

Policy Brief

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Supporting High-Quality Mental Health Services for Child Trauma: Family, Youth, and Consumer Involvement

Consumer and family involvement is the cornerstone of quality child trauma services programs. Without it, services and systems can become increasingly disconnected from the very people they exist to serve, resulting in systems where consumers are expected to “fit” available services, rather than having services designed to meet their needs. When services are designed in isolation from the people they serve, they are not only less effective than those that grow out of more collaborative approaches, they may also have features that can retraumatize youth and families. The repercussions are serious, and may result in poor clinical outcomes, as well as consumer frustration with service systems, and reluctance to seek help in the future.

Fortunately, there is a gathering awareness in the child trauma and mental health fields, that in order to provide effective mental health interventions to traumatized children, partnerships must be built among youth, families, caregivers, and professionals. These alliances must be based on mutual respect, a common commitment to healing, and shared responsibilities for planning, selecting, and evaluating trauma services and supports. This policy brief describes some of the many benefits of such partnerships, outlines potential barriers to building them, and offers strategies for engaging and maintaining youth and family involvement. It also points readers to resources that provide more information on these topics.

Partnerships with Consumers and Caregivers: A Key to Quality Services

The benefits of consumer and family involvement – for services, systems, and most importantly, consumers and families themselves – are well-documented.

Research bears out the value of consumer-provider partnerships. Research supporting family and youth involvement in children’s mental health care has found that family participation promotes positive changes in the way children are served, including increased focus on the family’s role in treatment and recovery itself; provision of services in settings outside of the clinic (such as home, school, shelter, etc.); greater cultural sensitivity; and a community-based system of care that serves the multiple needs of the family.¹ Studies have also found that family participation improves the process of delivering services and their outcomes^{2,3} and that youth and

family involvement in service planning also helps service coordination.^{4,5} Additionally, research specifically related to child trauma has shown that family involvement in treatment improves outcomes for youth and family members.⁶

Systems improvement is facilitated. Ongoing input from youth and families enables service providers to continuously improve the quality of information and services related to child trauma and its treatment. When youth and families are included, they become full participants in national efforts to increase the public's awareness of child traumatic stress and improve policies and services. Youth and families can also be powerful agents for spreading the word about services to others who need help, and can serve as mentors and examples to their peers.

A gathering consensus is emerging that consumer and family involvement is not only valuable, but necessary. In recent years, there has been increased recognition of the importance of involving youth and families at the program, administrative, and policy decision-making levels. The Surgeon General's Report on Mental Health (1999)⁷, the final report of the President's New Freedom Commission on Mental Health (2003)⁸, and the USDHHS and SAMHSA reports on the transformation of mental health care (2005, 2006)^{9,10} all make the case that a transformed mental health system will be family- and consumer-driven. The New Freedom Commission report, *Achieving the Promise: Transforming Mental Health Care in America*, cites the movement to increase youth and family involvement as an "opportunity to fundamentally alter the form and function of the mental health service delivery system"

Partnerships foster dynamics essential to recovery. Trust, respect, and hope play critical roles in recovery from traumatic experiences. At the core of our existence as human beings are some basic needs: to be safe, to be connected to other human beings, to have hope in difficult times, to see ourselves as deserving of love and respect, to have confidence in our abilities to make decisions, and to have the power to direct and change our lives. A system committed to creating meaningful partnerships between professionals and consumers respects and reflects these basic human needs.

When service providers and systems take the time to meaningfully involve consumers in efforts to change and improve services and systems of care, hope is created. In practical terms, consumer and professional partnerships demonstrate respect, address the issues that are important to consumers, and find solutions that work better than traditional approaches.

Overcoming Challenges to Consumer and Family Involvement

Although the benefits of consumer and family involvement are many, challenges do exist. These can include the following:

- **Confidentiality Concerns.** Service providers may perceive a conflict between the need to safeguard the privacy of youth and families, and the desire to involve them in public service center or system activities. Youth

and families may have both unique and shared concerns about losing their privacy when asked to divulge details of their experience or treatment in more public venues.

- **Clinical Issues.** Particularly in the area of trauma, therapists and consumers may be concerned that greater system involvement could potentially re-expose consumers to traumatic events or information. Care also must be taken so that clients never feel that their therapy or the good will of their treatment providers hinges on their participation in optional activities.
- **Attitudinal Barriers.** Staff attitudes and misconceptions about people with mental health service needs can make it difficult to create an organizational environment and culture that welcomes consumers' ideas and sustains their involvement. In such environments, youth and family members may not feel welcomed, respected, supported, or "heard" by agency staff.

Stigma can create barriers to seeking help or becoming involved in the service system. Trauma exposure itself often leads to feelings of shame, blame, and embarrassment which may be compounded by the stigma surrounding mental illness. Shame and misconceptions about trauma continue to inhibit people from seeking treatment, talking about their treatment with others, and becoming involved in the mental health care system.

- **Resource Barriers.** Lack of finances or other resources can also inhibit youth and family participation in treatment or related activities. Many caregivers may have low incomes, face myriad life stresses, and have sole responsibility for their children. Caregivers may not be able to take time off from work. They may not have access to affordable transportation or child care that would enable them to attend meetings.

In addition, many public and private insurance funders continue to "divide up" the family by refusing to pay for full family participation in services. Often, evidence-based family interventions cannot be delivered because of the way in which insurance and financing systems are structured.

Service providers and systems that want to increase consumer and family involvement must be prepared to address these challenges. Those who provide trauma services can take many steps to overcome barriers and facilitate consumer and family involvement in services planning, delivery, and evaluation.

Strategies to Increase Consumer and Family Involvement

Despite the challenges to consumer and family involvement, there are many ways for service providers and systems to overcome them. In October 2005, the National Child Traumatic Stress Network (NCTSN) convened a Family and Consumer Engagement Planning Meeting to develop a guiding framework, vision, and goals for involving families and youth at both the clinical and organizational (or systemic) levels. Meeting participants included youth and family members who had experienced trauma or traumatic loss and received related services, trauma service providers, and members of national organizations that represent youth and families.

Participants developed the following strategies for creating, increasing, and refining partnerships with youth and families at the treatment and organizational levels. They agreed that any effort to fully engage youth and families must be two-pronged, affecting both the clinical and organizational levels.

Clinical Partnerships

Clinicians and clinical programs can take a number of steps to develop effective treatment partnerships with youth and their families. Following are some of the ways to structure consumer-centered treatment programs and approaches:

- **Involve youth and family actively in all stages of the treatment process.** Youth and families should be actively involved in identifying treatment goals, making treatment choices, and assessing and updating their treatment plans. Youth and families must be recognized as experts on their own experiences, needs, and behaviors. Consumers and clinicians should work together to identify treatment priorities and desired outcomes.
- **Provide information on an array of service options.** Before determining their course of treatment, consumers should be well-informed about therapy choices — even if some choices would require referral to another provider. There should be full disclosure of the strengths and weaknesses of treatment options, and the rights of consumers throughout the treatment process.
- **Maintain cultural and linguistic competence.** Consumer-centered care requires that providers understand, respect, and respond to the role culture plays in seeking help, understanding information, and relating to the provider and to other family members. Culture includes beliefs and practices based on a range of factors such as race, ethnicity, region, class, sexual orientation, gender identity, faith community, and more. Treatment should be provided in the language preferred by the youth and family. Families new to US mental health services (e.g., recent immigrants) should be educated about the various systems with which they might become involved.

- **Institute practices that facilitate access to care.** Consumers and families typically face multiple time demands, including school, work, and child care. Access to services is increased through flexibility in the scheduling of visits, and in the location and length of sessions. Providers should be readily available, including by telephone, throughout treatment. When needed, organizations should assist families in negotiating with other systems or institutions (e.g., schools) to allow youth to attend appointments.
- **Identify funding resources.** Lack of finances is a significant barrier to care for many families. Service providers should help families identify and apply for funding sources, and assist them in navigating health plan eligibility and managed care processes. For insured families, providers should help them explore alternatives when coverage is exhausted.
- **Establish mentorship programs.** Some organizations offer youth and families who have completed treatment the opportunity to become mentors for new youth and families entering treatment. Organizations can support peer-to-peer mentors by offering related training, ongoing guidance, or a special support group for mentors.
- **Promote policies that support consumer and family involvement.** Public and private policies can facilitate — or hinder — efforts to deliver consumer-centered care. For example, public and private funding streams should support and evaluate the involvement of consumers in treatment planning and assess their satisfaction with outcomes. Organizations can establish policies requiring that treatment goals be agreed upon jointly by the provider and consumer, and that treatment plans record progress toward those goals.

Partnerships at the Organization or System Level

While crucial, clinical level consumer-provider partnerships alone are not enough to ensure quality of care. All systems and organizations are driven by policies and protocols that affect the delivery of services. Consumers and family members should be fully involved in informing such policies and practices. The following are some of the ways to establish consumer-centered organizations:

- **Fully involve consumers and families in program and organizational planning.** To ensure the quality of care, youth and families should participate as partners at all levels of program design, development, implementation, and evaluation. Because there are different ways in which individual youths and families are comfortable about becoming involved, they should be provided a menu of options. Such options could include reviewing materials, commenting on proposed center/system goals and activities, designing and conducting staff trainings, and participating in the evaluation of programs.

- **Include families and consumers in governing bodies and processes.** Youth and families should help make decisions about the policies of the organization and be considered an integral part of program governance. Policies should be instituted to ensure this occurs, such as requiring consumer-family membership on boards of directors and other governance and advisory bodies. Additional input mechanisms, such as youth advisory boards, should also be established. Such bodies should not only include current service users, but also past users, such as young adults who were in foster care or utilized mental health services as children. In looking back at their treatment experience and its impact on their adult lives, these individuals can provide powerful insights into the strengths and weaknesses of service systems.

Other supports are also necessary. In order to achieve meaningful involvement, youth and families must be equipped to fully participate in bodies (e.g., boards of directors) and processes (e.g., meetings). Organizations should provide related information and training to participating youth and families. Coaching, mentoring, and preparation should also be available where needed.

- **Provide financial support.** Participation in organizational activities can compete with time spent in paid employment, and often involves costs such as transportation and child care. Organizations should assess what youth and families need to maximize their participation, and provide concrete assistance that addresses those needs. Such assistance might include stipends, translators, interpreters, transportation, child care, and flexible meeting times and locations. Organizations can also build incentives for youth involvement in programs by providing college and job references, and offering community service hours.
- **Maintain cultural competence.** Consumer-centered organizations ensure that their youth and family involvement initiatives are culturally competent. Participants in these initiatives should represent the diversity of the consumers in the community, and materials should be translated into languages that are spoken in the community. Outreach efforts should not only target culturally and racially diverse populations, but also populations such as youth with disabilities and youth who are lesbian, gay, bisexual, and/or transgender.
- **Promote policies that support family and consumer involvement.** Ultimately, public and private funders should require service systems to have meaningful partnerships with consumers. Accreditation organizations and quality assurance bodies should also recognize consumer involvement as a crucial factor in the provision of quality care, with evaluation processes that address this quality component. The service systems and providers with whom they become involved should adapt their services and supports to address the cultural and linguistic needs and preferences of youth, families, and consumers.

For More Information

Meaningful youth and family involvement – at both the clinical and organizational levels – yields multiple benefits. While there are challenges to such involvement, there are also proven strategies for overcoming common barriers. The NCTSN publication, *Pathways to Partnership with Youth and Families in the National Child Traumatic Stress Network*, covers the issues presented in this policy brief in greater detail and provides organizations with some tools for assessing how well youth and families are integrated into their own activities. For more information, please visit the NCTSN website at www.nctsn.org or contact Philip Little for further information (plittle@psych.duhs.duke.edu).

This brief was prepared by Kristine Buffington, MSW, trauma therapist, trainer, consultant on family/consumer issues, and former NCTSN Steering Committee member, Toledo, Ohio; Ellen Gerrity, PhD, Associate Director, National Center for Child Traumatic Stress, UCLA and Duke University; Cynthia Folcarelli, President and CEO, Vanner Street Group, Washington, DC. For further details regarding the content presented in this briefing, please contact Dr. Gerrity (egerrity@psych.duhs.duke.edu).

References

- ¹ Knitzer, J. (1993). Children's mental health policy: Challenging the future. *Journal of Emotional and Behavioral Disorders*, 1(1), 8-16.
- ² Koren, P. E., Paulson, R. I., Kinney, R. F., Yatchmenoff, D. K., Gordon, L. J., & DeChillo, N. (1997). Service coordination in children's mental health: An empirical study from the caregiver's perspective. *Journal of Emotional and Behavioral Disorders*, 5(3), 162-172.
- ³ Cooper, J. L., Masi, R., Dababnah, S., Aratani, Y., & Knitzer, J. (2007, July). *Strengthening policies to support children, youth, and families who experience trauma*. New York: Columbia University Mailman School of Public Health, National Center for Children in Poverty.
- ⁴ Curtis, J. W., & Singh, N. N. (1996). Family involvement and empowerment in mental health service provision for children with emotional and behavioral disorders. *Journal of Child and Family Studies*, 5(4), 503-517.
- ⁵ Thompson, L., Lobb, C., Elling, R., Herman, S., Jurkiewicz, T., & Hulleza, C. (1997). Pathways to family empowerment: Effects of family-centered delivery of early intervention services. *Exceptional Children* 64(1), 99-113.
- ⁶ National Child Traumatic Stress Network. Partnering with Youth and Families Collaborative Group. (2008). *Pathways to partnerships with youth and families in the National Child Traumatic Stress Network*. Los Angeles, CA and Durham, NC: National Child Traumatic Stress Network.
- ⁷ U.S. Center for Mental Health Services & National Institute of Mental Health. (1999). *Mental Health: A report of the Surgeon General*. Rockville, MD: Department of Health and Human Services, U.S. Public Health Service.
- ⁸ President's New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America (USDHHS Publication. No. SMA-03-3832)*. Washington, DC: U.S. Government Printing Office.
- ⁹ Substance Abuse and Mental Health Services Administration. (2005). *Transforming mental health care in America: The federal action agenda: First steps*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.
- ¹⁰ Substance Abuse and Mental Health Services Administration. (2006). SAMHSA action plan: Mental health systems transformation. Retrieved February 10, 2008, from http://www.samhsa.gov/matrix/SAP_mh.aspx
- ¹¹ Council on Accreditation. (2008). *Council on Accreditation standards (8th ed.)*. Retrieved July 20, 2008, from <http://www.coastandards.org/>