantial number of NWI members believe that there is currently not enough knowledge about wraparound implementation to justify creating standards, and that doing so would stifle the kind of innovation and creativity that is necessary for producing new program models.

Another tension that has been described in the literature on communities of practice is that between designed and emergent activities (Wenger, 1998b). *Designed activities* are those that are planned out in advance, in order to achieve a particular goal or outcome. In contrast, *emergent activities* arise from interaction and participation in ways that are unplanned and unpredictable. In recent years, the NWI's work has included both designed and emergent activities, and managing both sorts of activities has at times led to challenges. Overall, designed activities have received relatively more attention and resources from the NWI, in part because funders of the NWI have required specific plans for work and products prior to funding. The designed activities tend to be planned primarily by the co-coordinators, though the activities focus on priority areas identified by the membership. In addition, the co-coordinators do seek members' input on plans for addressing these priorities through consultation with members and/or through periodic member surveys.

The process of gathering input into designing activities is fairly ad hoc, however, and the net result is that some members do not see the process of making decisions about priority work areas—or strategies for accomplishing goals in these priority areas—as reflecting the democratic, collaborative ethos of wraparound and the NWI. While it is difficult to know how many members are dissatisfied with the NWI on this point, it is clearly true that at least some members are dissatisfied with decisions about how the planned activities are carried out, feeling that certain other members and/or the co-coordinators have disproportionate power to steer the NWI in ways that may reflect the biases of their particular role types (i.e., academic researchers) or perspectives on mental health interventions (i.e., that the field will benefit from some type of centralized guidance to ensure quality of implementation). At least among some members, this dissatisfaction is intensified because they feel that, through the NWI's collaborative work, their own intellectual capital has been used to move the field to a point where wraparound is becoming over-standardized and/or excessively "manualized."

Emergent activities, on the other hand, appear most obviously at annual members meetings of the NWI. At one of the early meetings, rather than completing the meeting agenda planned by the co-coordinators, the group decided instead to define a series of priority areas and to use a substantial portion of the meeting time to generate specific goals and plans within these areas. The larger group then broke up into smaller workgroups, each of which created a plan for which

workgroup members would have primary responsibility for carrying out which plans. Since that time, the workgroups have endured from year to year; however, workgroup success in making progress on plans has been mixed. One workgroup, the family partner task force, has been particularly successful in setting goals and working steadily year over year to achieve them (though, of course, in doing so, the family partner group transformed the emergent activities into a series of planned activities).

Other groups have in general been less successful in achieving their goals. This is at least in part due to the fact that NWI members have little spare time to accomplish the ambitious plans they lay out in the workgroups, and the NWI has only limited ability to support members to do the work. A further difficulty arises because, when workgroups convene each year, new emergent activities are often prioritized over those on the existing plans, so a whole new set of goals is put in place. At one of the annual meetings, after a discussion that noted lack of progress on workgroup plans, a group of members argued that the co-coordinators should be more supportive of the workgroups' plans and should devote more of their energies and resources to workgroup-related tasks. However, this has only happened to a limited extent, in part because the sum total of work proposed by the workgroups is overwhelming. Furthermore, the co-coordinators' motivation to support workgroup plans is attenuated by the changing nature of the plans (as described above), as well as the fact that the co-coordinators and their staffs have contractual commitments to funders that require focusing on the planned activities.

The NWI's work is also heavily influenced by even larger tensions within the field of children's mental health. Alongside the trend to redefine authority and expertise, perhaps the other most influential trend in the field is the drive to create and implement evidence-based practices (EBPs). In some ways, this is an uncomfortable and curious state of affairs, since the EBP movement is most clearly tied to a modernist, empiricist agenda, while efforts to redefine authority and expertise are expressions of postmodern and post-postmodern impulses that severely critique the modernist worldview. Yet a closer inspection suggests that these two trends are also—at least in some corners of the field—engaged in a creative tension that drives productive innovations. On the one hand, we see some EBPs that are designed to be more flexible and responsive to client goals and perspectives and other EBPs that recognize client/consumer expertise by incorporating peer-delivered services and/or support. And on the other hand, we see a growing literature that seeks to create practice-based evidence and/or to establish empirically the effectiveness of perspective-blending approaches like wraparound. Members of the NWI are in general very supportive of efforts to build an evidence base demonstrating wraparound's effectiveness and of using empirical methods to study training effectiveness and other areas of implementation. Members of the NWI thus appear quite willing to tolerate the tension between modern and (post-)postmodern impulses as they participate in efforts to ensure the integrity, quality, and effectiveness of wraparound.
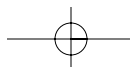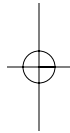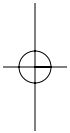
Continued Evolution

As Wenger (1998b) points out, the tensions outlined above can take the form of a dialectic that drives innovation, creativity, and the creation of intellectual and social capital within a vibrant community of practice. But the tensions and challenges that the NWI has encountered are also connected to real dangers and threats, both to the vision and goals of the NWI and to the community of practice itself, should significant numbers of members become deeply disaffected. It remains to be seen whether the NWI can somehow manage these kinds of tensions—and others—in a productive manner.

In response to some of these challenges—as well as to other factors—the NWI is in the process of reconstituting itself organizationally and, at least in part, financially. With the firm support of members, as expressed during the 2009 annual meeting, the NWI is transforming into an organization partially supported by member contributions. Members will pay a yearly subscription, with funds going to support the community of practice aspect of the organization. The NWI will continue making its collaboratively developed products available to the public, but members will have access to a restricted Web site that hosts forums, blogs, and directories that are intended to promote direct member-to-member communication (i.e., without facilitation by the co-coordinators or staff, though facilitated work will also continue). At the same time, the organization will be conducting a membership drive in an effort to expand membership beyond the initial highly experienced members. Finally, the NWI has formed a twelve-person advisory board to help guide planning for the near future.

It is hoped that these changes will help address the downside of some of the challenges and tensions that the NWI has encountered. For example, if enough people become members, their contributions should create a revenue stream that is independent from outside funders, giving the NWI more autonomy and enabling the organization to be more flexible in responding to emergent priorities. Furthermore, a more flexible revenue stream will make it easier for the NWI to provide modest stipends to support members' contributions to various activities and projects that the organization undertakes. This is particularly important at the early stages of developing products and tools. Providing input in these early stages generally requires a fair amount of effort from each person involved, in contrast to providing input or critique at later stages, when products have already been substantially developed. In the past, providing stipends appears to have been successful, with the availability of this small level of support promoting higher levels of member participation during the more effort-intensive early stages of collaborative work. A higher level of member participation may also help the organization accomplish more overall and achieve a larger number of the many goals that have been prioritized in the (mostly unrealized) workgroup plans. Finally, it is hoped that the creation of the executive board will lead to a more participatory process for organizational planning and direction-setting.

Of course, if these tensions are truly inherent in communities of practice, it is neither possible nor desirable to eliminate them entirely. Some degree of member dissatisfaction is inevitable, and the co-coordinators have adopted two main strategies for managing some of the core tensions. One is to avoid pushing too hard for reification in areas where there is controversy, despite possible pragmatic advantages to the field for doing so. In general, it appears that moving slowly can allow a limited consensus to form, which in turn may provide the foundation for the next small step (which may in fact be in a somewhat different direction than that which might have originally been imagined by people involved in the controversy). The other strategy is to try to hold open channels for hearing and considering disagreement and dissatisfaction as it arises. In one example relevant to the tension between reification and participation described above, a group of members wanted to reopen the discussion of the description of one of the wraparound principles, several years after work on the principles document had been completed. The discussion was indeed revived, and eventually a formal consensus-building process was pursued, with the entire membership invited to participate. Ultimately, changes were made to the *Ten Principles of the Wraparound Process*, the most fundamental document of the NWI's reified knowledge base, and a report was produced, describing why the changes were made and summarizing the process that led to the revised version of the principles document (Bruns, Walker, & the National Wraparound Advisory Group, 2008).

Conclusion

In the introduction to this article, we argued that the field needs new strategies to drive solutions to its most profound and enduring shortcomings: racial and ethnic disparities, lack of client engagement and retention, poor outcomes, and so on. However, as things stand, the resources for creating new knowledge (or for creating and sharing knowledge in new ways) flow in enormous disproportion to work undertaken in a more traditional, modernist mode, and the problems related to uptake, relevance, and feasibility in the real world persist. Despite the many challenges and tensions that complicate the work of communities of practice, our experience with the National Wraparound Initiative suggests that it is well worth exploring how this kind of collaborative approach can be used as a way of driving creative problem-solving and stakeholder investment in the service of improving outcomes for children and families.

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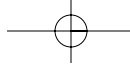
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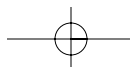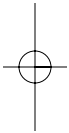
Understanding Parents' Perspectives on the Transition to Kindergarten: What Early Childhood Settings and Schools Can Do for At-Risk Families

Anna M. Malsch, Beth L. Green, and Brianne H. Kothari

This paper addresses the importance of parent involvement in facilitating positive transitions from early childhood settings to elementary school for children with challenging behaviors and/or those at risk for more serious emotional/behavioral disorders. Qualitative interviews with parents of children with social-emotional/behavioral challenges, their Head Start teachers and advocates, and their kindergarten teachers were conducted to gain an understanding of how these parents experienced various transition activities provided by preschools or receiving schools and how these activities functioned to help support parent involvement in the transition process. Based on these data, we developed a conceptual model linking parent needs to elements of transition supports that can be provided through preschools and receiving schools. Key elements of this model include communicating information, providing emotional support, and preparing parents to act as their children's primary advocate within the school system.

Keywords: transition; Head Start; children's mental health; parent engagement

Introduction

The transition to kindergarten sets the stage for future academic success as well as for children and families' relationships with the educational system (Pianta & Cox, 1999; Schulting, Malone, & Dodge, 2005). Yet this transition can be overwhelming for children and families, particularly when children have emotional or

behavioral challenges. Transition supports provided by key early childhood and school personnel help ensure successful transition. There are discussions of transition best practices in the existing literature and a particular focus on the importance of involving parents in the transition process. However, few studies have focused on understanding parents of children with emotional or behavioral challenges and their perspectives on the transition process and what they feel they need to best support their children. In this study we present a parent-informed understanding of the most important elements of transition supports and provide some recommendations for how best to integrate these practices into the family, preschool, kindergarten, and community contexts. Drawing from these parent perspectives, as well as from information collected from preschool and kindergarten teachers, we propose a conceptual model linking key elements of transition practice to parent involvement in children's transition to kindergarten.

Importance of Transition to Kindergarten

Entering kindergarten is a major milestone in the lives of children and families. Children and their parents encounter new relationships, roles, cultures, opportunities, and responsibilities. The experience of starting school involves complex and significant change (Bohan-Baker & Little, 2002) that may be particularly challenging when children have social-emotional or behavioral challenges (Rosenkoetter, Hains, & Fowler, 1994). When transition is successful, children are engaged and feel positive about school, parents are partners in their children's learning, and schools provide experiences that value individual children and promote their success (Ramey & Ramey, 1999; Wright, Diener, & Kay, 2000). For children with social-emotional challenges, successful transitions result in children, parents, and teachers being better prepared to be successful in school. However, children with emotional or behavioral challenges are more likely to have difficulties transitioning to school, which in turn can set them on a negative developmental trajectory if their transitions are difficult (President's New Freedom Commission on Mental Health, 2003; Osher, Magee Quinn, & Hanley, 2002).

Transition Best Practices

Based on social-ecological and developmental views of transition that emphasize the importance of understanding the contexts in which children and families make transitions, and the relationships among home, school, and community groups that support the child (Pianta & Kraft-Sayre, 2003), a number of "best practices" in transition to kindergarten have been identified. Effective transition supports, it is hypothesized, do the following: (1) view transition as a long-term process, beginning in the preschool years and extending into the kindergarten year; (2) build relationships, communication, and collaboration across settings; (3) promote continuity across settings; (4) prepare, partner with, and involve parents; and (5) prepare children, building needed academic, social-emotional, and other competencies (Dockett & Perry, 2001; Pianta & Kraft-Sayre, 2003). A theme

throughout all of these guiding principles for transition practice is the importance of parent involvement. Parent involvement in transition-related activities has been found to be associated with higher levels of involvement in children's schooling post-transition, a key factor in later academic success (Schulting et al., 2005). Further, studies have suggested that preschool teachers can play an important role in facilitating successful transition. Parents appear to have more communication with preschool teachers (compared to elementary and other teachers), and report high levels of trust and positive regard for them (Pianta, Kraft-Sayre, Rimm-Kaufman, Gercke, & Higgins, 2001). A study examining the experiences and concerns of parents of children who had been in early childhood education programs and were transitioning to kindergarten (McIntyre, Eckert, Fiese, DiGennaro, & Wildenger, 2007) found that parents generally wanted more involvement in, and information about, the transition process while their children were in preschool. Parents also expressed a desire for certain supports that they were not receiving, such as written communication from kindergarten teachers, visits to the kindergarten classroom, and informational meetings on transition. They were interested in information regarding their child's kindergarten teachers and knowing more about the academic expectations in kindergarten and what they could do to help prepare their child.

In order for parents to be involved in the transition, it may be particularly important for early childhood programs to promote parent empowerment, specifically in terms of parents' ability to advocate for themselves and their children in the school system. Scheel & Rieckmann (1998), in their discussion of the empowerment of parents of preschool children with behavioral or emotional disorders, emphasize that parent empowerment within the preschool setting provides a foundation for parents' involvement in other contexts, such as schools and service systems. Feeling empowered and having the ability to advocate for their children may be critical to helping parents overcome the many identified barriers to parent involvement in the transition process and in their children's later school careers, such as work schedules, lack of child care, language differences, transportation problems, and parents' history of negative school experiences (Rimm-Kaufman & Pianta, 2005; La Paro, Kraft-Sayre, & Pianta, 2003).

The Current Research

In the current research, we seek to gain a deeper understanding of how parents of children with emotional or behavioral challenges, as well as preschool and kindergarten teachers, experience a variety of transition activities and supports, and how these activities may function in regard to parental involvement in transition. We bring together parents' views of their children's transitions, along with the perspectives of the Head Start staff (teachers and family advocates) and kindergarten teachers working with these families, to provide multiple perspectives on the transition process and how these three stakeholders support children with emotional or behavioral challenges. The following research questions guided this exploratory study:

Research Question 1

What was the role of the Head Start program and the kindergarten school in the transition process for parents and their children with emotional or behavioral challenges?

Research Question 2

What did parents view as the most important transition activities, and how did those activities support the transition process?

Research Question 3

What linkages in the transition process most need to be improved, and what other barriers overcome, to best support transitions for children with emotional and behavioral challenges and their families?

Methodology

Sample   These data were collected as part of a larger study evaluating the implementation of an intervention designed to enhance program and staff capacity to support children with social-emotional challenges and ease their transitions to kindergarten (results from which are described in Green, Malsch & Hood [2011]). For the current study, data from the control and intervention years have been combined, as the key research questions are not evaluative in nature. Children were selected to participate in the study if they: (1) showed evidence of a developmental delay or suspected delay in the social-emotional area on validated assessment tools (determined in one program by scores in the atypical/concern range for the social-emotional subscale of the Ages and Stages Questionnaire [ASQ], and in the second program by scores of 60 or above on the behavior problems component or 40 or lower on the protective factors component of the Devereux Early Childhood Assessment [DECA]), and (2) their Head Start teacher/staff member had concerns about the child's ability to transition successfully to kindergarten either because of these social-emotional issues or because of the teachers' concern about the parents' ability to successfully support the child through the transition process. Children who were participating in Early Intervention/Early Childhood Special Education (EI/ECSE) were not eligible for this study. Head Start staff nominated children for the study and obtained consent from parents to be contacted by the researchers. Members of the research team then contacted parents by telephone to explain the study. Of 59 families referred to the research study, 57 (96%) agreed to participate and completed an initial interview.

As part of this study, qualitative telephone interviews were conducted to collect information about the transition process for children at high risk for transition problems. Telephone interviews were conducted with 50 Head Start teachers and family advocates, and 15 management staff in the winter or early spring prior to children's transition to kindergarten. Telephone interviews were conducted with 57 parents in the late spring or early summer prior to their children's transition to

kindergarten. In situations where children had two parents, the primary caregiver (typically the mother) was interviewed. Parents were interviewed a second time in November–December after their children had transitioned. Of those parents interviewed in the spring, 44 (80%) were also interviewed in the fall. Telephone interviews with these children's kindergarten teachers ($n = 45$, 82% of the teachers of these children) were conducted in November–December as well.

Interview Instrument

Head Start staff interviews consisted of primarily open-ended questions focused on understanding the nature, timing, and frequency of transition activities and supports provided by the Head Start Program; the barriers and challenges to communicating with kindergarten teachers and schools; their perceptions of the effectiveness of the transition activities; the barriers and challenges to engaging parents in transition activities; and staff perceptions of the most effective transition activities. The Head Start staff interviews were not focused on the particular target child but rather on the general transition process. Specific questions about additional transition activities or supports for children with challenging behaviors were included.

Parent pre-transition (spring) interviews consisted of primarily open-ended questions focused on what transition supports they or their children had received from either Head Start or the school (nature, timing, and frequency), their perception of their child's readiness for school, the extent of their concerns with their children's successful transition, what was most helpful about the transition supports they had received, and how they felt transition supports could have been more helpful. Post-transition interviews asked about any additional transition activities or support provided since the last interview; their perceptions of how successful the child's transition was; their level of communication with the child's kindergarten teacher during the transition; and their perceptions, post-transition, of what could have made the transition process easier.

Kindergarten teacher interviews consisted of primarily open-ended questions about the target child's transition (any challenges, issues, or concerns), how involved the parent was in the child's school, what information or communication they had received from the parent and/or Head Start program prior to transition, what kinds of transition supports were provided by the school, and what information or activities they felt would make transitions more successful. Thus these interviews included both specific questions about the transition of the identified child, as well as general questions about the nature, frequency, and timing of transition activities provided by the school and level of communication and collaboration with parents and Head Start around transition.

Results

Sample Characteristics   Participants were parents, Head Start staff, and kindergarten teachers from two sites in the Pacific Northwest. Overall, 57 parents (30 from Site A and 37 from Site B), 50 Head Start staff (18 from Site A and 32 from

Site B), and 47 kindergarten teachers (25 from Site A and 22 from Site B) participated in the interviews. The large majority was female (92.3% of parents, 100% of Head Start staff, and 98% of kindergarten teachers). Of those who reported their race/ethnicity, the majority was Caucasian/European-American (parents: 68.8% Caucasian, 24.4% Hispanic/Latino, 6.6% mixed race; Head Start teachers: 78.7 % Caucasian, 12.8% Hispanic/Latino, 4.3% Native American, 4.3% mixed race, 2.1% Asian; kindergarten teachers: 95.7% Caucasian, 2.2% Hispanic/Latino, 2.2% other). The interviewees' ages ranged from 21 to 64 years.

Coding

Interviews were transcribed and entered into NUD*IST (Non-numerical, Unstructured Data Indexing, Structuring, Theorizing) software (Qualitative Solutions and Research Pty Ltd & La Trobe University, 1993). Interviews with Spanish-speaking participants were conducted in Spanish, transcribed in Spanish, and then translated into English before coding.

For the present study, first-level coding was developed to capture the barriers and facilitators of parent involvement in transition activities. Preliminary codes were developed by the four-person research team, each of whom read through three transcripts and identified categories describing the relevant transition activities related to involving parents in the process. The team met to share their categories, develop operational definitions for each code, and to come to consensus on a set of codes. Subsequent transcripts were read by pairs of researchers who met weekly to review coding and discuss any discrepancies and to reach consensus about coding each exemplar. The first set of codes consisted of the following categories of activities that could be implemented by either Head Start or the receiving school:

1. Key transition activities by either the Head Start program or the receiving school (or comments about the absence of these activities):
    *   encourages parents to be involved in transition activities
    *   facilitates parent visits to receiving school/classrooms
    *   facilitates children's visits to receiving school/classrooms
    *   facilitates parent communication with kindergarten teacher/school
    *   holds parent group meeting focused on transition
    *   holds individual teacher-parent conference focused on transition
    *   provides information to parents about transition process
    *   provides information to parents about kindergarten environment/ expectations
    *   empowers parents to advocate for children's needs within school system
    *   involves parents in supporting children's school readiness skills
2. Barriers to parent involvement in transition, including: (1) communication barriers, (2) transportation, (3) language, (4) motivation/interest, (5) employment, (6) cultural issues, (7) single-parent status, and (8) poverty

Analysis

Subsequent analysis of coded data focused on establishing substantive themes and relationships among primary-level codes that informed the key research questions (Strauss & Corbin, 1990). Specifically, we were interested in understanding: (1) what were the most important aspects of transition activities for parents, (2) how these transition activities were experienced by parents in terms of facilitating positive involvement and transition, and (3) the extent to which the activities promoted connections across the three settings. For the current study, three members of the research team, including the principal investigator, read through the coded information listed above. Each reader developed a set of themes and identified source coding in the interview that supported the theme. Team meetings were held to discuss the proposed themes and to review the evidence in support of the theme. Discussion of each theme involved review of evidence from the coded interviews, discussion, and consensus-building around the importance and uniqueness of each theme and how each identified theme contributed to our understanding of the process of parent involvement in transition.

Based on these discussions, we developed the conceptual model shown in figure 1. The model is rooted theoretically in developmental models of transition that see successful transition as a result of interconnected relationships between schools, early education settings, parents, and communities (Pianta & Kraft-Sayre, 2003). The focus of the model was on understanding how the transition activities provided by Head Start and the schools helped to engage parents in the transition process, thereby supporting children's transition success. Analyses showed that

Figure 1. Links to Parent Involvement in Children's Transition to Kindergarten
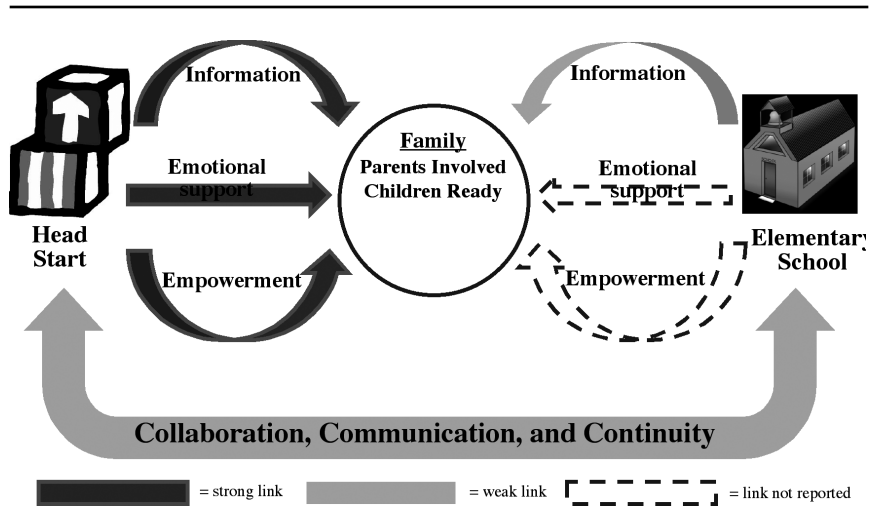
transition activities tended to focus on three key dimensions, all of which played a role in fostering parent involvement: (1) *providing information*, including basic logistical information, information that helps parents understand the similarities and differences between Head Start and kindergarten settings, and information about ways parents could be involved in the transition process; (2) *emotional support* and encouragement; and (3) active *empowerment* of parents to act as advocates for their children in the school system. In addition, collaborative linkages between Head Start and the school were seen as important in supporting parents and building a foundation for parent involvement. The model depicts the strength of each of these linkages among the three contexts (Head Start, family, and school) based on the perspectives of participants in the current study. That is, while all of these links may be important, some were reported to be actually occurring, while others were viewed as important but were less frequent or nonexistent in terms of parents' experiences.

Information

Providing parents with information about the logistics of the transition process (how to register, when to register, when orientations and other meetings are, when they can visit the schools, etc.) as well as details about the elementary school context (dates and times school starts, options for a.m./p.m. kindergarten, how to request or find out which kindergarten teacher their child is getting, information about the school daily routines and calendars, transportation options, etc.) was one of the key things that parents talked about as important for helping them with the transition process. It also appeared to provide the foundation for reducing parents' feelings of helplessness and engaging them in the transition process. For these parents, information truly was power, and many felt that, without Head Start, they would have lacked critical information for understanding and negotiating the transition process.

> They [Head Start] were pretty much the ones that did everything to help us transition by giving us information and talking to us about it. They let us know what we needed to do and what we could do.—*Parent*

This was especially true for parents who were experiencing the transition to kindergarten for the first time:

> The other thing that was very helpful is that Head Start organized a big meeting for principals and teachers from the elementary schools to come to. They gave lots of information about what school was like, when to register, where we might be sending our kids, and to get to know some of the people that were there. This was very helpful to me because this is my first child going to kindergarten and I really didn't know anything.—*Parent*

Head Start played a major role in providing logistical information regarding important dates and events, such as kindergarten roundup and registration. Most often this occurred through paper documents sent home (either by Head Start or

the receiving school) or through meetings/home visits. However, it was clear that it wasn't simply providing information, but *how* Head Start provided the information that was important. Specifically, parents and teachers talked about how Head Start staff provided information early and provided opportunities for follow-up and questions.

> We let them know when kindergarten roundup is coming. We let them know when dates are coming up through a letter. We provide transportation when necessary. We let them know what's happening and if there's anything we can do to help.—*Head Start Teacher*

> His Head Start teacher sent things home and gave us papers during home visits, like notices on what days we had to be at kindergarten to sign up. She gave us the papers way ahead of time, so it gave me time to get stuff filled out and turned back in.—*Parent*

A number of kindergarten teachers reported having parent-teacher conferences in the first week of school, where they had an opportunity to get to know the child, do initial assessments, and speak with the parents. Parents who participated in these generally found them to be helpful and reported receiving useful information.

> [The kindergarten teacher] had a class before school even started. She explained the folders, the schedule for the week, what they would be doing, and they all got to sit in their own spot.—*Parent*

> At the conference, I talk to parents about emotional and behavioral problems and other potential concerns. I also do a quick check on the child to determine what level they are at. These conferences take place during the first two days of school.—*Kindergarten Teacher*

In addition, opportunities to learn from other parents (and, for experienced parents, to share their knowledge and expertise with their peers) were seen as extremely valuable. This helped new parents and offered a chance for experienced parents to take a leadership role:

> We got to hear from parents who already had kids in kindergarten. The people who were sending their first kids to kindergarten were nervous and insecure. But we could share a little bit with them the kind of help that the schools give. We gave them tips. I have a nine-year-old; I shared my experiences with them. Lots of sharing.—*Parent*

Types of Information Provided

Information provided by Head Start and the schools fell into three primary categories. First, as described above, parents needed and received considerable amounts of logistical information about the transition process, kindergarten schedules, the registration process, and so on. Second, Head Start in particular tended to provide information to parents about ways that they could be engaged

in the transition process, including concrete things that they could do to learn about the elementary school and to help their children feel more comfortable and prepared:

> [The Head Start teacher] gave us lots of information, like worksheets on preparing for kindergarten. The sheets said things like, it was a good idea to meet the kindergarten teacher before school starts and that we should familiarize ourselves with the new school.—*Parent*

Thus information was not just about the logistics, dates, and schedules but also concrete suggestions for things that parents could do to be involved with the transition process. Many parents and teachers also indicated both general and specific ways in which they were involved in helping children to become behaviorally ready for kindergarten. Head Start staff spoke about the ways they involved parents who, in turn, would involve their children. For example, Head Start staff discussed how they talked to parents about specific things they could do at home to help this process. Head Start staff told parents about explicit ways that they could set boundaries with their children and develop habits that would help better prepare their children for kindergarten:

> We talk to mothers about the stress children are going to go through so they can help them with that during the summer to prepare the child and give the child security.—*Head Start Teacher*

Head Start staff also mentioned paying special attention to working with parents whose children had specific behavioral issues that needed to be addressed, such as anger management and emotional control. Parents stated that staff helped bring important factors to their attention in an effort to get parents more involved, which they found to be very helpful.

> It was just that they brought things to my attention that I could work on with [child's name]—that [he] had some anger issues and played a little rough with friends. They showed me different ways to teach [him] about his feelings and anger management ideas for me to teach [him].—*Parent*

Third, Head Start and the schools provided information to parents and children about what to expect in the kindergarten setting. Information about how the kindergarten and Head Start settings would be different was seen as especially important for Head Start parents. Parents reported that Head Start staff explained what kindergarten was going to be like:

> Talking with [Head Start staff] and getting a refresher of what to expect and just having her be there to help out if I had any questions was the most helpful.—*Parent*

> One of the things we do in the spring is to have a day where they come and visit and get to know the classroom, so it isn't so overwhelming when they start. I think that is really important.—*Kindergarten Teacher*

One elementary school had a special three-week summer program designed to support Spanish-speaking children making the transition to kindergarten. Children attended school during this period for two hours per day and were oriented to the school building and spent time getting to know their teacher. Although only one of the Head Start children in the study was enrolled in this program, it was described as very helpful:

> She was in the Jump Start program. They went to school for a couple hours a day and got a backpack filled with school supplies. She loved it! It made her so excited for school.—*Parent*

In addition, kindergarten teachers often came to Head Start parent meetings to talk about what kindergarten would be like and what parents should expect. Kindergarten teachers acknowledged that there are significant differences between the Head Start environment and elementary school, especially for parents:

> I think the biggest adjustment might be for the parents because I think that they've had a lot more one-on-one with Head Start teachers and then they come here to a regular school, and I have to divide my time between a lot more parents. I think that is hard for these parents.—*Kindergarten Teacher*

A final aspect of information provision that deserves mention is the consistent translation of information provided by Head Start and support for non-English-speaking families. Hispanic families are a growing, but still relatively small community within the programs studied, and a number of parents commented that schools were unable to translate or were inconsistent in their assistance with translation:

> We provide translation and all materials [are] translated. I go with the parent to kindergarten roundup and translate as much as I can. When I have a parent-teacher conference in kindergarten, I will go to that if they want. The kindergarten doesn't have a translator. I keep in much more contact with families who don't speak English. It's tricky. I don't want to leave them hanging because the school doesn't have a translator.—*Head Start Teacher*

Emotional Support and Encouragement

In addition to providing information to parents, a key aspect of the transition supports provided by Head Start involved emotional support and encouragement. Head Start staff reported ways in which they encouraged and supported parents through the transition process. In turn, parents described the things that Head Start staff did to help them feel more comfortable with the transition process. Emotional support and encouragement was not mentioned as a part of what schools provided for families by any of the participants.

> Because I didn't know anything, I was always wondering what we needed to do, and especially because I don't speak English. I was scared, and the things they [Head Start] did made me feel more relaxed about the whole thing.—*Parent*

Oftentimes this emotional support was given or received in conjunction with more instrumentally supportive activities:

> We discussed reading with him and activities to do over the summer with him to prepare him for kindergarten so he didn't forget all of the letters and numbers and things he'd learned at Head Start. . . . [His Head Start teacher] also let us know that if we had a hard time transitioning him the first week of kindergarten that she'd make time in her schedule to come to his new school and talk to him about that this was his new class, that the teacher was his friend, and that he'd be safe here.—*Parent*

Parents talked about the role of the Head Start program in helping reduce children's worries and fears about starting kindergarten. This included both general activities that may have helped reduce anxiety among all children by helping them to become more familiar with the circumstances and expectations that they would encounter in kindergarten (such as taking field trips to the school, visiting the school playgrounds, and visiting kindergarten classrooms), as well as specific work for children and families with particularly heightened anxiety.

Empowerment

Head Start staff talked about working to help empower parents; in turn, parents we spoke with felt a sense of empowerment. Staff encouraged parents to assert their personal influence by taking initiative in regard to their children's education.

> I stress to parents how important it is to be involved with the school. I stress that they should ask questions of the teachers. It doesn't matter if you think it is not important, you should still ask the question.—*Head Start Family Advocate*

> I told them never to hesitate speaking up to the teacher or principal about anything they are concerned about. How they, the family, are in charge of his education.—*Head Start Teacher*

Parents reported that Head Start staff helped them to do things they might not have otherwise done:

> She just told me about how I could go down there right before school started and meet the teacher and tell her about [child's name] year and Head Start so that she could have a heads-up.—*Parent*

Head Start staff used several strategies for supporting parents to be proactive in communicating with the school, including modeling and providing tools that encouraged communication with the school:

> I call them [the kindergarten school] from home visits to demonstrate how easy it is to get their help.—*Head Start Family Advocate*

> The center manager gave me examples of letters to the teacher and all kinds of information on what to ask the teachers.—*Parent*

Head Start staff encouraged parents to visit the school in advance and attend the pre-kindergarten events. Head Start staff also identified and recognized parents' fears and encouraged parents to move beyond those uncertainties. Many Head Start staff understood that the kindergarten environment would be quite different for children and families, and they also knew that once families left Head Start, parents would need to take on more responsibility in regard to their children's schooling:

> As teachers, we empowered the parents to get their transition needs met because, once they leave Head Start, they become responsible to do all the work. The [transition planning process] was validating to parents that they can take control.—*Head Start Teacher*

Barriers to Parent Involvement

The two most consistent barriers to parents feeling engaged in the transition process were: (1) lack of communication with or from the school, and (2) problems relating to these low-income parents' work status or schedules. Other barriers included: (3) feeling that Head Start staff lacked key logistical information about the kindergarten system; (4) language and translation problems; (5) personal situations, such as health problems; and (6) having multiple children to care for.

School Communication with Parent

Head Start parents reported a number of problems communicating with schools about their children's transition, and many experienced frustration with communication in terms of the transition process as well as with ongoing communication after their children started school. Perhaps the most consistent theme was the lack of information from the school in advance of school starting and a feeling that the school was not interested in what parents had to say:

> Right before they informed us who his teacher would be, I had to call the school and ask because I hadn't heard anything. I asked, "Is my child even enrolled in kindergarten? Because I haven't heard anything." They said they were still reviewing applications [one week prior to school starting], so they didn't know.—*Parent*

A few parents reported attempts to communicate their concerns about their child but felt that the school was unresponsive:

> They really didn't care that there were concerns, just that they would take care of it when [child's name] went to school. They were polite, but didn't take our concerns seriously. They just said, "Don't worry about it," which kind of bugged me. But what can you do?—*Parent*

Other parents reported that efforts on the part of Head Start to help facilitate transition-related activities were not successful:

> [The] Head Start teacher did call the elementary school a couple of times to see if we could get in the school ahead of time, but she got the same response I did when I called [that visiting during the day was not allowed].—*Parent*

However, other parents reported concerns about the frequency of communication with teachers after school started, and were especially concerned about the lack of communication around specific behavioral issues that the child was having:

> I really haven't had any communication with the teacher since the beginning of school. . . . I had one conversation with [child's] teacher about the school bus problems, and she was quite rude to me, so I haven't wanted to talk to her about anything since then.—*Parent*

Several parents noted that the information provided by schools was overwhelming:

> They send home PTA stuff, but it's hard to understand. It's so jumbled that it's hard to understand what all of the information means on the flyers.—*Parent*

A number of parents were also concerned about requests for money from the schools with insufficient warning:

> We didn't get anything in the mail until a week before school. I was thinking, "Well, some people, like our family, we need to save money for the all-day kindergarten program [$230/month]." So it would be nice to know in advance.—*Parent*

However, it deserves mention that several kindergarten teachers described engaging in efforts to communicate with parents:

> I send out letters to parents before school starts, inviting them to come in before school. But usually I don't hear from most of them.—*Kindergarten Teacher*

> I feel pretty good about what we do to provide information about starting school to parents. We have the roundup, we send information in the mail, we give them lots of information . . . but some parents just don't seem to respond.—*Kindergarten Teacher*

Work/Work Schedules

The other primary barrier that emerged for parents was difficulty engaging in transition activities such as orientations, roundups, and parent meetings because of parents' work schedules. This issue is exacerbated for these parents, who often work hourly jobs at non-standard hours, which poses a challenge for Head Start and the schools:

> I don't have time to visit or volunteer in the classroom because I work two jobs.—*Parent*

> I am not really sure [what transition events were] because my husband left for Mexico, so I had to work extra, and I didn't have time to go to parent meetings.—*Parent*

Language Barriers

Language barriers and the lack of translated materials were mentioned by a number of parents:

> All of the written and oral information that was presented to us was in English, so there were many of us parents that didn't understand. After the orientation, we asked the school interpreter to explain to us in Spanish, and this was great. I do speak and understand English, but the problem is that this just isn't the same culture, and for this reason sometimes I don't understand.—*Parent*

Head Start often helps to bridge this gap during the transition process:

> When [parents] are frustrated with schools for not being bilingual, I will step in and translate or step in for them during the phone call for support, clarity.—*Head Start Teacher*

Other barriers mentioned by parents included having other children to take care of, high family mobility (resulting in uncertainty about which elementary school the child will attend), and chronic health problems being experienced by parents and/or children.

Summary of Findings

Results of this study suggest that Head Start plays a key role in facilitating parent involvement in the transition process. In particular, parents valued the information that helped them to navigate the logistics of transition, helped them to understand and prepare for what the kindergarten setting will be like, and provided concrete ways for parents to be involved in the transition process. Head Start staff also helped support parents and children emotionally, reducing their stress and anxiety around the transition process. Finally, Head Start staff and parents talked about the ways Head Start helped them build skills and confidence to be advocates for themselves and their children during the transition process. Transition supports provided by schools primarily involved providing information to parents, although a number of parents felt that the information was late in arriving, and not sufficiently helpful. Parents who experienced events that brought Head Start and schools together—such has having school staff attend Head Start parent meetings or having Head Start staff attend school orientation sessions with them—found these bridge-building opportunities to be extremely useful. Opportunities for children to visit the kindergartens, including one transition-specific, specialized program, were also valued by parents.

Discussion

Implications for Transition Practice

Findings from this study underscore the importance of collaborative efforts between Head Start and other early childhood educators, families, and schools to effectively support families whose children have social-emotional challenges in the transition to kindergarten. At least in the communities involved in this study, parents reported significant transition support from the Head Start program, but little support beyond basic information from the elementary schools. The lack of significant transition supports being provided by schools, especially transition supports that reach back and start before the beginning of the school year in ways that might help to ease parent's and children's fears about schools, is consistent with prior research (Schulting et al., 2005; Early, Pianta, Taylor, & Cox, 2001). This study highlights the relevance, from the parents' perspectives, of viewing transition as a developmental process embedded in multiple social contexts. This view may be particularly important for children with emotional or behavioral challenges who are at risk for difficult transitions.

Our findings offer a greater understanding of the needs of parents and inform the development of new strategies to address the challenges involved. For example, successful transition supports that involve developing positive relationships between parents and kindergarten teachers before the beginning of the school year may be especially important for children at risk for difficult transitions. The importance of providing emotional support and encouragement, in addition to concrete information, was highlighted by these parents.

The qualitative data reflecting themes of encouragement and empowerment speak to the need for early childhood educators to prepare parents to act as their children's primary advocate within the school system. Furthermore, collaborations between Head Start and elementary schools that can help to reduce the culture shock experienced by these parents are important. Parents who are prepared by Head Start to act as advocates for their children can too easily be dissuaded in their efforts by school systems that are not responsive to their inquiries and requests. By prioritizing parent involvement in transition processes and procedures, the stress experienced by families and children during a time of significant change can be reduced.

Finally, schools need to begin to move beyond the traditional transition activities such as roundups and rigidly scheduled preschool parent-teacher conferences in order to better meet the needs of families who are at high demographic and social risk, especially when these families also include children with social-emotional challenges. Individualized and personal outreach may be far more likely to engage and support these families. Schools may need to devote more resources to providing meaningful, individualized transition supports that build relationships between families and schools, such as home visits to entering families, better pre-kindergarten orientation of parents and children, and engaging preschool teachers and early educators in facilitating parent-school relationships.

One major barrier to implementing improved transition practices at all of the elementary schools in this study was the practice of waiting to make kindergarten assignments until immediately before the start of the school year. While the reasons for this practice were clear from school administrators' perspectives (many children do not register until right before school, decisions need to balance the distribution of children across multiple classrooms, etc.), this practice was a significant barrier to a number of potentially important transition activities that should ideally occur in the spring prior to the child exiting Head Start. Head Start staff expressed a strong desire to meet with kindergarten teachers to share information about specific children; this was largely impossible given the ways schools assigned children to teachers. This practice further limits the ability to provide any individualized outreach to families or children by schools until very near the start of the year.

Another clear implication of these findings is the need for enhanced transition supports to make formal and explicit the focus on parent involvement and to view parent involvement as a mutual, reciprocal process—not just placing the responsibility on the parent to become involved. Such simplistic models of parent involvement (e.g., offering opportunities for parents to become involved and providing basic logistical information only) may be sufficient for well-resourced middle- and upper-class families with children without emotional or behavioral challenges. However, for parents struggling with poverty and whose children have emotional or behavioral issues, such a perspective significantly underestimates the barriers faced by these parents. Strikingly, parents in this study were eager for information about the transition process and highly valued the transition supports provided by Head Start. However, they also faced significant barriers to being involved in their children's transition, many of which were related to the family's poverty status. Thus the families in this study represented a group whose children may benefit the most from improved transition supports but whose demographically high-risk status makes engaging in transition supports even more difficult. Clearly, for many of these parents, involvement in the transition process must include active outreach from schools and school staff, including individualized contact prior to school starting. This study suggests that this contact should include not only information but emotional support and encouragement, provided in a way that recognizes and encourages parents as advocates for their children in the school system. This may represent a more significant practice and policy change for schools and elementary school educators than is the case for Head Start staff, who are guided by federal policy to engage and involve parents directly in the service provision process.

The current study also highlights the importance of listening to families when developing and implementing transition practices. These parents clearly articulated both the strengths of the transition supports they had received and their frustrations with a lack of transition information and support. Their experiences underscore the need for individualized supports that provide information in multiple ways (e.g., written, through orientation sessions, and via parent-to-parent information-sharing) and at multiple times and which bring families to the table in engaging in transition-planning with representatives from both preschool and

elementary school partners. Practices that consistently demand parents to rearrange their schedules, secure child care and transportation, and bring their own translators are clearly insufficient for adequately reaching higher-risk families. Elementary schools have much to learn in this regard from Head Start programs, and strengthening the partnerships between Head Start and other early childhood educators and school systems might have the added benefit of helping schools do a better job at engaging these populations.

Limitations

The current study sought to gain a deeper understanding of the transition process by examining parents' experiences of various transition practices. While these qualitative methods were appropriate to this goal, the results should be considered exploratory and descriptive. Future studies that can examine the linkages in this conceptual model directly, using more quantitative methods, are needed to test the model empirically. It is important to note that this study was not able to measure either parent involvement or the success of these children's transitions quantitatively. Thus the extent to which these transition practices are associated with more positive child or family outcomes remains to be tested.

Further, the results are based on a relatively small sample of parents and children from two Head Start programs that engaged with a small set of elementary schools. The linkages in the model may be different in different community contexts. Many early education settings outside of Head Start do not provide the types of transition supports described here, and, indeed, the transition practices across Head Start programs vary considerably (Mangione & Speth, 1998). The model does, however, point out key aspects of transition practices that can be used by both early education and school programs to guide the development or improvement of current transition practice and policy.

Areas for Future Research, Practice, and Policy

Understanding which transition practices provided through schools and early education settings are most helpful in supporting children with emotional or behavioral challenges to transition successfully to kindergarten remains an area greatly in need of more empirical research. Interventions designed to test the efficacy of specific practices or sets of practices on parent involvement and transition success can begin to help develop this knowledge base, as can large-scale survey research such as that done by Schulting and her colleagues (2005). This research can also help to move the field toward greater understanding of the importance of transitions for at-risk families and has the potential to influence transition policies at the community level. Not surprisingly, a key issue mentioned across the board by both Head Start staff and kindergarten teachers was the concern with the lack of time and resources for more comprehensive transition practices. Clearly the burden for implementing more time-consuming (but potentially more effective) transition supports cannot rest solely with classroom and direct service staff, but

requires leadership commitment to the importance of transition practices that support relationship-building, information-sharing, and continuity across home, early childhood, and school settings. Research that can carefully document the type and intensity of transition supports parents receive from both early childhood and school settings, and which tracks children's academic and social outcomes from preschool through the kindergarten transition, will help to bolster the need for such policies. In addition, some changes in attitudes, especially within the school system, toward greater recognition of the level of effort and skill needed to successfully engage parents *on their own terms*, may be especially important for the success of at-risk children.

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Managing Communication at the Work-Life Boundary: Parents of Children and Youth with Mental Health Disorders and Human Resource Professionals

Julie M. Rosenzweig, Anna M. Malsch, Eileen M. Brennan, Katherine J. Huffstutter, Lisa M. Stewart, and Lisa A. Lieberman

Using qualitative methods, this study explored communication challenges experienced by parents of children or youth with mental health disorders when seeking family support in the workplace and by human resource professionals when responding to parents' requests. Five focus groups of twenty-eight employed parents and three focus groups of seventeen human resource professionals included participants who were predominantly female, European-American, and middle-aged. A communication boundary management model emerged from transcripts: parents communicated across the boundary between family and work and drew upon past experiences with disclosure and courtesy stigmatization in the workplace as they made decisions about revealing family information to human resource professionals. As parents and human resource staff grew in communication competence from prior experiences, negotiation regarding possible workplace supports progressed to more satisfactory outcomes. Recommendations for mental health service providers include exploring family members' work-life integration experiences and providing information about workplace supports and effective communication strategies.

When parents first observe that their children or youth are experiencing social, emotional, behavioral, or academic challenges beyond those of peers of similar ages, everything in their lives begins to shift. These parents focus their resources on understanding what is happening with their children or youth, first through comparisons with other children's development and conversing about parenting practices with other parents and family members. The sense that something is wrong marks the beginning of the "experience trajectory" for parents of children or young people with mental health challenges (Rosenzweig & Kendall, 2008), a process that unfolds over time as parents make sense of what is taking place, involve professionals, live on an emotional roller coaster, and craft a new vision of family life. In the earliest stages of the trajectory, employed parents continue working, proceeding as normally as possible, attending to job responsibilities and communicating with coworkers. Initially, the parent is distracted during work by concerns for the child or youth. When it becomes necessary to receive phone calls at work from care providers or school personnel and to take the child or youth to multiple health-care appointments, these distractions can turn into frequent work interruptions (Jett & George, 2003).

At the point when family life has clearly spilled into work life, the parent faces a series of decisions about how to respond to the rapidly emerging mental health–care needs of the child or young person while effectively sustaining employment. In addition to the practical dimensions of these decisions, there are significant personal dimensions as well. For instance, the parent strategizes about how to take time away from work for the child's or youth's multiple appointments and respond to the unpredictable care responsibilities that arise, while carefully considering to whom and what to disclose within the workplace regarding the child's or young person's mental health challenges and care needs. Concerns about courtesy stigmatization (Goffman, 1963) and fears about workplace questions of loyalty and performance can inhibit the parent from seeking formal workplace support, such as requesting a flexible work arrangement, or pursuing emotional support from the supervisor and coworkers (Lewis, Kagan, & Heaton, 2000).

Information about what strategies these parents use to balance their concerns with their needs for workplace support to meet exceptional caregiving responsibilities (Roundtree & Lynch, 2007) is largely unknown (Rosenzweig & Huffstutter, 2004). Likewise, the level of organizational knowledge about the exceptional caregiving needs of parents of children or youth with mental health disorders and responses to associated workplace support requests is largely uncharted. This article discusses the results of an exploratory study by the Work-Life Integration Project to identify the communication concerns and resolution strategies used both by employed parents of children or youth with mental health disorders

when seeking support within the workplace and by human resource (HR) professionals when responding to the parents' requests for support. By means of an exploratory focus group study employing qualitative methods, three basic questions were examined:

1. How do parents of children with mental health disorders manage the boundary between home and work by deciding to disclose or conceal their families' needs?
2. What factors affect parents' negotiation with HR professionals about work adjustments and employment-based supports?
3. What are the outcomes of workplace negotiations or concealment of family needs reported by parents and HR professionals?

Boundary/Border Theory

Historically, the domains of work and home were separated by gender, place, roles, and responsibilities. In contemporary society, these dimensions of work and home have become increasingly less constrained. The concepts of boundaries and borders are used by work-family scholars to describe and examine an individual's experience when the domains' dimensions are held separate or converge (Ashforth, Kreiner, & Fugate, 2000; Clark, 2001, 2002; Desrochers & Sargent, 2003), and to look at the related outcomes for the individual and the organization. Although there are some conceptual differences between boundaries and borders, their similarities help identify important mechanisms of boundary/border construction and transitions between the domains of work and home. Boundary theory is conceptualized as a general psychological perspective related to the meaning individuals assign to their roles and responsibilities within various life domains and how they negotiate transitions between them (Desrochers & Sargent, 2003), whereas border theory was formulated within work-family studies by Clark (2000, 2002), who defined borders as "lines of demarcation between domains" that can be physical, temporal, or psychological" (2000, p. 756). Boundaries and borders alike are characterized by properties of permeability, flexibility, blending, and strength. Desrochers and Sargent (2003) discuss work-family boundary blurring, which involves confusion in demarcating work and family roles when one or both of these domains is highly permeable. The extent to which a worker can create boundaries through rituals that signify psychological transitions between home and work (Ashforth et al., 2000), as well as the frequency of border crossing can create boundary blurring or provide a better sense of integration between work and non-work domains. According to border theorists, work and family are considered to be separate domains, with individuals crossing over the borders of each proactively in order to create a meaningful state of balance (Clark, 2001, 2002). Borders do not exist in a fixed state but can contract or expand according to needs and demands of the domains.
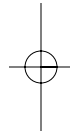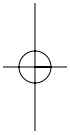
Communication across and within domains is a core activity utilized by individuals to negotiate the separation and integration of work and family responsibilities. Research suggests that permeability and flexibility in the boundary/border of the work domain are associated with greater cross-border communication about home life (Clark, 2002) and that supportive workplace communication is correlated with job satisfaction (Lambert, Kass, Piotrowski, & Vodanovich, 2006). Individuals have different preferences and needs about the degree of permeability and flexibility of work and family boundaries/borders (Desrochers & Sargent, 2003). Communication strategies to manage boundaries/borders are developed by individuals both proactively and reactively, depending on needs and circumstances in each domain.

The nature of exceptional care responsibilities in which parents of children or youth with mental health disorders are engaged require that domains' boundaries/borders be flexible and permeable. Work-life integration rather than segmentation is necessary to meet care needs and fulfill work tasks. In general, work-life integration focuses on the extent to which a person is able to weave together personal, work, and leisure time in a way that brings satisfaction and meaning and contributes to the overall quality of family life and individual well-being (Rapoport, Bailyn, Fletcher, & Pruitt, 2002). As a construct, work-life integration includes an analysis of the ways in which work responsibilities, family life, and leisure time are organized and structured in the context of the family at any particular point in time (Lewis, Rapoport, & Gambles, 2003). Any one particular aspect of integration is connected to one's stage within the life course and supports available for the individual within the family system, the work system, and the larger community.

Organizational Support for Work-Life Integration

Flexibility in when and where work and family responsibilities are met, family leave policies, and dependent care supports are crucial for employed parents with exceptional care responsibilities to facilitate work-life integration. According to Emlen (2010), flexibility is a broad-based concept and, in the context of work-life integration, it is the ability of family members to alter some part of the work/family/child-care system. This definition is particularly pertinent to parents of children or young people with mental health disorders. A lack of relevant community-based supports forces these parents to rely primarily on employment-based flexibility in order to achieve greater work-life integration (Rosenzweig, Brennan, & Ogilvie, 2002). Among the most significant missing resources appropriate for these families are: inclusive child-care providers; appropriate public transportation; and evening or weekend appointment availability from providers of health care, mental health care, social services, and special education. Unable to find or afford community-based services and resources, an employed parent may seek formal or informal support from the workplace, making requests for flexibility that may require disclosure of the child's or youth's mental health challenges.

Flexible work arrangements typically involve the alteration of work hours and/or places of work in order for employed family members to meet their work and family responsibilities. Flexible work arrangements can be formal or informal. Formal arrangements are written into company policy and generally approved through a formal process involving a manager and the HR professional in the company, while informal arrangements are utilized on an as-needed basis and may need approval by the direct manager (Eaton, 2003) or include a worker-to-worker request. The benefits of work flexibility for both organizations and family members are well documented. With respect to organizational benefits, a meta-analysis demonstrated that flextime had positive effects on productivity, job satisfaction, satisfaction with work schedule, and employee absenteeism (Baltes, Briggs, Huff, Wright, & Neuman, 1999). Benefits to organizations of flexible work options include employee retention and engagement (Galinsky, Bond, & Hill, 2004; Richman, 2006). Family members who use flexible work arrangements, particularly those who have high levels of family responsibility (Shockley & Allen, 2007), report lower levels of work-family conflict as well as lower levels of stress and burnout (Grzywacz, Carlson, & Shulkin, 2008), demonstrating the effectiveness of flexible work arrangements as both an organizational and family best practice.

The HR professional can be a pivotal source of formal and informal support for the employed parent of a child or young person with a mental health disorder. Although roles and responsibilities may vary depending on the size of the organization, HR professionals can enhance work-life integration for employees through direct contact, policy and program development, and enhancement of the workplace culture (Sutton & Noe, 2005; WorldatWork, 2005). In addition, they can serve as mediators between supervisors and/or managers and employees struggling with work and exceptional caregiving responsibilities; assess the work-life needs of employees caring for children or youth with disabilities; disseminate information about work-life policies, programs, and community resources; and advocate on behalf of employees to upper management about work-life issues related to caregiving (Milliken, Martins, & Morgan, 1998; Unger, Kregel, Wehman, & Brooke, 2003).

HR professionals are key influencers of organizational culture through working with top executives as strategic business partners and interacting with managers, supervisors, and the employees they supervise. Organizational culture has been shown to mediate the use of work-life benefits (Thompson, Beauvais, & Lyness, 1999), establishing that the availability of policies that purportedly endorse family-friendly practices does not indicate that employees will utilize them (Goshe, Huffstutter, & Rosenzweig, 2006). Employees are sensitive to the verbal and nonverbal messages in the workplace that shape the family-friendliness of an organizational culture. Kirby and Krone (2002) call for an examination of the communicative nature of work-life policy implementation, noting that utilization of supports for managing dependent care, in particular, is a function of discourses across all levels of employees.

Unfortunately, employed parents of children with mental health challenges and HR professionals often face barriers to finding common ground on which to build solutions that address both the parent's work-life needs and business objectives. The workplace is not immune to the stigmatizing social-cultural narratives about mental health disorders that are present in the larger community. Parents of children with mental health disorders are acutely aware of the stigma surrounding mental health disorders and have experienced blame for their children's problems (Corrigan, Watson, & Miller, 2006; Corrigan & Miller, 2004). It is not surprising that parents are reluctant to disclose their children's mental health status to people outside the family (Corrigan et al., 2006; Larson & Corrigan, 2008), let alone to their coworkers, because it may mean risking their jobs to care for their children. HR professionals are confronted with dilemmas of their own, including how to equitably respond to all employees (Grandey & Cordeiro, 2002) and what questions to ask employees when family issues are interfering with work.

Boundary Communication Management

Access to workplace formal or informal supports by the parents of children with mental health disorders involves a reciprocal process of communication between the employee and the HR professional—and often times a supervisor. The knowledge and use of effective interpersonal communication strategies by all parties are crucial for parents to improve their level of work-life integration and for the organization to meet its goals. The concept of communication competence has been gaining increased attention by organizations as a means of improving job performance (Payne, 2005). Although a comprehensive definition of communication competence is somewhat elusive, most scholars rely on Spitzberg and Hecht's (1984) two primary dimensions of effectiveness and appropriateness as foundational (Gross, Guerrero & Alberts, 2004; Lobchuk, 2006; Payne, 2005; Schrodt, 2006; Thompson, 2009). Contributors to the discussion also agree that communication competence is contextual and influenced by situations and goals (Cegala, Socha McGee, & McNeilis, 1996; McNeilis, 2001; Query & James, 1998). Payne (2005) defines organizational communication competence as:

> The judgment of successful communication where interactants' goals are met using messages that are perceived as appropriate and effective within the organizational context. Communication competence in organizations involves knowledge of the organization and of communication, ability to carry out skilled behaviors, and one's motivation to perform competently (p. 65).

While work-life scholars discuss communication as a vehicle for managing boundaries/borders of work and non-work domains, there has yet to be an in-depth examination of the communication competent processes or strategies that are effective in achieving the individual's or organization's preferred level of integration or segmentation. In addition, it is crucial that the examination of communication competence at the work-life domains' boundaries/borders include

the processes and management of private information disclosure. In Petronio's (1991) discussion of communication boundary management, the nuanced process of disclosing private information delineated the vulnerabilities for both the revealer of the information and receiver of the information. Further exploration of this dyadic exchange, especially when the disclosed information is unsolicited, could greatly assist in further understanding the experience of a parent strategizing about how to disclose a child's/youth's mental health status within the workplace and the organizational response to receiving the information. Although disclosure decisions across domains have not yet received a thorough examination, a limited investigation exploring employee disclosures about a child's mental health disorder in the workplace has indicated that parents weigh benefits and risks before sharing with HR professionals, supervisors, or coworkers (Rosenzweig & Huffstutter, 2004). This risk-assessment process allows the individual to create a necessary protective boundary to manage the flow of information (Petronio, 1991).

The notion of risk assessment is further supported by Edmondson and Detert's (Edmondson & Detert, 2005; Detert & Edmondson, 2006) discussion of verbal communication from an employee to a person in a position of power and the necessary use of an upward voice. Speaking up, particularly when an upward voice is necessary, depends upon whether an individual perceives that it is psychologically safe to do so and whether speaking up will make a difference (Detert & Edmondson, 2006). The person in authority who is the recipient of the employee's communication is influential in the employee's decision about giving voice to opinions or needs.

A particularly high-risk situation for parents of children or youth with mental health disorders is asking a supervisor or human resources professional for flexibility in their work schedules to meet the caregiving needs of their families. Parents' disclosures about their children's or youths' mental health challenges may enhance access to necessary support for work-life integration (e.g., gaining a flexible work arrangement) or may negatively affect their work experience through increased incidents of courtesy stigmatization, which can involve isolation, shame, and silencing because of their relationship to a person with a stigmatized identity (Goffman, 1963). Stigmatization associated with a mental health disorders in general, and courtesy stigmatization in particular, are contextual variables across work-life domains that prevent parents of children with mental health disorders from speaking up.

Methods

Because the research questions in this study are new to the fields of work-family studies and children's mental health, and are exploratory in nature, investigators utilized qualitative approaches. Data collection involved the use of focus groups to gather data and a grounded theory approach (Strauss & Corbin, 1998) for data analysis. A focus group approach was selected since it provided the opportunity to collect the language used by participants individually and collectively to

frame their experiences of workplace discussions about the family situations and to examine the emerging social creation of meaning from the statements of participants, which is not possible from individual interviews (Smithson, 2006). Grounded theory is an inductive research method where theory is developed on the basis of the researchers' coding of transcripted materials (Strauss & Corbin, 1998); it is appropriate for exploratory research that aims to develop a conceptual model.

Participants

Participants for the focus groups were recruited through parent support and advocacy networks and human resource professional organizations in the Pacific Northwest and through the Research and Training Center on Family Support and Children's Mental Health (RTC) Web site. Participants who indicated an interest in participating were given information on the study purpose and were invited to contact the research team to sign up for the focus groups and obtain further information on any questions they may have had regarding the study. Parents and HR professionals were paid $25 for their participation in the focus groups.

Twenty-eight female caregivers of children with emotional or behavioral disorders participated in a total of five parent focus groups, ranging in size from two to 12 participants, that were conducted between March and May 2005. Parent ages ranged from 30 to 57 years ($M = 39$, $SD = 9.1$), and their median family income was between $30,000 and $39,000 per year. Family members cared for a total of 59 dependents, aged one to 36 years, of whom 43 (75%) had emotional or behavioral disorders. Approximately half (52%) had two children under 18 years at home, and half (54%) shared parenting duties with another adult. Participants were European-American (68%), African-American (15%), Hispanic (7%), and mixed race (2%). Most (68%) had high school as their highest level of education. Parents spent between five and 83 hours per week in care activities and between seven and 60 hours in paid work. Of those who reported a job with benefits (68%), most had flexibility (79%), sick leave (75%), vacation time (71%), Family Medical Leave Act coverage (64%), and health insurance (61%). Table 1 contains information about the parent participants' education, type of job, level of employment (full-time vs. part-time), and size of the employing organization.

Three focus groups were conducted with 17 HR personnel who shared their perspectives about workplace issues and practices specific to employees meeting care needs that compete with work obligations; the groups ranged in size from five to six participants. Participants were generally in their mid-adulthood ($M = 45.2$ years, $SD = 8.4$), female (87.5%), European-American (88.2%), and experienced ($M = 15.6$ years in HR, $SD = 9.1$). The majority held professional certification (58.8%), supervised others (82.4%), worked in organizations employing 100 workers or more (81.2%), and were employed full-time in HR (87.5%). A more complete demographic breakdown of HR participants can be seen in table 1.

Table 1   Summary of Focus Group Participant Characteristics

Participant Type	Characteristic	N	%
Parent	Education		
	Less than high school/GED	3	10.7
	High school diploma/GED	16	57.1
	Associate degree	4	14.3
	Four-year college degree	2	7.1
	Graduate degree	3	10.7
	Type of job		
	Executive/manager	2	3.6
	Professional	23	82.1
	Administrative	2	7.1
	Service	1	3.6
	Organization size (four parents did not respond to this question)		
	under 100 employees	16	66.7
	100–499 employees	4	16.6
	500–999 employees	2	8.3
	1,000–10,000 employees	2	8.3
	Full-time vs. part-time work		
	Full-time	20	71.4
	Part-time	8	28.6
HR Professional	Education		
	High school diploma/GED	1	5.9
	Four-year college degree	11	64.7
	Graduate degree	5	29.4
	Type of HR job		
	HR Director/Manager	10	58.8
	Consultant	3	17.6
	Recruiter	2	11.8
	Specialist	1	5.9
	Retired	1	5.9
	Years in HR Field		
	less than 5 years	1	5.9
	5–10 years	5	29.4
	11–25 years	8	47.1
	more than 26 years	3	17.6
	Organization size (one HR professional did not respond to this question)		
	under 100 employees	3	18.8
	100–499 employees	5	31.3
	500–999 employees	2	12.5
	1,000–5,000 employees	6	37.5
	Have direct contact with employees (one HR professional did not respond to this question)		
	Yes	14	87.5
	No	2	12.5

Procedure

Because within-group homogeneity allows participants to discuss topics in terms that are familiar to the other focus group members (Hughes & DuMont, 1993), two separate types of focus groups were conducted: (1) those consisting of employed parents of children with mental health disorders, and (2) those made up of HR professionals. Participants in both types of groups were asked to complete three forms upon arrival: (1) a general consent for participating in the focus group; (2) a consent to be audiotaped; and (3) a short questionnaire to collect demographic, job-related, and caregiving information. Two facilitators were responsible for conducting the groups by asking the research questions and guiding the group discussions. The focus groups began with facilitators' welcoming participants, introducing the study, addressing participant questions, and following procedures for informed consent. Facilitators introduced basic group ground rules and then introduced the first question. Focus group questions differed between the two types of groups but stayed the same within the parents' and the HR professionals' groups.

Data Collection

Prior to running the focus groups, the research team met with project advisors who were parents of children with emotional and behavioral disorders and HR professionals to determine a set of loosely structured questions to be used to guide the discussion in each of the five parent groups and three HR groups. The goal of the focus group guides was to orient participants to the topics and then to proceed to more specific questions that would add to the validity of the study by allowing "thick, rich descriptions" of study themes (Creswell & Miller, 2000, p. 128). In each focus group guide, discussion emerged from six general questions that explored the ways in which family and work domains intersected or had sharp boundaries. Parents were asked to reflect on their workplace experiences with people or programs that made it easier to care for their children with mental health disorders and to manage crises that arose with their children. Parents also responded to questions regarding their communication at work about their children's situations and what assistance they received from HR professionals. The HR focus group participants were asked how they would work with employees who were having difficulty managing both work duties and their children's mental health problems and to discuss both successful and challenging experiences related to this set of employees. Both types of groups ended with questions to participants regarding the resources that would be most helpful to them.

During the sixty-minute, audio-recorded focus groups, participants were encouraged to share their individual experiences and to build on the discussion of the other participants. The focus group facilitators supported the discussion and used probes to clarify responses as appropriate (Morgan, Krueger, & King, 1998).
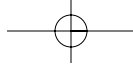
Any changes, additions, or modifications were made to the flip-chart notes as needed. Questions were considered exhausted when participant responses slowed or stalled in the discussion. When this occurred, one of the facilitators would reiterate the question and prompt participants for any additional thoughts (Krueger, 1994). Multiple sources of data (audio transcripts, field notes, flip-chart notes) were collected for each focus group, helping to insure the validity (credibility) of researcher interpretations of the data (Creswell & Miller, 2000).

Data Analysis

Written focus group transcripts were prepared from the taped focus group discussions, and the text was entered into NUD*IST (Non-numerical, Unstructured Data Indexing, Structuring, Theorizing) software (Qualitative Solutions and Research Pty Ltd & La Trobe University, 1993) to manage the qualitative coding and analysis. Researcher field notes were also added to the data file to aid in the analysis, and flip-chart materials were consulted. Four members of the research team met in pairs first to establish initial codes using an iterative approach, beginning with careful reading of each transcript. The identification of preliminary codes was followed by meetings of the research team to discuss and compare interpretations of the first level of data coding, and to develop more substantive coding based on themes. Once the secondary/axial coding was established, a model that was used to explain the major themes and relationships among them was developed. This model was informed by the theoretical and empirical literature on boundary/border theory. During this process, the research team worked both independently and collaboratively to define and redefine the categories by immersing themselves into the data again to validate the emerging structures and ensuring confirmability of the findings. This process was considered complete once all the major codes and their relationships had been accounted for in the model.

Results

The transcript analysis revealed that negotiating the permeability and flexibility of work-home boundaries/borders within the workplace setting is challenging for both parents of children/youth with mental health disorders and HR professionals. The conceptual themes that emerged as central are represented in figure 1, a model of communication boundary management, which was developed from the parents' and HR professionals' discussions of the negotiation process for workplace supports. Past experiences with disclosure of personal information and courtesy stigmatization weighed heavily on both groups. Parents reported basing their decision to disclose or conceal their family's situation on these prior experiences; disclosure was also related to the communication competence they had developed based on past experiences. If employees decided to disclose their family's needs and entered into negotiation at their workplace for flexible work

Figure 1. Model of Boundary Communication Management by Parents
of Children/Youth with Mental Health Disorders and Human
Resource Professionals

Note. Model of boundary communication management derived from analysis of transcripts of focus groups involving 28 parents of children/youth with mental health disorders and 17 human resource professionals.
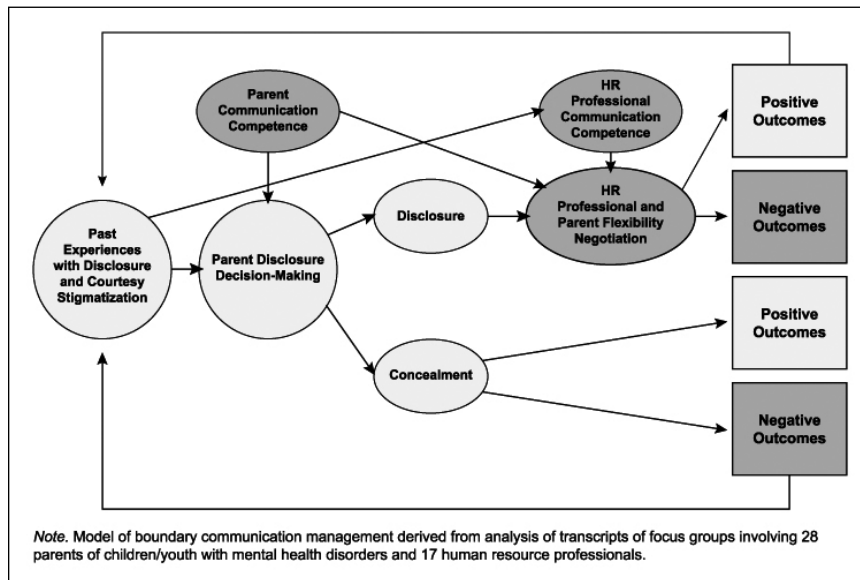
arrangements, both positive and negative outcomes resulted. This negotiation was affected greatly by the levels of communication competence the parents and the HR professionals had achieved through past experience. On the other hand, parents and HR personnel discussed the decision of some employees to conceal their family's situation, which also resulted in positive and negative outcomes. Each of the conceptual themes will be discussed in greater depth.

Boundary Management: Lessons from the Past

Family members were asked to reflect on experiences they had in their workplaces that helped them meet their responsibilities. The employed parents revealed the lasting impact of their past experiences with crossing the boundary between work and family and the way these experiences shaped their willingness to tell HR professionals, supervisors, and coworkers about their children's or youths' mental health problems and their families' needs.

Past Disclosure

Some employed family members had positive experiences as a result of past disclosures of their family challenges and needs. We heard from parents who were in workplaces where they were able to put plans in place to manage those challenges and garner a great deal of HR staff, supervisor, and coworker understanding, which made disclosure less stressful and more effective. "If I have to leave work
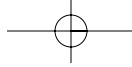
immediately, there are designated people that I talk to and that I trust, that I know will inform the other people that need to know, like my supervisor."

It helped to work in a family-friendly environment where others struggled to meet family needs and received flexible work arrangements. One mother who frequently was able to get workplace flexibility commented, "For the most part, I think it has helped working in an office where the majority of the women are mothers. . . . I think along with just having a place with [coworkers having] various issues . . . it has made them more understanding and accommodating." However, she went on to say that she still got "that leery feeling" and that "I don't want to feel like it is [seen as] a problematic issue and happening constantly."

Past Courtesy Stigmatization

Time and again parents in focus groups talked about the courtesy stigmatization they felt in the workplace and the chilling effect that it had on their willingness to cross the boundary from family to work and to disclose their children's mental health issues to HR professionals, supervisors, or coworkers. One mother felt judged when she disclosed her sons' problems and asked for flexibility:

> When my problems kind of first started with my boys, my boss was good about letting me off, but they always made me feel like they were looking down on me. . . . They would say, "Here she is, having trouble with those kids again." I just felt it when I talked to them, so I stopped. I finally quit the job.

In some cases, parents reported being direct targets of courtesy stigmatization and heard their employers or coworkers label them as ineffective parents, professionally incompetent, or lax workers because of their children's difficulties and their requests for workplace supports. One mother reflected on workplace attitudes as being part of a wider societal misconception about parental responsibility for children's mental health problems: "Most of this isn't just from the workplace, but the attitude of, 'What did you do wrong as a parent?'—that judgmental attitude. Like when something comes up, 'Why didn't you anticipate it?' 'Why didn't you fix it beforehand?'" Working parents also reflected that their professional competence was under heavier scrutiny: "If you can't handle your child, can you do your job?" HR professionals commented that in some working environments, there was little tolerance for those who took time off for any reason. An HR staff member at a manufacturing business commented: "They are physical workers, and they don't have a lot of patience for allowing employees, who are supposed to be there working hard, to be off for whatever reason."

HR professionals also reported that family members watched what happened to their coworkers to see whether others were being negatively labeled or sanctioned due to their caregiving responsibilities for children with difficulties. For example, one parent explained, "Other employees will watch how their peers are treated, and they pick up on that." Another mother said:

> [I have a coworker] who misses more time than I do, so I think I kind of watch to see if she's going to get into trouble. . . . The phone rings, and I am holding my breath. If it is for her, I am like, "Whew!"

Although family members may not have had either direct or indirect experiences of stigmatization, they still talked about being concerned about the possibility that they would experience negative appraisals from peers. An employed parent lamented that her colleagues really misunderstood the nature of children's emotional or behavioral problems and felt that she was seen as shirking her work responsibilities when she asked for flexibility. "But still [coworkers] don't look at mental illness like a broken leg. That's hard, because I think that sometimes people do think . . . you are just trying to get out of work."

For some parents, their history with courtesy stigma was so overwhelming that they accepted blaming messages and applied them to themselves. "I believed that anybody who knew what was going on with my child was right, that my kid was just bad. Eventually that worked into, 'I must be a bad mom, too.'"

Boundary Management: Communication Strategies and Competencies

Communication is an integral component of the management of the boundary between work and family. Both employed parents and human resource professionals must have a set of communication strategies that they successfully apply to negotiations for workplace flexibility. Communication competence reflects the ability to communicate one's view and needs as well as the ability to understand the perspectives and needs of others. There are two primary dimensions of communication competence: relational development and information exchange. Both dimensions are usually present in negotiations between parents and HR staff. For example, when parents disclose their children's mental health status to an HR professional or supervisor, they may share information about diagnosis and what is involved in the care/treatment. It is important to note that parents often make a decision about *how much* information to share, reflected in the levels of disclosure discussed above. In response, the HR professional is likely to share information about workplace policies and available flexibility options. Relational development includes promoting an atmosphere of warmth, trust, and support. Both parents and HR professionals contribute to this relational development by actively listening, being honest, and by being responsive to requests and suggestions.

In our analysis, communication competence emerged as a central concept that was both informed by previous experiences with disclosure and stigmatization, and also served as an aid to both parents and employers in their negotiation process.

Developing Communication Competence

The past experiences of both parents and human resources personnel related to disclosure and stigmatization were critical in the development and application of communication competence. For parents, past experiences informed their current communication strategies for when and how to disclose their family situation. In some cases, their previous experiences had been so negative that it led them to conceal, rather than disclose their situation. One parent's previous

experience disclosing to her supervisor was met with a lack of understanding and stigmatization:

> My direct supervisor is not very family-oriented. She doesn't have small children. She has a stepdaughter who is older. She doesn't seem to have that sensitivity that some of us who have got kids in the household have. She tends to say more things like, "Can't somebody else handle that?" "Isn't there something else you can do?" In order to kind of get around that sometimes, I just don't talk to her.

This reflects the notion that the decision-making process itself around disclosure and concealment involves communication competence, in that a parent takes in information regarding who is a safe person to talk to and who is not. On the other hand, sometimes parents had positive experiences that led them to feel comfortable communicating with their supervisors and HR personnel:

> My workplace, because of my work environment, which is a family support center, I think everyone knows my story. I think that gives me support that I need, because if I am having a difficult time, I can go to my boss, and because of her education, she can give me the support I need.

Further past experiences helped parents to develop communication skills they could use when choosing what and when to disclose:

> I knew what I needed to ask, in order to put it upfront, prior to me saying that I would do the job, was I have learned through the years what kind of flexibility I need and what might cause a problem with an employer.

HR professionals and supervisors also drew on their previous experiences when communicating competently with their employees. In some cases they drew on their own personal experiences:

> Being a parent myself, I guess I can empathize [with] and understand the demands. For example, friends who have children with special needs, I see what they have to do in their work life, and I can always apply what I understand from that to our employees as well.

Others drew on the past experiences and expertise of their colleagues:

> When there is an issue, I [find] it very important and helpful to get the EAP [Employee Assistance Program] involved with me, to get ideas, brainstorm with them on what I should suggest as solutions to the person, besides just steering the employee to them.

Another said, "I know that a week doesn't go by, seriously, that I don't make at least a couple calls to the other . . . benefit managers and say, 'You guys have this situation? How have you handled it?'" When HR professionals or supervisors did have some prior experience that guided their responses to workers, it did not go unnoticed by employees. One parent said:

> I worked where two of the men in higher ranking positions had children with special needs of one type or another. They knew what it was to have to juggle a schedule for doctor's appointments or mental health issues. One of them also had a child that was severely emotionally disturbed, and there were frequent calls to the school for his wife. They understood. That made them more tolerant of me.

Communication Competence and Disclosure

The communication competence that employed parents develop becomes very important in their decisions about disclosure in the workplace. Communication competence that reflects skills having to do with information exchange were frequently mentioned by parents. In particular, the acknowledgment of the need to educate their employers was stressed:

> I think that is one of the hardest things that I've had to do, is explain my position in order to help my son, and it goes into the workplace, as well . . . they just see a child who has emotional and behavioral problems, and they don't understand that there is a root to it. It is hard, but I am determined to get through it.

This was a skill they enacted even if they did not want to: "You end up almost having to educate people about what you are going through on a regular basis. It is like, I don't want to educate anybody." Part of communicating competently is providing the information that will best help the parents address their needs and cope with any potential crisis. In other words, they anticipate what they may need and communicate the information to set the stage:

> I could say, "I need to leave," and I could share later, if that is what I needed. I wasn't questioned, but because they knew a little bit about my family background, they realized it was a crisis, and I could get up and leave.

The relational development dimension of communication competence was also important in decision-making. One parent spoke of her strategy of being very open about her child's disability in an effort to avoid stigmatization by her coworkers:

> I am just a person who is very open about my situation. I don't try to hide it or keep it a secret, and I have pictures up around my desk, and people ask me about her. I talk very openly about it. I think that that takes away the stigma of mental illness, so that when there is a situation, other coworkers are not getting jealous, or, 'Why does she get special privileges?' or things like that.

Decisions to Disclose or Conceal Family Needs

HR professionals and employed parents both reflected on the difficult boundary management involved in disclosing personal circumstances about one's family life. An experienced HR staff member said of his employees, "They are afraid you are going to categorize [them] if [they] tell you that [they] have a mental health issue in [their] family, or whatever."
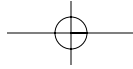
Human resource focus group participants were also aware of the requirements for confidentiality imposed by federal regulations. "More and more the government is requiring [us] to say less and less to anybody about the circumstances of their employee." A parent employed in a large health-care organization said:

> Over the years . . . I've watched processes change where now we try to ensure confidentiality, that I am not asked as I am being hired or being interviewed, "Do you have children?" "Are there going to be any challenges that you may face?" Because no one asks me, then the burden on me is to choose to tell or not to tell.

HR participants made it clear that despite the difficulties they might face, it was important for employees who were having difficulties at work due to family caregiving responsibilities to disclose their need for flexibility and to work through their issues and needs:

> [Employees say,] "Oh, I need to take this time off. I have to work this short shift." They think there is only one solution to the problem. Part of what I feel is my job is as an HR person, and just as a human being, is to help them identify other options that may be available to them.

Employed parents took very different approaches to disclosing their children's mental health problems and their need for flexibility, primarily due to their prior experiences with disclosure and stigmatization present in the workplace. Three types of disclosure on the part of parents were identified through transcript analysis: (1) full disclosure, (2) limited disclosure, and (3) full concealment.

Working in a human services organization, one mother opted for full disclosure of her family situation, "You have to let people know what is going on, because it is impacting your ability to do your job and to do it well, and to keep up with the things that are the highest priority." Another said, "I've just now become very upfront. 'This is how I live . . . I know I can do this job, but I have to have some flexibility."

Some parents were able to get the help they needed at times of crisis using limited disclosure. One parent recalled of her strategy during a crisis, telling her supervisor, "I have to get my son out of restraints . . . that would be the code that I would say to [her] . . . I think that would be it, as far as me having to leave immediately." This mother understood that her supervisor would cover for her, but she did not have to detail what the crisis was, and why she needed flexibility.

Other parents chose full concealment and practiced self-censoring of information about their families. A few participants reported that they did not disclose their family situation during the job search or at the beginning of their employment until they had built a solid work history in the organization:

> If you ask for that flexibility upfront, and they have two candidates and one of them isn't asking for a whole bunch of time off and saying that they may need this and need that, they are probably going to weigh in on the one with less baggage.

Some family participants revealed that they told edited and altered stories about their families to their coworkers so that they did not expose their personal struggles. "Bending the truth" also allowed relief from the chaos of family life that the structure of the workplace can offer. After a particularly stressful vacation, one family member said in response to coworkers' inquiries, "'Oh, it was lovely, thank you' . . . I live it 24/7, so sometimes at work is my time to not have to deal with it."

HR participants discussed what happened when employed parents faced struggles at home but wouldn't disclose them at work. "Sometimes I hear it from a performance problem. [Supervisors] may not know there is an issue going on, and then we find out that it has to do with a family issue." One HR professional commented, "Sometimes women feel that they can't bring it forward because they will be viewed as not being able to manage their family plus their work. So a lot of women will just try to suck it up and get through it."

Communication Competence and Negotiation

Just as communication competence affects a parent's decisions and strategies around disclosure, it also comes into play during the actual negotiation process itself. A particularly relevant concept that parents were skilled at communicating was reciprocity. For example, one parent knew that, not only did she have to explain and share information about her situation, she also had to communicate her commitment to her job and take into account the needs of the workplace:

> I found out . . . that I have to verbally say, "Look, we've had three bad nights. It is not good. Something is not working, and I am going to have to focus on that or I am not going to get back into business." They are able to accept that because they know when I get back to business, I am going to get the job done and that there is a balance . . . I give everything I can give but have to recognize there is a certain point where you have to say, "Look, I have to take care of this, or it is not good for any of us."

One parent was well informed and approached the negotiation with clear knowledge of what she could expect from her employer:

> I am pretty familiar with my specific employer's workplace policy, so I know how far I can push, and I know what my rights are, and I know what I can't ask for or shouldn't ask for. . . . Yeah, I get twelve weeks a year [Family and Medical Leave Act], and every July I submit paperwork to the doctor and [say], "This is a lifetime, ongoing condition, so expect this paperwork every year."

A parent expressed her own concern about how to balance the needs of her child and the needs of her job, reflecting the honesty component of relational development:
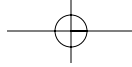
Open communication—"This needs to be done by this date," and "My son just had an episode at school, and if I have to leave, this is what I have right now on my desk, and I will get to this tomorrow." . . . This is what is really helpful for me.

The communication competence of HR professionals is also reflected in the negotiation process. As would be expected, an important part of an HR professional's communication competence is information-sharing:

I found my role this time just providing resources and information. "This is what is covered under mental health, under our health plan. Here is the information. Here is the EAP. Here are a couple of other resources you can call." Because this employee, the daughter is 18–19 and is having a lot of behavioral and mental health issues.

Many HR participants described the more relational aspect of communication competence. They felt active listening was a major part of the negotiation process:

I think I've found that one of the most important qualities for me, as an HR person, was the ability to just sit and listen. The employees would sometimes come in and talk to me, and they just want to talk. You get done with the conversation, and they are, "Thank you for listening. I don't need to do anything about this. I just needed somebody to talk to."

And: "My resources, I guess, are being a good listener, and not just piping in and telling them what to do, but really listening." Similarly, one HR professional stressed the need for actively involving employees in the discussion: "But, really, we would involve the employee in those discussions very regularly because they are going to give us the best indication of what their need is. I think where we go astray is where we don't involve them." An HR participant approached the situation with a more holistic perspective, understanding that the employee's challenges would not disappear solely as a result of flexible work arrangements and recognized the stress associated with the situation:

Even if you get your hours changed and you get your schedule accommodated, you are still going to be under a great deal of stress. You want to make sure that you try to help them figure out ways to deal with that as well, in addition to supporting their shift changes.

An employee's account of her negotiation at her workplace demonstrates the employer's relational communication competence and the support she felt she received:

If I need to go, "Is it okay if I go?" They said, "Oh, yes." I didn't believe them at first, but it is true. They not only let me have time, but they also offer to have somebody come with me, to support me. If I am out of time, and I am quite often now, they offer to call my husband and meet him someplace for my child. They have been very, very supportive.
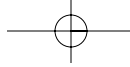
Boundary Management: Outcomes of Disclosure and Concealment

A major consideration with regard to this research relates to the significant challenges these employed parents have in managing the boundaries of work and family, all the while acknowledging the skill it takes to manage exceptional caregiving and employment and, on the employer side, the organizational necessity for retaining highly skilled workers. Clearly, communication competence—on both the employee and the organizational side—is a critical factor in achieving some semblance of integration in work and family life. However, communication is complicated and nuanced for parent/caregivers, with both positive and negative consequences. Positive outcomes of full or partial disclosure include increased access to formal and informal supports, such as flexible work arrangements and social support from supervisors and coworkers. On the negative end of the spectrum, disclosure can be a pathway to courtesy stigmatization, concerns about equity, unfair scrutiny, resentment from coworkers, and even job loss. On the other hand, communication competence is also about knowing when not to talk. Positive outcomes of concealment included avoiding stigmatization, equity concerns, scrutiny, and resentment from colleagues. Maintaining employment, experiencing a break from home life, and the feeling of normalcy were considered benefits of concealment by parent/employees. Yet withholding information also was associated with negative practical outcomes such as the parents' inability to access flexible work arrangements or formal supports and some psychological disadvantages as well, such as feeling isolated and alone.

Discussion

This study has explored communication boundary management in the context of the workplace specific to the flexibility needs of employed parents of children or youth with mental health disorders. The study was based on small purposive samples of parents and HR staff members, and the focus groups were held in one northwestern metropolitan area of the United States, thus findings cannot be generalized to populations outside the region. The study does, however, contribute to an emerging knowledge base of how family members of children with mental health disorders and other disabilities seek out workplace supports and how the workplace responds to these employees' exceptional caregiving experiences and needs (Rosenzweig & Brennan, 2008; Malsch, Rosenzweig, & Brennan, 2008).

Results from the focus group discussions have provided a greater understanding of communication boundary management strategies used by parents and HR professionals related to the employee disclosure decisions about their children or youth's mental health status and needs. Exceptional care responsibilities for a child or youth with significant mental health challenges often necessitate a high degree of permeability and flexibility in the boundaries/borders at the work-family interface. In part, the construction and management of these boundaries/borders is dependent upon the support that the parent can access within the workplace. A valuable source of support that the workplace may provide is flexibility in the time and location in which work tasks can be executed.

The very nature of asking for workplace flexibility brings personal life into the work domain. When parents of children or youth with mental health challenges disclose about their families' lives, the boundaries/borders between work and home are altered, regardless of reasons or goals for the disclosure. The decision process surrounding disclosure of personal or private information is shaped by multiple variables, such as prior experiences of disclosing the information, cultural beliefs about the information to be disclosed, the goal of disclosing, the context in which the disclosure will be made, and the recipient of the disclosure. Parents of children or youth with mental health disorders are acutely aware of being blamed by others for their child's or young person's condition; are expert monitors of stigmatizing comments; and carry with them a history of their voices being silenced, their concerns minimized, and their requests for support denied. It is not surprising that parents are frequently guarded about disclosing across contexts; nonetheless, the parent continually weighs the risk of self-disclosure, the need for privacy and protection, and the possible benefits of sharing.

Disclosure of children's or youths' mental health challenges and boundary communication management has also been examined through the lens of communication competence. Disclosure of personal information frequently takes place within a dyad. The communication competence of each dyad member, the discloser and the receiver, shapes the interpersonal interaction. Each member of the dyad employs boundary management strategies to regulate the flow of information across the interpersonal boundary (Petronio, 1991). The disclosure process needs additional study, including a closer examination of the receiver/responder's experience. This study indicates that the HR professionals employ certain strategies to maintain the communication boundary around work when the parent discloses personal family information. Such strategies inform the response and the outcomes of the interaction. Not only is the immediate communication boundary being managed, the HR professional is also managing boundaries of organizational confidentiality and privacy.

Communication competence includes motivation, knowledge, and skill dimensions, as well as contextual components (Payne, 2005). The data suggest areas of competencies across these dimensions that would enhance positive outcomes for the parent and the workplace. For instance, knowledge areas might include: children and adolescent mental health diagnoses, exceptional caregiving responsibilities, relevant federal legislation, and specific workplace policies and practices. Communication competencies in context and content, for example, specific to disclosure and requests for flexibility warrants further study. Additional research is also needed to understand the interaction between disclosure, communication competencies, and communication boundary management (Cowan & Hoffman, 2007).

This research is timely given current economic conditions and the aging of the workforce. Sound policies—both within organizations and with respect to supports designed to help families—need to be developed in order to help parents maintain employment and organizations retain workers. Indeed, parents of children with mental health disorders demonstrate high levels of creativity and
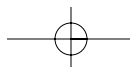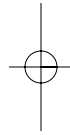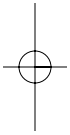
exceptional problem-solving skills. Current organizational research indicates that diverse employees make a significant contribution to organizational effectiveness (Cunningham, 2009; Van de Ven, Rogers, Bechara, & Sun, 2008). In order to reap the benefits of this "invisible" 9 percent of the workforce (Perrin et al., 2007), parents and HR professionals need support in developing communication competence. Furthermore, mental health and other helping professionals need to incorporate communication competence into their assessments and interventions in order to assist parents when they are struggling with employment and caregiving.

Recommendations for Service Providers

Any family, whether or not the child/youth has a mental health disorder, interacts in a variety of systems in the course of daily life (e.g., educational, employment, spiritual, and health care). Most often, working parents whose children deal with mental health challenges also utilize a mental health provider or family support professional to assist them in addressing a child's needs. Effective mental health practice with families affected by children/youth's mental health challenges must therefore involve thoughtful exploration of all key systems with which that family interacts, including the workplace. Parents walk a tightrope in balancing workplace responsibilities with caring for a child challenged by a mental health disorder. Often working parents are not completely aware of legal rights available to them in the work setting.

When a mental health practitioner or family support worker provides services to parents whose children have such challenges, they typically focus on educational issues or concerns. If that child or adolescent has an Individual Education Plan (IEP) or a 504 plan for accommodations, it would be reasonable to expect that professional to be informed about IEPs and/or 504s (Malsch et al., 2008) in order to coach parents to advocate effectively, on behalf of their child or youth. In the same way, therapists and family support professionals should make sure to initiate a discussion regarding how they are managing the child's or youth's care needs with their employment responsibilities. Because parents may not be aware of their legal rights in the workplace, professionals should also take steps to understand the specific legal work-family provisions to which employees are entitled, such as the Family and Medical Leave Act (FMLA), Americans with Disabilities Act (ADA) protections, Employee Assistance Programs (EAPs), or flexible work arrangements (Malsch et al., 2008). Equipped with this information, the mental health or family support professional can then empower working parents to advocate effectively by making use of those legal provisions that will allow for more productivity at work. They can educate working parents about their rights, but more important, explore areas where the worker could potentially speak up to exercise those rights.

Mental health and family support professionals must be clear that their job is to help working parents be aware of their legal rights. Giving specific advice to follow could result in detrimental outcomes, such as urging a parent to disclose a child's

diagnosis that results in stigmatization. It would be better for that professional to ask pertinent questions that will guide parents to make their own informed decisions. What follows is a list of suggested questions for mental health or family support professionals to use for best practices.

1. How do you perceive the balance between home and work demands?
2. How do you feel you are currently managing your job responsibilities? What is going well? Where are the greatest challenges?
3. What would make it easier to do your job?
4. Do you know what legal protections are in place for working parents?
5. What might get in the way of your exploring options for flexibility at work (e.g., part-time, flexible scheduling, job share, or working from home)?

Mental health and family support professionals need to view challenges in the workplace as a systemic issue, rather than as an individual's problem. Given that one of every eleven working parents has a child with some kind of disability (Perrin et al., 2007), probability is high that work-life issues will be a key area of concern. A thorough assessment must validate the workplace as one of many arenas in a person's life that need to be explored.

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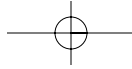
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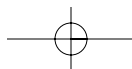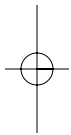
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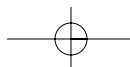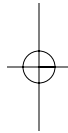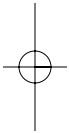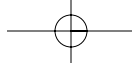
Defining Youth Success Using Culturally Appropriate Community-based Participatory Research Methods

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This article reports on the development of a culturally grounded method for measuring outcomes and demonstrating the effectiveness of culturally specific services for Native American youth. This method was developed out of a community-based participatory research project involving Native elders, families, youth, and community partners, as well as the board, staff, and management of an agency serving an urban American Indian community. Through a series of focus groups, community members defined success for Native youth. Responses were analyzed using the four quadrants of the Relational Worldview model (Cross, 1995), an indigenous way of understanding life from a concept of wholeness and balance as a framework. This article describes the use of focus groups in this context and the cultural adaptations necessary both in conducting the groups and in the analysis of the data. Focus group results and next steps in the development of a practice-based approach to demonstrating the effectiveness of culturally specific services are summarized. Findings illustrate the need to broaden definitions of

success used to guide the development and evaluation of effective services beyond those usually used to identify evidence-based practices, as well as the importance attached to Native youth gaining spiritual understanding and knowledge and skills in traditional cultural practices as essential elements of achieving community-defined outcomes.

Introduction

As policymakers and service providers have sought to identify and deliver effective interventions with children, adolescents, and families, they have increasingly turned to evidence-based practice (Burns, Hoagwood, & Mrazek, 1999; Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001; Hoagwood, Burns, & Weisz, 2002; Singh & Oswald, 2004). Evidence-based practice (EBP) is defined by Hoagwood, Burns, and Weisz (2002) as "knowledge obtained through scientific methods about the prevalence, incidence, or risks for mental disorders, or about the impacts of treatment or services" (p. 392). An advantage of EBP is the increased likelihood that services will be effective, both in terms of costs and in terms of dependable outcomes. However, there are disagreements about the restricted definition of what constitutes evidence and growing concern about the mandated use of EBPs, especially with populations with which a particular EBP has not been tested, such as culturally diverse youth, youth with complex disorders, and families who are less able to participate in services because of socioeconomic or cultural factors or family stress (Brannan, 2003; Espiritu, 2003; Margison, 2003).

Interventions that have been developed with culturally and linguistically diverse communities and are preferred by members of these communities have not been rigorously evaluated, and therefore there is no "scientific" evidence of their effectiveness (Huang, Hepburn, & Espiritu, 2003). However, existing research methods for establishing an evidence base are beyond the capacity of many community-based or culturally specific organizations whose staff and service users observe their outcomes to be positive. Also, some practices used in this type of agency are culturally accepted as effective, and it may be unacceptable to measure them using standard control trial methodology because of ethical concerns about withholding treatments believed to be effective (Isaacs, Huang, Hernandez, & Echo-Hawk, 2005).

Practice-based evidence (PBE) has been proposed as a complement to EBP. In general, PBE involves using information gathered from service providers and families to identify effective interventions, as well as areas for program or practice improvement and further research (Evans, Connell, Barkham, Marshall, & Mellor-Clark, 2003; Lucock et al., 2003). This article describes a community-based participatory research project designed to build practice-based evidence (PBE) with stakeholders in the Native American Youth and Family Center (NAYA), a direct service organization serving American Indian youth and families in Portland,

Oregon. The article also provides a methodology for other culturally specific and/or community-imbedded programs and practices to study the effectiveness of their services.

The study was designed collaboratively with two goals: (1) to create a culturally grounded participatory method to document the effectiveness of culturally specific services, and (2) to develop a process within community-based programs for conducting evaluations based on "good outcomes," as defined by the cultural community served. Three organizations—a community-based agency providing culturally specific direct services to Native American youth and families, a national Indian child welfare research and advocacy organization, and a national research and training center focused on family support and children's mental health—partnered to develop this participatory action research project. To be competitive in the nonprofit service sector, the agency's challenge was to demonstrate the effectiveness of agency services and the organization as a whole. This has become particularly necessary in an environment in which funders are increasingly requiring service providers to use EBPs as a condition of funding.

A participatory team of researchers, advocates, and service providers started the project with the premise that measuring effectiveness depends on measuring the outcomes that the community identifies as positive. This concept is consistent with participatory research and is relevant to culturally specific populations whose values may influence what is seen as important and what should be measured. After consulting with stakeholder groups, the team selected focus groups with cultural adaptations as the appropriate methodology to achieve the study purpose.

Literature Review

EBP has been defined in several ways, as a decision-making process and as a set of interventions. For example, EBP has been defined as the process of "the integration of best research evidence with clinical expertise and client values in a given organizational context" (Marsh, 2005) or "the basis for decision-making and action; a process for insuring that an individual or group of individuals gets the best possible intervention, service, or support based on an assessment of needs, preferences, and available options" (U.S. Public Health Service, 2000). Other definitions emphasize the "conscientious, judicious, and explicit use of current best evidence in making decisions" about the care of clients (Sackett, Rosenberg, Muir Gray, Haynes, & Richardson, 1996, p. 71). Currently, the best evidence used in determinations of EBP usually refers to the findings of randomized controlled trials (RCTs), efficacy studies, quasi-experimental designs, or series of single case studies (Burns, 2002). These determinations privilege RCTs as the "gold standard" of clinical decision-making (Tanenbaum, 2005) and have resulted in health insurance companies and some government entities approving lists of practices to be used to address specific conditions. However, culturally diverse youth are less likely to participate in such studies (Brannan, 2003), and there is an

underlying cultural bias when researchers, rather than community members, select the preferred outcomes to be studied (Slaton, 2003).

In some service sectors, such as children's mental health, there is controversy associated with the lack of shared meaning of EBP and especially the mandated use of EBPs. For example, Oregon legislation requires that by 2009, 75 percent of state funding for public youth-serving agencies must be spent on EBP, defined as a program that "(a) incorporates significant and relevant practices based on scientifically based research, and (b) is cost effective" (Oregon Senate Bill 267, 2003 [passed into law as ORS 182.325]). The legislation defines an evidence continuum with six levels, of which the top three emphasize RCTs and efficacy studies. Concerns have been expressed about characteristics of RCTs that challenge their status as the preferred research methodology for demonstrating EBP: (1) the determination of "evidence" is narrow and focuses on linear cause-effect relationships (Webb, 2001); (2) RCTs prioritize efficacy over effectiveness, and therefore EBP findings may lack relevance and generalizability to practice in community settings (Slaton, 2003; U.S. Public Health Service, 2000); (3) EBPs may not reflect the complicated lives and needs of many children and families (Brannan, 2003); (4) there may be no attention to family choice (Brannan, 2003; Huang et al., 2003); and (5) EBPs often neglect the cultural and contextual influences on children and families (Espiritu, 2003; U.S. Public Health Service, 2000).

Additional concerns have been raised about the types of interventions that have been recognized as EBP. Most EBPs exclude newly developed interventions and do not distinguish between what is ineffective and what has not been sufficiently researched (Lehman, Goldman, Dixon, & Churchill, 2004). RCTs favor therapies that are more easily codified in manuals, and short-term interventions that produce easy-to-measure symptom relief are studied more than interventions for more serious and complex conditions (Weisz & Kazdin, 2003). There are widely used practices for which little or no evidence base has been developed but that are believed to be effective and are highly valued by families, youth, and practitioners (Espiritu, 2003). In addition, there has long been recognition that "nonspecific" relationship factors (such as empathy and warmth) appear to matter more than the specific treatment, suggesting a need to focus on measuring engagement/therapeutic alliance (Jensen, Weersing, Hoagwood, & Goldman, 2005).

Similarly, to date EBPs have excluded traditional healing practices and therapies developed by specific cultural groups (Espiritu, 2003; Huang et al., 2003). Mainstream mental health services have not been seen as effective by culturally diverse populations who may prefer traditional healing practices (Lee & Armstrong, 1995; Lewis-Fernandez & Kleinman, 1995). Some interventions may not be feasible to test using traditional EBP approaches due to the spiritual or dynamic dimensions of the practices themselves and/or due to the small size of available samples, which do not lend themselves to systematic study (Espiritu, 2003). Also, ethical and privacy concerns may preclude the implementation of procedures such as random assignment of some participants to a control group or even, perhaps, observation.

There is a need for strategies to describe and document practices deemed as effective by specific communities and to identify the underlying program theory and necessary activities and processes so that their effectiveness can be evaluated. However, the characteristics of interventions that are community-preferred (individualization, flexibility, comprehensiveness, and provider/patient relationship) make them difficult to describe and evaluate (U.S. Public Health Service, 2000). Research and evaluation methods are needed that include in-depth, qualitative studies to elicit the perspectives of multiple stakeholders about what they perceive as valued outcomes and treatment methods, and to incorporate theories of change (U.S. Public Health Service, 2000). Therefore, practice-based evidence (PBE) has been proposed as a strategy for building knowledge of practices that work in natural settings and with diverse populations (Evans et al., 2003; Barkham & Mellor-Clark, 2003).

PBE as a Strategy for Building Knowledge of Effectiveness

PBE is a set of research methods that uses information gathered from service providers, families, youth, and other stakeholders to identify effective interventions and areas for program or practice improvement (Evans et al., 2003; Lucock et al., 2003). According to these authors, advantages of PBE include: (1) information about desired goals and outcomes comes directly from the people receiving services; (2) cultural factors can be explicitly included in interventions; and (3) effectiveness can be measured according to these outcomes. Many practice-based evidence approaches involve the use of participatory methodologies to identify goals, describe the experience of giving and receiving services, and identify sought-after outcomes (Meyer, Park, Grenot-Scheyer, Schwartz, & Harry, 1998). Participatory research is well-suited to building PBE because the researcher builds relationships with families, youth, service providers, and community members to discover the relevant questions to ask to gain rich and detailed data and to analyze, interpret, and report findings related to interventions and outcomes to maximize knowledge development (Osher & Telesford, 1996).

Some proponents of PBE suggest that qualitative methods are the most appropriate for gaining understanding of stakeholders' perspectives of interventions and outcomes in their own words. For example, PBE is particularly well-suited to studies of the quality of interventions (Margison, 2003) or unexpected results, such as early improvement (Stiles et al., 2003). Barkham and Mellor-Clark (2003) propose a cyclical model of PBE and EBP in which service systems develop and build an evidence base rooted in practice. In turn, the evidence base informs the development of finely tuned tests of specific hypotheses through efficacy research, with both types of research informing policy.

The need to develop the PBE knowledge base is especially critical for culturally diverse populations who may prefer traditional healing practices to conventional mental health services, which have not been seen as effective (Lee & Armstrong, 1995; Lewis-Fernandez & Kleinman, 1995). Cultural beliefs and practices have been found to affect patients' experiences of pain and healing and therefore should

be included in studies of effective treatments (Lasch, 2000). Cultural wholeness is believed to have both preventive and curative effects for indigenous people affected by drug and alcohol abuse (Kulis, Napoli, & Marsiqlia, 2002; Moran & Reaman, 2002). For Native Americans, cultural strengths such as family, community, spirituality, traditional healing practices, and group identity are key moderators of physical and mental health outcomes and substance abuse (Walters, Simoni, & Evans-Campbell, 2002). It is vital that these cultural factors be addressed in intervention research.

Research with Native American Communities

The challenges of conducting research in Native communities are well documented (Allen, 1998; Weaver, 1997). The historical practice of research in Native American communities has often meant that those being researched were left out of the process (Davis & Keemer, 2002). Frequently, Native communities were not made aware of the research findings and did not experience any direct or indirect benefits of the research that was conducted in their communities (Davis & Keemer, 2002). Because of past exploitation and negative experiences with researchers, Native American communities are likely to approach research with caution and distrust (Davis & Keemer, 2002). Yet research is critical to informing public policy. Increasingly, Native American communities, programs, and scholars are embracing research as important to documenting the effectiveness of culturally specific services and helping design and implement effective research approaches.

Several models have been developed for conducting culturally competent research in Native American communities (Running Wolf et al., 2002). For example, a model developed by McDonald (2002) is proposed as "a precursor toward establishing culturally appropriate treatments or community interventions, [which] is in the best interest of peoples of all nations" (p. 176). Researchers are urged to include members of the community in the design, methods, and dissemination of findings; to carefully consider the impact of the research on the Native community; and to ensure the cultural appropriateness of instruments and methods. The Office of Juvenile Justice and Delinquency Prevention (OJJDP) has identified guiding principles for conducting research with American Indian/Alaska Native communities: research should have practical and local relevance and should be characterized by community involvement and cultural sensitivity (Andrews, 2000). Taking time to build relationships with elders and other community leaders, participating in community activities, and sharing findings with the community are also recommended practices for culturally appropriate research with Native communities (American Indian Law Center, 1999; Council of National Psychological Associations for the Advancement of Ethnic Minority Interests, 2000; Norton & Manson, 1996; Sobeck, Chapleski, & Fisher, 2003; Tohono O'odham Nation Department of Human Services, 1996). In line with these principles, the research described in this paper is collaborative. The researchers partnered with the community in determining research questions, design, methodology, data collection, protocol, and ownership of data.

Community-based participatory research is about empowering stakeholders to tell the story of a community and its needs with rigor and give authority to their voice (Hall, 1975; Maguire, 1987; Minkler, Wallerstein, & Hall, 2002; Reason, 1994, 1996). Having the story articulated and substantiated and then presented to policymakers is a powerful method for promoting change. This means being able to use defensible data to document evidence of effectiveness of culturally pre-ferred practices and thereby compete with non-Native EBPs in the current policy environment and resultant marketplace. One of the most challenging and per-plexing aspects of EBP from a perspective of the Native community is the question "who gets to decide what is effective?" Measuring effectiveness means measuring achievement of selected outcomes, but whose preferred outcomes are used to establish effectiveness is a matter of social justice. This concept constituted an undergirding principle guiding our project.

Development of the Current Study

The present study was designed collaboratively to create a culturally grounded, community-based, participatory method to document the effectiveness of cultur-ally specific services and to develop a process for conducting evaluation based on community-defined outcomes. The three participating organizations came together because of the complementary contributions each could make to meet the challenge facing a culturally specific agency to be able to demonstrate the effectiveness of its services. This challenge was intensified by increasing require-ments that service providers use EBPs as a condition of funding, and particularly by the passage of Oregon Senate Bill 267 (2003), resulting in a state law (ORS 182.525) that set up requirements for evidence-based practices, with the effect of potentially limiting agencies' access to funding.

The Participating Organizations

The Native American Youth and Family Center (NAYA) values evidence and strives to provide the very best services it can to its population. Further, NAYA believes in the appropriate use of research so that its practices can be understood in the science-to-practice paradigm. This project postulates that knowledge obtained through scientific method is possible if the method fits the cultural con-text. The National Indian Child Welfare Association (NICWA) provides technical assistance to American Indian tribes and organizations and is building a reputa-tion for conducting research grounded in an indigenous worldview. NICWA also has a strong history of advocacy for American Indian children and families and the culturally specific agencies that serve them. NICWA's contribution to the pro-ject has been to bring indigenous models of research, credibility in the Indian community, and a strong desire to be able to document evidence of effectiveness in culturally based services where usual research methods may not be feasible or are undesirable. The Research and Training Center on Family Support and Children's Mental Health brings research skills and a history of working in participatory

research and training projects with family organizations and using research find-
ings to guide policy and program changes in child and adolescent mental health.

The Relational Worldview

The approach used in this project is unique in terms of the professional and cul-
turally specific attributes of the methodology and the extent of community
involvement. The theoretical model used to guide this research was based on the
Relational Worldview approach developed by NICWA (Cross, 1995). The Rela-
tional Worldview (RWV) is echoed within many tribal cultures by an emphasis on
the use of a circular rather than a linear concept of reality in which the four areas
of mind, body, spirit, and social context are interrelated and in which balance
among the four quadrants constitutes wellness (see fig. 1). Life is understood as a

Figure 1. Relational Worldview Model Applied to an Individual
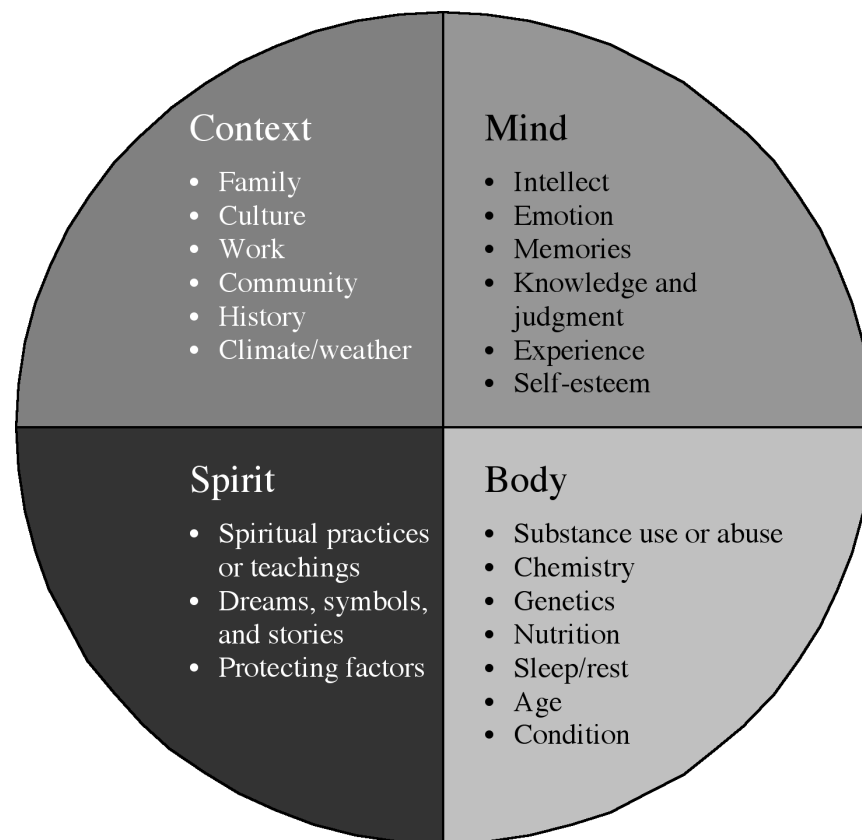
circle with the four quadrants creating a whole in which all things affect all other aspects of life (Cross, 1995). In this model, the context quadrant includes concepts related to the environment and relationships with others. The mind quadrant incorporates elements related to emotions, memories, and knowledge. Body refers to body chemistry, genetics, and physical well-being. The spirit quadrant includes spiritual teachings, stories, and other protective factors. The model incorporates interdependent relationships everywhere, and these relationships are understood as complex, dynamic, and patterned. Used as a paradigm for indigenous research, data are gathered across all four quadrants. The Relational Worldview directs the research team to gather data that include not only the relationships that emerge in each quadrant but also the patterns across the quadrants. By examining the patterns and seeing the trends within the data, new information emerges that is impossible to discern from a linear approach alone. The interaction between the linear and the relational patterns helps inform researchers across cultural boundaries: "Where the circle and the lines touch, opportunities for the joining of tribal and non-tribal perspectives exist" (Lowery, 1998, p. 127).

Methods

A research team was developed with representatives from the three participating organizations and with a high level of consultation with NAYA staff, elders, and program participants throughout the project. The development of the project was based on the belief that measuring effectiveness depends on measuring outcomes that the community identifies as positive, and only the community can determine what those are. After consulting with stakeholder groups, focus groups (Morgan, 1988) were selected as an appropriate methodology within a participatory model, adapted culturally to deal with the research challenges discussed above. Focus groups were believed to be useful for gaining participants' subjective perspectives on similar issues in their own words (Rodwell, 1998), and they are considered suitable for data collection with members of specific groups of people (Jarrett, 1993). Focus group questions were developed collaboratively with NAYA staff and advisors to gather information from key stakeholder groups about desired outcomes for Native youth and for NAYA's programs.

Youth were recruited by NAYA staff by first identifying young people who had participated for more than one hundred hours in one or more of NAYA's programs during the previous year, then issuing invitations and obtaining caregiver consent and youth assent. Family members were identified and invited in a similar way. The executive director of NAYA approached elders at one of their regular meetings, and board members were invited via e-mail and in person. A NAYA staff member mailed invitations to a focus group session to community partners. Separate focus groups were held with each of these groups, and separate meetings were also held with NAYA staff and program managers. The conduct of the focus group sessions employed usual focus group processes (Jarrett, 1993; Morgan, 1988), with a few notable exceptions. First, food was served, as is the cultural expectation of the community. All focus groups were held at NAYA, generally in the late afternoon or early evening. Time was allowed for socializing and signing

the consent forms as well as for late arrivals to get settled. This flexibility of agenda and time were included to intentionally accommodate the cultural norms of the participants. Second, the sessions were not tape-recorded on the advice of the project partners, due to the historic misuse of research methods and records. While the facilitator asked the questions, a note-taker recorded responses on flip charts as people spoke and periodically checked in with group participants to make sure the notes were accurate.

The focus groups participants responded to six questions: (1) What does success look like for Native American youth? (2) What is necessary to help support youth in achieving success in their lives? (3) What are the conditions that hinder a youth's progress toward success? (4) How do NAYA Family Center services contribute to a youth's success? (5) Are there other things that NAYA could be doing that would be helpful? And (6) is there anything you would like to add that we have not talked about? Throughout the focus groups, the four quadrants of the Relational Worldview—context, mind, spirit, and body—were used as probes to elicit more detailed responses. In addition, a probe for question 1 was used to clarify how participants defined success: what is it that distinguishes between youth who you see as successful and youth who are not as successful given a similar situation?

Participants

Separate focus groups were held with members of all stakeholder groups, with a total of 98 participants. Participants were as follows: middle school youth ($n = 6$), high school youth ($n = 6$), youth in foster care who participate in NAYA's programs ($n = 7$), families of youth ($n = 7$), elders from Portland's Native communities ($n = 11$), NAYA's board of directors ($n = 7$), community partners ($n = 11$), and NAYA staff and management (total $n = 43$). Each participant signed an informed-consent form, but no demographic data were collected.

Data Collection

Respondents' answers to the questions were recorded on large sheets of paper and posted on the walls around the meeting room so that participants could see that their contributions had been noted and they could suggest additional ideas. Subsequently, notes were typed and prepared for analysis. Before analysis began, the notes from each group were sent to participants with a request for feedback and corrections, as a member-checking strategy to increase the trustworthiness of findings (Lincoln & Guba, 1985).

Data Analysis

This article presents only responses to the focus group question, "What does success look like for Native American youth?" After the findings had been reviewed by participants and changes made based on feedback, a team of researchers, service providers, and advocates from the three participating organizations began the analysis process by reviewing and becoming familiar with the focus group data, an

important first step in qualitative data analysis (Morse, 1994). Then the team worked on grouping the raw data in themes and assigning codes as close as possible to the original words used by focus group participants. An initial process created some groupings simply by specifying the number of times a highly similar comment was made. Next, using a map of common themes, the team divided into two subgroups: one examined the responses by reading the answers to all questions within each focus group, while the other examined responses question by question across all focus groups. Each subgroup noted common themes as well as unique perspectives on the questions. Then the two groups came together several times to compare themes and to reach consensus regarding final coding decisions. This process of analysis and dialogue with multiple research team members is a necessary step in the process of collaborative research that is considered vital in the interpretive process, given the tendency of individuals to notice different ideas and concepts in qualitative data (Morse, 1994; Uehara et al., 1997).

At this point, the research team decided to begin the next steps of their work by focusing on findings related to outcomes. In order to understand the complex relationships between and among variables using a culturally based indigenous model, the team organized answers related to the question about outcomes ("success") for youth into clusters of related themes using a similar process of negotiation, and then linked the themes with the mind, body, spirit, and social context quadrants of the Relational Worldview model (Cross, 1995).

There was a high rate of agreement among coders as they sorted items into the four quadrants. After sorting the items independently, the research team met to discuss the findings, compare the sorting, and reach consensus on categories of findings. For those few items that were placed in different quadrants by different raters, a consensus approach was used, with NAYA representatives having the final determination.

In addition, follow-up meetings were held with NAYA staff and the community. The raw findings regarding youth success sorted into the quadrants of the RWV were presented, and the participants were asked if the findings fairly represented what they had said in the focus groups. The purpose of this approach was to build trust as well as an investment in the outcome of the project, which is consistent with the principles of community-based participatory research (Whitmore, 2001). Responses to other questions were later analyzed and reviewed by NAYA staff to develop a theory-of-change model to be used to develop a data-informed case-planning process.

Findings

Characteristics of success mentioned in the focus groups were categorized into several themes within the context, mind, spirit, and body quadrants of the Relational Worldview model (shown in fig. 2). In the report of findings that follows, themes in each quadrant are illustrated by an example of a phrase used by participants.

Figure 2. Definitions of Youth Success
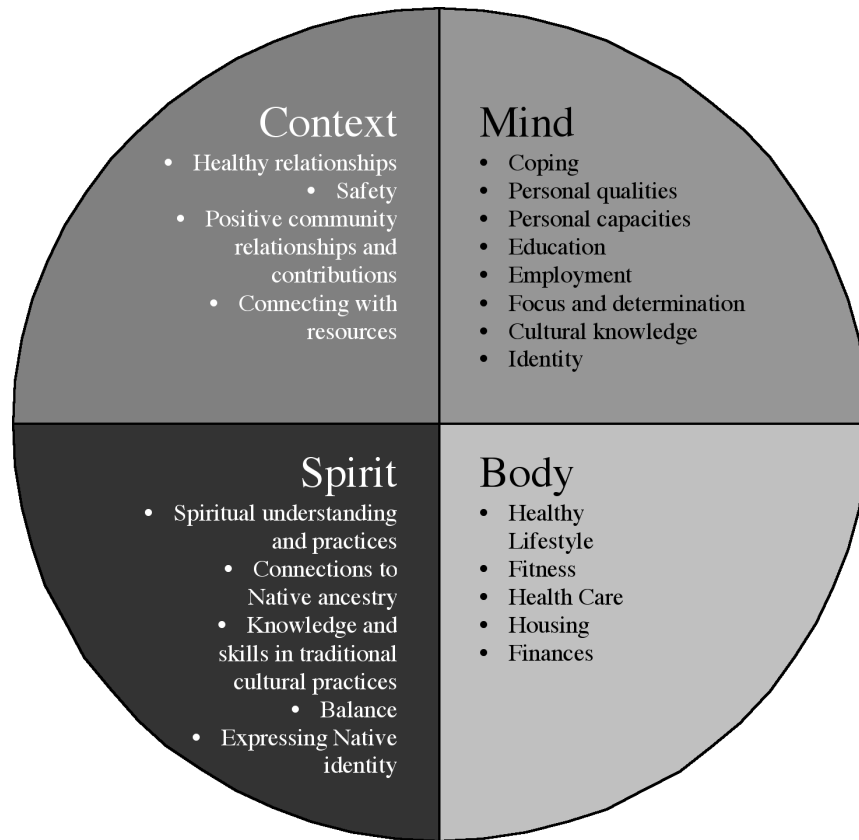
Context

Within the context quadrant, the themes associated with youth success were categorized as healthy relationships, safety, positive community relationships and contributions, and connecting with resources:

- Healthy relationships: "following and/or being a positive Native American role model"
- Safety: "avoiding unsafe people and situations"
- Positive community relationships and contributions: "feeling meaningfully engaged, having purpose and value within one's community, family, or place of employment"
- Connecting with resources: "accessing health care"

Mind

Youth success definitions related to the mind quadrant were categorized as being linked with the themes of coping, personal qualities, personal capacities, education, employment, focus and determination, cultural knowledge, and identity:

- Coping: "understanding of spirituality for emotional well-being"
- Personal qualities: "self-acceptance, self-reflection, generosity, self-awareness, self-control"
- Personal capacities: "finding constructive, nonviolent ways to solve problems"
- Education: "education is the gateway to opportunities"
- Employment: "getting and keeping a job"
- Focus and determination: "being goal-oriented, visualizing the future"
- Cultural knowledge: "knowing tribal history and being able to move forward"
- Identity: "[youth] positively identify with their heritage"

Body

Themes of youth success categorized as being related to the body quadrant of the RWV model included healthy lifestyle, fitness, health care, housing, and finances:

- Healthy lifestyle: "recognize wisdom to care for self and use knowledge"
- Fitness: "physical activities, such as hiking, rafting, walking, provide options for healthy living and positive experiences, respect for body"
- Health care: "be successful in alcohol and drug treatments"
- Housing: "long-term, safe, and stable housing"
- Finance: "paying bills on time, ability to manage, and being responsible"

Spirit

Response themes related to youth success and assigned to the spirit quadrant of the RWV model were spiritual understanding and practices, connections to Native ancestry, knowledge and skills in traditional cultural practices, balance, and expressing Native identity:

- Spiritual understanding and practices. "understanding and fulfilling seventh generational obligations" (oral traditions of several tribes hold that any decision or action taken today should be considered for its impact on the seventh generation yet to come)
- Connections to Native ancestry: "respect for creator, creation stories, where you come from"
- Knowledge and skills in traditional cultural practices: "connected to Native American side"

- Balance: "seven ways of walking—health, family generations, silence, joy, generosity, honoring the four directions, and compassion"
- Expressing Native identity: "positively identify with heritage, connect to culture"

Discussion

This study represents the first effort to identify outcomes preferred by stakeholders at a culturally specific agency serving urban Indian youth and families. Findings indicate that stakeholders identified indicators of youth success in all domains of life captured in the RWV, and there was a remarkably high level of consistency across stakeholder groups. Members of the research team particularly noted the consistency between youth and elders' responses. Participant comments indicated that youth, families, elders, community partners, and service providers value a wider range of outcomes than are commonly specified in EBP research, and they point to the need for an expanded definition of youth success to guide interventions. Several preferred areas of outcomes that stand out as distinct from usual EBP research include cultural knowledge, spiritual understanding and practices, connections to Native ancestry, and knowledge and skills in traditional cultural practices.

Several limitations of the study should be noted. Study participants constituted a deliberately identified sample and therefore may not be considered representative of the wider population of Native American youth, families, or service providers. Many of the respondents' comments reflect a generalized urban Indian experience heavily influenced by plains, plateau, and coastal tribal cultures. Therefore, generalizations from these findings to other similar populations should be done with caution. In addition, the decision to not tape-record the focus groups may be considered by some researchers to be a limitation. However, the research team made this decision based on community feedback and based on models of culturally responsive research, which recommend a high level of community involvement in decision-making (McDonald, 2002). Also, the use of member-checking and community forums, as well as the high level of NAYA staff participation in the analysis of findings, provides support for the credibility of the findings reported here and is consistent with participatory approaches to research.

Despite these limitations, study findings provide a valuable picture of how Native American stakeholders conceptualized youth success and yield key information to guide members of the research team in identifying items to include in an assessment and case-planning tool. The findings highlight participants' orientation to holistic concepts of success rather than the specific, narrowly defined outcomes usually measured in RCTs and used to assert the effectiveness of specific EBPs. The findings demonstrate the importance of culturally based indicators such as knowledge and skills in traditional cultural practices in assessing youth well-being and success, in addition to conventional measures such as educational

achievement. For example, in our project community, elders stated that Native youth who succeed in getting high math scores in school may be seen as successful in the mainstream, but if they do not know appropriate cultural protocols (e.g., proper greeting of an elder) of the Native community, then they are not successful in those things valued by their community.

The non-Native participants of the research team were particularly struck by the participants' emphasis on culturally based outcomes to define youth success, such as the "seven ways of walking," being knowledgeable about tribal history and ceremonies, participating in cultural crafts and activities, and understanding Native spiritual beliefs. This focus on the whole person rather than on isolated behavior changes helped the team maintain an expanded vision of change and thus what constitutes evidence of effective practice. Research team members noted, for example, that these outcomes are linked with other outcomes defined by funders, such as school success (Friesen et al., 2010). In addition, the findings are compatible with other research on Native well-being, which indicates that cultural pride is a predictor of success in other domains of life, such as social functioning and drug- and alcohol-free lifestyles (Kulis, Napoli, & Marsiqlia, 2002; LaFramboise, Hoyt, Oliver, & Whitbeck, 2006).

The experience of participating in the project resulted in rich learning by all research team participants. As is noted in other participatory research, the process of doing the research was slower because of the participation of stakeholders from different settings (Turnbull, Friesen, & Ramirez, 1998; Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998) and out of respect for members of Native communities who have experienced significant harms from inappropriate research (Norton & Manson, 1996; Sobeck et al., 2003). The research team took time and effort to build trusting relationships with members of the Native community over a period of five years by attending social events, sharing findings at several stages of the research, and taking care to follow through on commitments, as recommended in literature in successful community-based participatory research with Native communities (Norton & Manson, 1996; Weaver, 1997).

Next Steps

As noted above, the research team is engaged in developing an assessment process and a case-planning and case-management tool to focus work with Native American youth on desired outcomes. The assessment tool incorporates measures and indicators identified for core outcomes in each quadrant of the Relational Worldview (RWV). To the extent possible, it is being developed using existing, well-established measures for examining the selected outcomes. The assessment process will be used to assess youth needs, strengths, and challenges as they first access services and to measure their progress over time. Data from the assessment process will be used by the staff to inform the case plan and further contribute to a data-informed practice approach consistent with the cyclical model of "rigorous and relevant research" recommended by Barkham and Mellor-Clark (2003, p. 324).

This framework will then be used with individual youth as an individualized case-planning tool that encourages each youth to add her or his own goals and outcomes. NAYA staff plan to consolidate their current approaches to case-planning that vary across programs into a common case plan. This assessment measure, along with the case-planning tool, will serve as the basis for tracking the progress of individual youth; the data will also be aggregated for program evaluation purposes and reporting. Thus, the findings of the project have provided a solid foundation for an integrated PBE approach to the development of measures for effective, culturally specific services for urban Indian youth.

Conclusion

The Relational Worldview (Cross, 1995) provided a background and a frame of reference for members of the community-based participatory research team to make sense of participant responses to questions about their definitions of success, that is, preferred outcomes for Native youth. Co-principal investigators from each perspective intentionally joined the Western and the indigenous models to create an approach that could be both credible in the Native community and scientifically rigorous enough to stand up to mainstream scientific scrutiny. This approach provides a model for other service providers and organizations serving culturally diverse populations to be able to define culturally appropriate outcomes, develop evidence of the effectiveness of their services, integrate program evaluation, and improve the quality of their culturally specific services. Further, this type of practice-based evidence has the potential to satisfy decision-makers and funders who are increasingly seeking to direct funding to interventions of known effectiveness for different populations. Focus group methodology, adapted for the specific cultural setting, allowed the researchers to study community-defined, preferred outcomes that are measurable. In addition, through full participation of the stakeholders in organizing and presenting the findings, the researchers were able to develop the credibility and buy-in needed to integrate measurement methods into the organization. Together, the research team is developing clear outcomes, selecting reliable measures, and integrating data-gathering with case-planning to form a research-to-practice framework that yields highly reliable, practice-based evidence of the effectiveness of community-based, culturally specific services.

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Supports for Young People with Mental Health Conditions and Their Families in the Transition Years: Youth and Family Voices

Pauline Jivanjee and Jean Kruzich

Young people aged 17 to 24 with mental health conditions face significant obstacles in obtaining services and supports as they negotiate the transition from adolescence to adulthood. For many of these young people, results of an "unsupported transition" include high rates of unemployment, homelessness, and incarceration, as well as substance abuse, unplanned pregnancy, and engagement in high-risk behaviors. In general, families want to be supportive, but they struggle to understand the unique needs of their children and to be involved in their treatment. This article reports on a qualitative study of the experiences and perceptions of transition-age youth and their parents of using mental health services and informal supports. Findings indicate that youth and parents appreciated service providers who were compassionate, well trained, and responsive to needs, and that they appreciated family and peer support. Participants complained about ineffective and unhelpful staff, the lack of relevant services, and youths' loss of eligibility for services at age 18. Ideal supports include families; peer support and leadership development groups; accessible, appropriate services; and responsive, compassionate service providers. Optimal supports and services will be more likely when young people and families are included in service planning and delivery.

Keywords: youth in transition; young adults with mental health conditions; family support; peer support; mental health services

The transition from adolescence to adulthood is marked by role transitions such as finishing education, beginning full-time employment, and forming adult relationships. In the transition to adulthood, young people also begin to develop responsibility for themselves, make independent decisions about their own beliefs and values, and move toward achieving financial independence and relationships with parents as equal adults (Arnett, 2000, 2001). Some young people also take on additional responsibilities as parents. At the same time, parents experience their own transitions as they redefine family relationships and renegotiate rules and limits as their children move toward greater degrees of independence (Blacker, 2005; Preto, 2005). However, for young people with serious mental health conditions, the transition years are fraught with challenges resulting from their struggles with symptoms; from the prevalence of stigmatizing attitudes among teachers, service providers, peers, and others that affect their integration into the community; from their difficulties in accessing appropriate mental health and other supportive services and community supports (Vander Stoep, Davis, & Collins, 2000); and from the bewilderment of their ill-prepared parents (Harden, 2005). Many of these difficulties are even more profound for culturally diverse youth in communities where stigmatizing attitudes are common and options for obtaining help are more limited (Dialla et al., 2000; DiCerbo, 2000; Fox, Becker-Green, Gault, & Simmons, 2005; Lindsey et al., 2006).

While the developmental processes of transition occur gradually and are linked with cultural expectations, institutional transitions are "abrupt, arbitrary changes in status" linked to changes in legal status and eligibility for services, often related to age (Davis, Green, Beckstrom, & Wing, 2005; Davis & Koroloff, 2007; Vander Stoep et al., 2000, p. 6). Many youth with mental health difficulties are ineligible to receive services from the adult mental health system because of "arbitrary distinctions between the nature of serious mental health conditions in minors versus adults," and for those who are eligible, there are few specialized services available (Davis & Hunt, 2005, p. iv). Frequently, when young people lose coverage under their parents' insurance policies, they are required to apply to different providers and meet different eligibility criteria (Podmostko, 2007), and they may fail to gain access to public or private services (Davis et al., 2005), resulting in many "falling through the cracks." The lack of access to appropriate mental health services is compounded by the lack of availability of transition services for this population (Davis, Geller, & Hunt, 2006).

Estimates of the number of youth and young adults aged 16 to 25 with a mental health disorder vary between 2 and 6.5 million, of whom a small percentage, estimated to be between 6 and 33 percent, receive mental health services (Vander Stoep et al., 2000). These young people encounter barriers to community integration related to the prevalence of stigmatizing attitudes (Gowen & Walker, 2009) and are at risk of a range of negative outcomes, including dropping out of school, unemployment, homelessness, involvement in criminal activities, substance abuse, and early pregnancy (Armstrong, Dedrick, & Greenbaum, 2003;

Blackorby & Wagner, 1996; Kortering, Braziel, & Tompkins, 2002; Newman, Wagner, Cameto, & Knokey, 2009; Podmostko, 2007; Vander Stoep et al., 2000; Zigmond, 2006). While the prevalence of mental health disorders increases in young adulthood, due to the later age of onset of some disorders, studies have revealed "precipitous decline" in mental health service utilization after the age of 18 (Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008, p. 373). This finding may be associated with young people losing access to school-based mental health services.

While only a small proportion of young people with serious mental health conditions receive services, even fewer receive services that they perceive as helpful. When asked about their experiences with transition services, both young people with mental health conditions and parents have been critical of their limited involvement in planning services and of the relevance and helpfulness of services provided (Davis & Butler, 2002). Most families want to be helpful but lack skills to assist their young adult children with mental health conditions. Often they are "deskilled" in their interactions with mental health professionals, some of whom implicate families in "causing" the mental health condition (Harden, 2005, p. 216). These difficulties are compounded after the child has legally become an adult (at age 18, or younger for some types of health-related decisions), when parents are excluded from the treatment relationship and service providers are unwilling to share information about the child's diagnosis and treatment because of confidentiality laws (Davis et al., 2005; Vander Stoep et al., 2000). It may be especially difficult for culturally and linguistically diverse parents to be involved in planning for transition services for their children because of language and cultural factors. Providers may fail to reach out to diverse parents, interpreting their constrained involvement as lack of interest (Geenan, Powers, & Lopez-Vasquez, 2001).

In summary, the literature indicates that young people with serious mental health conditions face significant hurdles in their journey to adulthood, that they encounter barriers to community integration, that supportive services are lacking, inadequate, or difficult to access, and that their primary support system, namely their family, is deliberately excluded from services. With few exceptions, there is little research to suggest how families and peers can best support these young people; additionally, there are few firsthand reports from the perspectives of young people and parents, and those that do exist focus on the shortcomings of policies and services. This article reports on findings from separate focus groups with a sub-sample of pairs of transition-age youth with mental health needs and their parents, focusing on their experiences and perceptions of receiving formal mental health services, as well as family and peer support and the ways that these types of supports enhance young people's sense of community integration. The sample was part of a larger study that examined community integration across a wide range of domains (Jivanjee, Kruzich, & Gordon, 2007, 2009). Throughout the article, "transition-age youth," "young people," "youth," and "youth and

young adults" will be used interchangeably to indicate young people age 17 to 24 who have a mental health condition. "Parents," "family members," and "families" will be used to refer to parents or other adults who are primary caregivers or parent figures for youth in this study. All young people who participated in the study had received mental health services and/or were referred to participate by mental health professionals who viewed the youths' mental health needs as interfering with their daily functioning.

Methods

At each research site in two northwestern cities, advisory groups were developed that included ethnically and racially diverse young adults with mental health conditions and family members of young people with mental health services involvement. Advisory board members provided consultation at all stages of the project, including the development of recruitment materials, pre–focus group questionnaires, and focus group questions. Focus groups were selected as the major method of data collection because individuals are less likely to feel vulnerable in a group than in a one-to-one interview and are more likely to feel a greater degree of control over how much they wish to contribute to the discussion (Farquhar, 1999; Jarrett, 1993). Focus groups also have the benefit of not discriminating against people who have difficulty reading or writing (Owen, 2001). Given the sensitivity of the topic, the researchers also recruited, hired, and trained young adult research assistants who had experience using mental health services and used family members to assist with recruiting participants and facilitating focus groups.

Youth research participants were recruited through contacts with local mental health agencies, youth advocacy/support groups, colleges, alternative schools, and youth employment organizations. Parents were recruited through their membership in family support organizations. Project staff distributed brochures, flyers, and electronic bulletin board announcements inviting young people aged 17 to 24 with mental health difficulties and families of such youth to participate. The research team made deliberate attempts to seek ethnically and racially diverse participants with some limited success. In total, twenty focus groups were held, of which twelve were with youth and young adults and eight with parents. Most youth participants were not related to the parent participants; however, approximately one third of the entire sample was parent-child pairs who participated in eight separate focus groups, four with young people and four with parents. These participants comprise the sample for this analysis. While the larger sample was quite diverse in terms of race, ethnicity, and social class, the sub-sample of parent-youth pairs described here was less diverse.

Participants

Participants of this sub-sample were sixteen young people and their eighteen parents (both parents of two youth took part). Fourteen of the sixteen youth

participants were male with an age range of 17 to 23 and a mean of 19.4 years. Responses to the demographic questionnaire indicated that fourteen were European American, with one Native American and one Pacific Islander. Thirteen youth participants reported that they were living with one or both parents, while two were living with extended family; one youth checked "living alone or with room-mates." Seven youth participants indicated that they had graduated from high school or obtained their GED; six had not graduated and two reported that they were still in high school. While five youth reported that they were in full-time or part-time school or employment, six reported that they were unemployed and three that they were unable to work; two reported that they were participating in supported employment or vocational rehabilitation.

Sixteen of the eighteen parents in the focus groups were female and the age range was 37 to 60 years of age (mean 46.3, *SD* 7.4). Most participants were mothers, with two fathers, one aunt, and one grandmother who were primary caregivers. Sixteen family members reported that they were European American, plus one Native American and one Hispanic. The most frequently reported youth diagnoses were: bipolar disorder (8), depression (6), learning disabilities (6), attention-deficit disorder (3), behavioral disorder (3), obsessive-compulsive disorder (2), and post-traumatic stress disorder (2); other diagnoses were endorsed by one participant and many participants reported multiple diagnoses for their child. Table 1 summarizes youth participants' self-reported use, need, and access to mental health services.

Data Collection

Parallel versions of the same focus group questions were used with parents and young people, with questions focused on the meaning of community integration for transition-age youth with mental health needs; barriers and supports to their community integration; hopes, goals and dreams for youths' futures; and advice to other parents and youth with similar concerns. Prior to each focus

Table 1   Youth Report of Current Use, Need and Access to Services by Percent (*N* = 16)

| Service	Currently receiving	Needed, but not received	Offered, but could not access
Medication	10	1	1
Individual counseling	3	0	1
Case management	7	1	1
Mentoring	1	2	1
Employment support	2	3	1
Support group	3	1	1
Drop-in center	1	1	1
Group counseling	2	1	1
Wraparound	2	1	1
No services	1	NA	NA

group, participants also completed parallel versions of a two-page questionnaire that included questions about demographics; youth living arrangements; involvement in school and work; and need for, access to, and use of mental health services. Focus groups were held in a range of community settings. Based on the assumption that participants would be more comfortable talking with someone who had shared similar experiences (Jarrett, 1993; Morgan, 1988), youth focus groups were facilitated by a youth research assistant and family focus groups by a family member; in each case one of the principal investigators or the project manager acted as a co-facilitator. Refreshments were provided and each focus group lasted about 90 minutes; participants were paid $30 in appreciation for their time. Focus group discussions were tape recorded (with participants' consent) and transcribed.

Data Analysis

Questionnaire responses were entered into SPSS and descriptive statistics were computed. Focus group transcripts were entered into N6 qualitative analysis software (QSR International, 2002). With the assistance of the software, all team members participated in data analysis, following instruction in the constant comparison method, originally developed by Glaser and Strauss (1967) and updated by Charmaz (2005). Team members read transcripts and completed preliminary independent coding for categories and themes using the original questions to guide their analysis of participants' definitions of community integration, barriers and supports to community integration, goals, and advice for others in a similar situation. After this preliminary analysis, team members met and compared the categories and themes they had inductively derived. In a series of negotiations, the individual coding lists were combined into a shared coding map and then team members coded two transcripts and added additional codes as they emerged. In further team meetings, the team engaged in intensive reviews of these coded materials and reconciled codes. Finally, after team members had reached a satisfactory level of consistency in coding, they coded the remaining transcripts independently. More detailed descriptions of the team-based interpretive data analysis process are provided in Jivanjee, Kruzich, and Gordon (2007, 2009). Categories of participant comments that emerged during analysis were usually situated in specific contexts and relationships. The report of findings that follows is focused on participant reports of experiences with mental health services and support from families and peers.

Findings

As recorded in table 1, these young people and family members reported only limited use of mental health services. In the report of qualitative findings that follows, youth and parent responses regarding positive experiences with services are presented first, followed by challenges related to services. Following these sections,
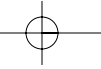
we present youth and family perspectives on family support for youth, and peer support for both youth and families. In each section of findings, we first present youth perspectives and then family perspectives.

Positive Experiences with Mental Health Services

Both youth participants and parents expressed appreciation for helpful ser-vices, with youth making positive comments about service providers' responsive-ness while families emphasized practical supports and providers' willingness to communicate with them.

Youth Reports   Several young people reported helpful experiences with counsel-ing, particularly where service providers were responsive to their needs, taught them useful skills, or gave them hope for a better future. A young man reported:

> I had counseling. I had it once a week. It was pretty fun. It helped me a little . . . just talking to them helps me do better during the week. It made me look at what I did during the week and what I could change if I did something bad, to make it better.

Another young person described a counselor's assistance:

> He had good advice on how to calm myself down, gave me some things called cognitive thinking skills that I started using . . . basically, some tools to use to calm myself down and get my mind straight and things like that.

One young man appreciated his counselor's responsiveness and availability: "He was . . . cool. Whenever I needed to talk, he would be there. He would come by. It was like 4:00 in the morning and he would come over and talk to me." Other young people described service providers who had been especially helpful; as another young man commented, "She helped me a lot through a lot of this stuff, and she is still helping me. I don't know, she just gives me that little glimmer of hope and that's cool."

As shown in table 1, over half of the youth participants were currently using medications, and several young people reported that medication was helpful in managing their symptoms. One young man appreciated his psychiatrist's approach: "My psychiatrist has been willing to try all sorts of different medica-tions . . . [and] not over-prescribing."

Family Reports   Parents tended to emphasize the value of practical help and resources, including wraparound services, respite care, appropriate medication, and providers' willingness to collaborate with and support them. One parent was pleased with a case manager's activities to help her son reintegrate into the community and his willingness to consult with the family: "He was also open to hearing his dad's and my thoughts on what we thought would be especially help-ful for ——." Similarly, one parent reported that a psychiatrist partnered with the

family: "What also worked for —— was having a psychiatrist that asked for input and accepted our input, our observations." Several families had received wraparound services and they were generally enthusiastic about this support. For example, a parent commented on the power of the wraparound team to meet her son's needs:

> One of the biggest pieces for him was to have a mentor. Wraparound team, thank you! That also mandated the school to get more involved, I think, too, because there was then an expectation that the district was part of that team.

Parents who had worked with a wraparound team reported that they felt supported; as one mother put it:

> It is kind of like a support group . . . that wraparound team helps me know how to continue to be in his life in appropriate ways and where to draw lines with him, that kind of thing. It really has helped my parenting skills.

Another parent described the help she received from the wraparound team and a parent partner (a parent with experience navigating service systems on behalf of a youth or young adult with a mental health condition, and trained and hired to support other parents):

> [It] made it possible for me not to have all the answers . . . what she said is, "You no longer need to be his doctor, his therapist, his nurse, his playmate, his interpreter, his counselor, whatever professionals there were. You don't need to do that. All you have to do is be his mom."

Respite care was mentioned positively as a support to families. In-home respite care enabled one parent to keep her job:

> It allowed me to keep my professional life separate from my personal life, I guess is what I am saying . . . he was getting what he needed and I got a chance to kind of regroup before I had to go home to him.

Challenges Related to Inappropriate or Unavailable Services

In contrast to the positive reports, there were many descriptions of inaccessible and inappropriate services and unhelpful providers. Both youth and parents recounted stories of youth, who were unable to get appropriate mental health or school-based services, being referred to the juvenile justice system, which in turn resulted in more challenges for them.

Youth Reports   Youth reported that their inability to find appropriate mental health services was related to the lack of service providers who really understood them, providers' pessimistic attitudes, and the use of ineffective or problematic medications. One participant was critical of psychiatrists and other providers who did not take the time to get to know him: "A lot of the time they are wrong and

don't know the patient, because they are not willing to listen." Several youth wanted to find helping professionals and peers who had shared their experiences and would understand them, but they were discouraged because they could not find such people. For example, one young man commented, "It is hard to find people who have kind of gone through the same thing or understand and can support you." Similarly, a young man who had experienced an extended period of in-patient treatment said:

> The hospital . . . it held me back because the mindset of a hospital is really pessimistic and they give out a lot of pessimistic prognoses. They try to refute any sort of objectives that I had personally, like go to college. . . . They tell me things like, "You are going to be on meds the rest of your life. . . . You are going to be in and out of hospitals, in and off the streets."

While medications were helpful to some participants, others reported that they were ineffective. A young man said, "I've been on just about everything up until recent years, ever since I was a kid. They all worked to some degree for a while and then I would start getting immunities to them, and they would stop working." Some young people described their dislike of medication side effects; others were wary of medications and suspicious of the motives of physicians prescribing drugs. For example, one youth was critical of physicians who prescribe "a lot of medications that someone doesn't need or prescribing therapies that people don't need, just so that they can get the money."

Family Reports   Many parents were upset and angry about restrictive eligibility rules that excluded their children from services, particularly the loss of services when youths turned 18. They also complained about their children's lack of access to appropriate treatment and service providers' ineffectiveness in working with their children. One mother commented on the lack of understanding of her son's illness and the absence of support for him:

> My kid runs everybody off. We have gone through Big Brothers, so it gets really frustrating. I have even had counselors just throw their hands up going, "This kid is way over my head." I have had school counselors bail out. So it gets frustrating.

A grandparent reported that she had been told her grandson's difficulties were too serious for him to respond to treatment:

> Do you know what they say about kids like mine? "They are too severe for the program . . ." I have had mental health professionals working with my son walk away and say, "I am concerned for my own safety, so therefore I can't help your child." I am like, "Aren't you trained to work with kids like him?" I don't know why these people are being paid to serve kids like ours. They are judgmental. They are mean.

Other parents complained that they could not access needed services, usually because of budget cuts or restrictive eligibility rules. One mother described her frustration because of such barriers:

> Every time I try to get him help, even with respite care, they always say, "We don't have the funding for it." "We don't have this." "We don't have that." "He doesn't meet the criteria." "He is not severe enough." He just keeps falling through the cracks and they just keep pushing me away.

A mother reported the financial impact on her family of obtaining appropriate treatment:

> We went broke back then, because there were not community services in the state . . . at the level he needed, so we had to go private insurance and had an advocate to help us so we could access any insurance we could.

Several parents said that their children lost eligibility for health benefits or Social Security benefits when they turned 18, even though their conditions had not improved. One parent said her son would have no coverage after he lost his health insurance on his nineteenth birthday. Another parent said, "He just got declined by SSI. We have always been in private insurance, so we have no resource through the state or anything like that for him. He won't be able to get his medications." Another parent whose son had a developmental as well as a mental health disability described the lack of logic of his being denied Social Security:

> I just got the denial letter. . . He just turned 18 and they told me that he no longer qualified. I asked them why. They told me. I said, "He hasn't changed." . . . But the system has changed. I just need an opinion that says that his behavior is a direct result of his low IQ instead of his low IQ a direct result of his behavior.

Family Support

Both youth and family members talked at length about the assistance and support that family members had provided and continued to provide even after they turned 18. This sub-sample of pairs of parents and youth may not be representative of the wider population of transition-aged youth with mental health difficulties and parents of such youth. Because they both participated in the separate focus groups, they may be assumed to have closer and more supportive relationships than other young people and their parents, and their comments yield insights into the benefits of these supportive relationships. Parents also described their ongoing concerns about their children's well-being and their desires to support them, while also encouraging their independence as young adults.

Youth Reports   Several youth participants talked about positive support they received from their parents. For example, in response to a question about where youth participants received support, one young man responded, "Nowhere. My

parents." Another youth gave a more detailed response of his mother's efforts to assist him:

> My mom has helped me a lot. My mom has been a really big supporter of me trying to achieve my goals. She has been helping me out, because I want to move out. I turn 18 in like two weeks, and I want to move out and live on my own, but it is going to be hard for me because once I turn 18, the supports that I have, some of them are going to disappear. . . . I am going to have to be able to deal with my issues on my own and find other supports. My mom has been helping me out with figuring that stuff out.

A young man reported on his appreciation of the assistance his parents provided even though he was legally an adult:

> My parents have been a pretty big support, too. I'm 19, so I can't get support like I did when I was under 18, so my parents had to still kind of stay in there and help me through all the legal troubles and helped guide me through programs, support groups. They really helped me out and kind of gave me motivation to go out and get jobs and help me fill out the applications.

Another young man appreciated the support and advocacy on his behalf that his parents had provided throughout his illness:

> Family support was a big help for me when I was in the hospital. I probably would have stayed in there a lot longer if it wasn't for them. I know the hospital was planning on sending me to a group home once I turned 18. Actually they were going to send me to a group home until I turned 18, and then they wanted to send me to the adult ward in the hospital. But my parents stepped in and they really argued with them and they told him they would take me in, and they would help out. They would let me stay in their place, which I think is very fortunate for me, because a lot of people didn't have family support. . . . That was a big help for me in comparison to the other people in my predicament.

Family Reports   Parents reported wanting to assist their children and the challenge of finding a balance between supporting their children and encouraging their adult development. For example, a parent commented, "As parents you wonder what is the fine line between enabling your child or helping them." Another parent described her efforts to achieve a delicate balance of support and encouragement for her son's moves toward independence after a difficult adolescence in which he was hospitalized with a diagnosis of schizophrenia:

> Somebody with schizophrenia tends to rely on their family a lot and having common interests so you are not always thinking about bad stuff, you are focusing on the good things. Sometimes that takes planning and thinking through to make those things happen, and all the time trying to find ways to

push him out, encourage that, always letting him know that he has a choice. It is really okay to go and be with your buddies instead of come here.

Another parent described her offers to be as helpful as she could be to her son:

I told [name of son], "If you need me in there, you need to voice that. I can't say it for you and I can't ask to go in. So if it is something that you need me sitting there, just for your security or whatever, you say, 'I am not doing this without my mom present or my father.'"

Peer Support

Not surprisingly, given that the families who participated in these focus groups were members of family support organizations, they eagerly described the support they had received from other parents who had also raised a child with a serious mental health condition. Similarly, some youth participants appreciated receiving support from other young people.

Youth Reports   While some youth participants reported mixed experiences with support groups they had participated in, they noted that groups had been helpful when the members and leaders were similar in age, shared experiences with mental health services, and included activities focused on leadership development. One youth contrasted youth-oriented groups with typical adult-oriented ones:

There were a couple of groups that I have been to that were really cool, actually. Everybody in there was like 20. It is like the trials and errors of going through high school . . . things that we can relate to, going through what we have been through and trying to make it in life with all these obstacles. . . . Not just like, "Back in Nam, I blah, blah, and I started doing heroin," and they are like 85 years old now.

As a result of positive support group experiences, some of these participants were willing to help other youth who were struggling. For example, a young man said he was thinking, "What can I do to aid in this now? Where we could get together as people who are in the same position as me and form some sort of mentoring?" Some youth participants had become involved in a youth leadership development organization and they reported gaining skills as well as support networks of peers.

Family Reports   Parents saw the benefits of their children's involvement in receiving and providing support and engaging in advocacy activities. For example, a parent reported that her son had found a new community by becoming involved in a youth leadership program: "[Name of program] . . . is a supportive group of people that do the same thing for him that we do for each other, and that is make them feel . . . they are good people with a difficult childhood." This parent elaborated on the benefits of this group:

The youth are learning to be leaders in the community. My son is the vice president of the —— movement here in the state. That is the only thing that I really feel that has ever really given him any kind of purpose. It is just amazing. . . . He really understands the importance of the role . . . that he is talking about system design and designing it for youth like himself. . . . Your son may not want a therapist, but if he could connect with another youth . . . that could say, "Are you really thinking about what you are doing before you are doing it?" That is way more powerful than a lot of the paid professionals that run away from our kids because they are afraid of them, or say they are too extreme to meet criteria, or they are not extreme enough.

This parent talked about her son learning from observing her acting as an advocate for families and emulating her behaviors: "He will call me with people that he has met who need help and he knows how to access everything."

When asked what had been helpful to them in dealing with their child's illness, parents were enthusiastic about the support they received from other parents, especially through family support organizations. As one parent commented, "What helps me is the support that I feel from other families." Parents reported many benefits from their participation in a family support organization:

We have a great family organization structure here that is helpful for resources, information, training, and support. We also do peer supports, and it helps us as parents to have that extra support, too. It is just an awesome thing.

As mentioned earlier, several parents appreciated the assistance they had received from parent partners supplied by wraparound teams. One mother captured the critical element of empowerment offered by this support:

Peer mentorship that has occurred for parents . . . has been so successful, because actually when you empower a parent, it really does help us to change and see our children differently and do things differently for them.

Connections to other parents were described as a key to overcoming the shame that many parents felt:

One of the things that I think has been so helpful for us as parents to heal and not feel shame and guilt about our kids has been our support in our community. It is our [name] parent group . . . which is where a core group of parents got together for many, many years, going through the adolescent years with our kids. That has been the saving grace for us, to know that we are not bad parents. We are parents doing a difficult job with difficult kids.

Discussion

Focus group findings provide firsthand accounts of the struggles of young people with mental health conditions and their families to maintain supports for

successful transitions to adult roles and preferred levels of community integra-tion. While this was a small study with a sample of youth and family participants that cannot be assumed to be representative of all youth with mental health conditions and their families, we believe the findings provide much-needed first-person perspectives on the needs of transition-age youth. Caution must be used in considering the applicability of our findings to other youth and family popula-tions, particularly since our sample was not very diverse, although it is instruc-tive to link our findings with other research on related issues. Most youth partic-ipants were male and living with their parent(s), and most parent participants were female. Therefore it may be assumed that these young people's relationships with their parents were closer than youth living apart from family. Because of the overrepresentation of mothers and sons, further research will be needed to gain information about whether daughters and their fathers have had similar experi-ences. These parents were also actively involved in family support organizations, and as a result, they (and their children) were probably better connected with both professional and peer support systems, including advocates, than other sim-ilar families who are not members of family support organizations. Given the extent of challenges they reported, it is likely that other families would encounter even more difficulties accessing appropriate mental health services for their chil-dren. Ideally, we would have reported the comments of matched youth-parent pairs; but because of our open-ended questioning format, specific youth and par-ents did not necessarily address the same topics, resulting in our adopting a reporting format across groups.

Both young people and their parents recommended improving access to well-trained, compassionate service providers, and youth participants expressed appre-ciation for service providers who were responsive, available, hopeful, and focused on meeting their needs. This finding reflects findings from another study in which young people reported on the characteristics and behaviors of mental health ser-vice providers that were most acceptable to them, including "positive personality traits" ("friendly and nice . . . patient"), "active listening," and being "understand-ing" ("someone cares and can relate to what you are saying") (Hyman, Manion, Davidson, & Brandon, 2007, pp. 266–267).

While some youth and families spoke of positive experiences with mental health services, many of their accounts document difficulties in accessing appro-priate services and skilled service providers, especially after age 18. Other researchers have recommended that to improve mental health services, it will be necessary to eliminate the discontinuities between child and adult systems and to use definitions of disability based on functional impairment, regardless of age (Davis et al., 2005). The creation of developmentally appropriate supports (Davis & Hunt, 2005) is also integral to such improvement and is a key element of the evidence-supported transition model proposed by Clark and associates (Clark et al., 2002; Clark & Hart, 2009).

Families reported their commitment to assisting their young adult children, and they lamented the constraints on their helping roles resulting from being

excluded from services due to confidentiality rules. Young people expressed appreciation for the support and assistance they received from their families, even after they reached legal adulthood. There is a need for interventions to support parents during the transition years. Successful transition planning is based on mutual respect between professionals, youth, and families and is characterized by open and honest communication, a solution focus, knowledge of resources, and empowerment of youth and parents (Hitchings, Natelle, & Ristow, 1999). As noted by parents in this study and recommended by Preto (2005) and Leggatt (2007), connecting parents with other parents is vital to reducing families' feelings of isolation in their distress and gaining reassurance from those who have experienced the same or similar situations. There is a need to balance parents' desires to be involved in their children's care with young people's rights to confidential care (Fox & Limb, 2008).

Youth participants in our study were strengthened by peer support and opportunities to participate in youth leadership activities and assist other youth. A youth-led study specifically recommends creating opportunities for youth to use their experiences in helping others, as well as for family involvement in transition services (Federation of Families for Children's Mental Health [FFCMH] & Keys for Networking Inc., 2001). Literature suggests that peer support can take a variety of forms (Solomon, 2004). Peer support groups have been found to be an effective intervention for youth and family members dealing with a range of health problems, including Asperger's syndrome (Weidle, Bolme, & Hoeyland, 2006), traumatic brain injury (Hibbard et al., 2002), and HIV in adolescents (Funck-Brentano et al., 2005). Nascent research on peer-provided services versus standard services, albeit primarily with adults, has found improved outcomes for individuals with serious mental health conditions on a range of measures including alcohol use, empowerment, confidence, and functioning (Resnick & Rosenheck, 2008); lower rates of hospitalization (Lawn, Smith, & Hunter, 2008); and significantly increased consumer perceptions of motivation, knowledge of mental illness, confidence, and hope (Salyers et al., 2009).

Conclusion

As reported by youth with serious mental health conditions and their families, the fragmented system that youth must navigate as they attempt to transition to adult roles and achieve their preferred levels of community integration is fraught with challenges that compound the difficulties resulting from their diagnoses. Findings from this qualitative study provide consumer perspectives on improving mental health services for transition-age youth and their parents and strengthening family participation in services. Participants' comments also suggest the benefits of peer support for both parents of transition-age youth and youth themselves. These topics deserve to be examined further in future research designed collaboratively with young people and their families to address questions that are of concern to them and with more ethnically diverse samples that also include

greater representation of fathers and daughters. Youth transitions to adulthood and a fulfilling life in the community will be improved by the creation of a seamless mental health system serving all ages, with effective service providers who understand and have compassion for young people and a willingness to collaborate with them and, when appropriate, with parents. As the voices from this study attest, youth and families want service providers to ask them what would be helpful and to act on their recommendations. They want access to peer support to normalize their experiences and provide practical strategies for better futures. With such supports, challenges to successful transitions can be overcome, and young people can engage positively with their communities.

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