

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

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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 system 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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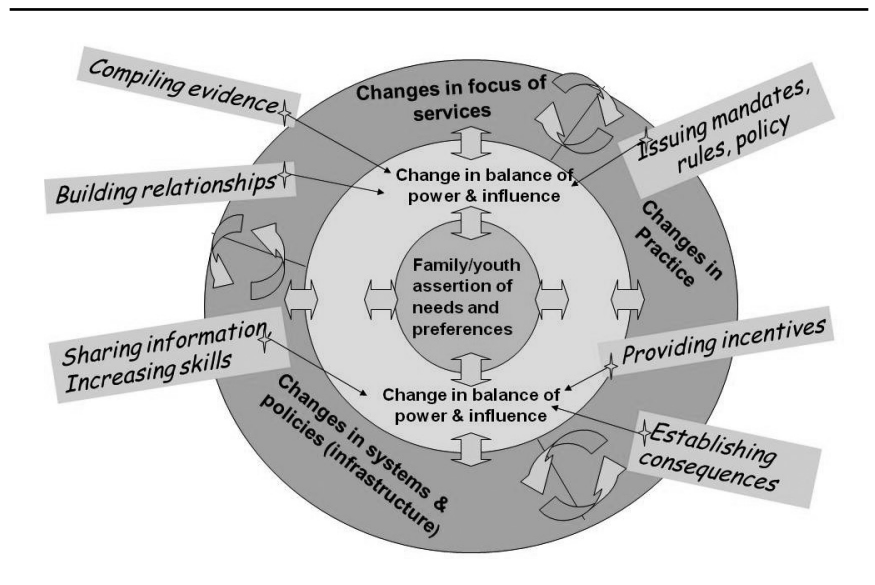
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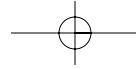
health field. Changes in practice from the early 1980s, when most families were denied authentic participation in treatment/service planning for their children, to today's "family-driven and youth-guided care" (National Federation of Families for Children's Mental Health [FFCMH], 2010; Osher, Penn, & 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 interpersonal 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.

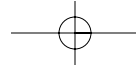
Providing Incentives, Establishing Consequences, and Issuing Mandates

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

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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.

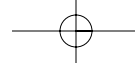
Recent examples of compiling both hard evidence and practice wisdom about developing partnerships with families and youth can be found in documents addressing family-driven care (Osher et al., 2008) and youth-guided services (Matarese, Carpenter, Huffine, Lane, & Paulson, 2008).

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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,



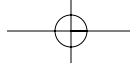
& Walker, 2009). Youth leaders from across the U.S. were sponsored to attend the Summit, and to present the results of their work to a conference plenary session. One result of the Youth Summit was a “youth mental health bill of rights.” Participants in the youth summit included representatives of a 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.

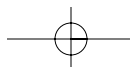
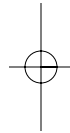
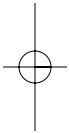
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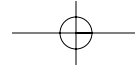
As family members expressed their vision for change (e.g., attention to the needs of the entire family, family support services defined as “whatever it takes” [National Federation of Families for Children’s Mental Health [FFCMH], 1992]), expansion beyond an exclusive focus on clinical treatment began 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.

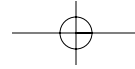
Family advocacy organizations are typically governed and staffed by family members and address four objectives: (1) mutual support and sharing of information, (2) advocacy on behalf of individual families and children, (3) modification and enhancement of the service delivery system, and (4) ensuring 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

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

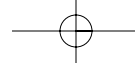
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Health Law, which count on family organizations and family members to compile information and provide testimony about their experiences.

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

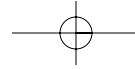
Research and evaluation efforts exist in many different forms, and it is not always easy to identify and track change over the past twenty-five years. The gold standard for research has been the randomized clinical trial, a research design and research process that is researcher-driven, historically 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.

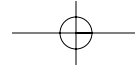
Although family members have achieved some influence in the evaluation of mental health services, particularly through the requirements of the national evaluation for the CMHI, no major federal research funder has yet required consumer involvement in the development of research projects, although some 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 wrap-around 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 wrap-around 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.

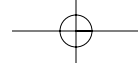
Incentives have also contributed substantially to the growth of wraparound. Most notable has been the federal Comprehensive Community Mental Health Services for Children and Their Families program (also called the Children's Mental Health Initiative [CMHI]), funded by SAMHSA. Funded communities are required 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

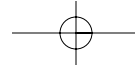
In this article we have presented a framework for understanding the impressive changes in the roles and influence of family members and youth during twenty-five years of reform efforts in children's mental health. We have also identified some of the important changes in practice, focus of services, policy, 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.

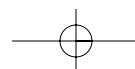
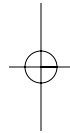
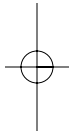
Clearly, over the last twenty-five years family members, services providers, administrators, and other stakeholders in the children's mental health field have used the strategies and points of leverage identified in the framework we have presented here. However, our retrospective analysis suggests that 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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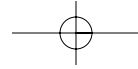


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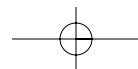
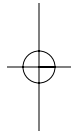
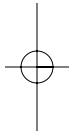


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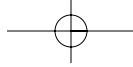


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