Pathways to Partnerships with Youth and Families

in the National Child Traumatic Stress Network
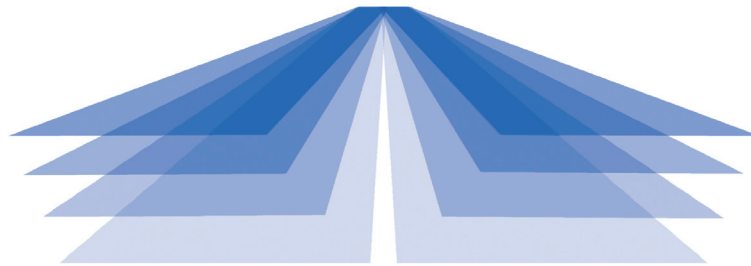
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Pathways to Partnerships with Youth and Families

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National Child Traumatic Stress Network
Established by Congress in 2000, the National Child Traumatic Stress Network (NCTSN) is a unique collaboration of academic and community-based service centers whose mission is to raise the standard of care and increase access to services for traumatized children and their families across the United States. Combining knowledge of child development, expertise in the full range of child traumatic experiences, and attention to cultural perspectives, the NCTSN serves as a national resource for developing and disseminating evidence-based interventions, trauma-informed services, and public and professional education.

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Message from the Steering Committee

We are writing to inform you of an expanding initiative within the NCTSN to increase the involvement of youth and families at the Network, center, and clinical levels. This initiative is being led by the Partnering with Youth and Families Collaborative Group and the National Center, with the support of the Steering Committee and the Advisory Board. SAMHSA also strongly supports this initiative.

The mission of the NCTSN's Partnering with Youth and Families Collaborative Group is to **"build a partnership among youth, families, caregivers, and professionals based on mutual respect, a common commitment to healing, and shared responsibilities for planning, selecting, participating in, and evaluating trauma services and supports."**

The Steering Committee of the NCTSN wishes to acknowledge its alliance with the Partnering with Youth and Families Collaborative Group in order to support the adoption of youth and families' involvement across the network. The NCTSN strives to meet the needs of traumatized children and their families in many different ways. Beyond clinical outcomes, it's difficult to gauge how we are doing at the individual and center levels. Are the youth and families who receive trauma-informed services from NCTSN getting what they need and want? Are services, programs, and materials as helpful, accessible, and meaningful to youth and families as they can be? The only way to answer these important questions is to ask youth and families themselves, and make sure our work reflects their answers.

The NCTSN recognizes the many different ways that youth and families can serve. Some family members may be comfortable serving as direct advocates or speaking publicly; others may wish to provide input more anonymously. Some may truly wish to move on following treatment, and we respect their right not to become involved. No youth or family member should ever feel coerced to volunteer, or feel that their decision to become involved (or not) will influence future treatment in any way. However, we also recognize that those youth and families who wish to become involved can do so only if given an opportunity. The key is to make a range of opportunities available with no pressure attached. Keep in mind that there are many ways for youth and families to get involved that do not require a constant retelling of their trauma narratives, but that may empower them to use their experience to help others.

The Partnering with Youth and Families Collaborative Group wishes to serve as a support to centers as they explore realistic ways to shift clinical and organizational practices to include youth and families who desire to become involved. The Collaborative

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Group offers suggested activities to create, increase, and refine partnerships, and to address the multiple barriers that can keep NCTSN sites from moving forward in this endeavor.

We encourage youth and families to become involved at NCTSN centers, with the understanding that every agency has its own governance rules and institutional culture, and that many centers may be able to implement only some of the suggestions offered. The NCTSN is a diverse Network and one size will not fit all centers.

The main purpose of this initiative is for all centers to provide respectful possibilities for partnership so that we can learn from those we serve. With the document that follows and its other efforts, the Collaborative Group has begun the dialogue and has committed to assisting centers to do all that they can.

The NCTSN, led by the Collaborative Group, will continue to seek new ways to ensure that the voices of the youth and families are heard in all aspects of the NCTSN's work.

We thank you in advance for your commitment to this vital initiative.

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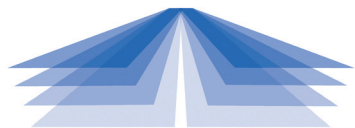
Foreword

Pathways to Partnerships with Youth and Families provides members of the NCTSN and other trauma-treating entities with a method for considering the role of youth and families in their organizations. The *Pathways to Partnerships* document is informed by the literature on youth and family involvement in mental health services, youth and family input, and our pilot results. This document contains two self-assessment questionnaires: one for clinical services, based on guidelines for family-focused assessment and treatment of trauma (Saltzman, & Lester, 2005) and the other adapted for program management and policies (Ahsan, & Cramer, 1998). *Pathways to Partnerships* also offers strategies for increasing youth and family involvement in all aspects of service delivery and includes useful examples provided by one NCTSN site. We hope organizations will use this document to identify current program strengths as well as areas that need improvement.

Getting Feedback

At a September 2007 face-to-face meeting of the Partnering with Youth and Families Collaborative Group, youth and family representatives, some of whom had experience as former clients of NCTSN sites, responded to a draft of this document. We incorporated their feedback in the following ways: On the clinical self-assessment tool we clustered most of the questions into five key areas: Acknowledgment, Safety, Partnership, Peer-to-Peer Support, and Hope. We moved the sections on Psychoeducation and Trauma Assessment & Treatment to the end of the questionnaire. Based on direction from the team of youth and family reviewers, we also added a few new statements about the importance of peer-to-peer support, the benefits of which are supported by the literature (Lefley, 1997; Chamberlin, 1995).

In the spring and summer of 2007, six NCTSN sites piloted both the clinical and program self-assessment tools. Clinicians and administrators provided feedback about how the tools were helpful and where they needed improvement. We want to thank the following organizations for their feedback and assistance with improving the tools and the document: National Center on Family Homelessness, The Kennedy Krieger Institute Family Center, La Rabida Children's Hospital-Chicago Child Trauma Center, The Jewish Board of Family and Children's Services, Chadwick Center for Children and Families, and The National Center for Child Traumatic Stress. As a result of their input we modified some of the ordering and instructions, altered the scales to include more response options, specified how the assessments should be administered, created clearer links from assessment items to related activities, and offered more resources at the end of the document.

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We welcome additional opportunities to further expand the scope, relevance, and utility of this document, and so urge you to provide feedback through our survey instrument located in the Evaluation section of the Appendices.

Pathways to Partnerships with Youth and Families also combines findings from the literature that attest to the importance of introducing, improving, and evaluating youth and family engagement in mental health services (McKay, 2004, 1996; Brannan, 2003, Staudt, 2003) with the key values and principles of trauma-informed clinical and organizational practices (Hodas, 2006; Fallot, & Harris, 2001). Trauma-informed practices emphasize a sharing of control between the clinician and client; client self-advocacy; and use of respectful, jargon-free language. We hope that *Pathways to Partnerships* will assist your organization in developing policies and practices that are responsive to the particular needs of your client partners.

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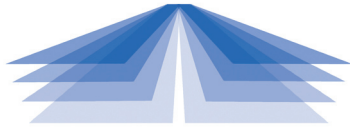
Early in its history, the National Child Traumatic Stress Network (NCTSN) developed a number of small groups to develop and review information and materials for youth and families who had directly experienced traumatic stress. In the spring of 2005, these groups decided to combine their efforts and plan a major Network meeting focused on increasing the participation of youth and their families in the Network. A survey was developed and disseminated to Network centers to collect data on youth and family involvement.

A steering committee—composed of family members, as well as staff members from the National Center for Child Traumatic Stress (NCCTS), the Substance Abuse and Mental Health Services Administration (SAMHSA), and NCTSN centers—was also formed to plan for this meeting.

In October 2005, NCTSN convened The Family and Consumer Engagement Summit in Arlington, Virginia. Approximately fifty people attended—about half of whom were trauma treatment providers. Most of the other attendees were youth and family members who had experienced trauma or traumatic loss and had received services from a Network center. Among them were refugee families who had endured war and violence, families who had lost members to homicide, victims of domestic violence, and youth who had witnessed school violence.

Other attendees included foster and adoptive parents; six youth, some of whom were formerly in foster care and who represented the UFoster Success program in Utah; and youth and family members from some of the NCTSN centers. Members from national organizations that represent youth and families—including the National Alliance on Mental Illness, Voices of September 11th, The Shaken Baby Alliance, Family Voices of Northern Virginia, and the Federation of Families for Children's Mental Health—also participated.

The purpose of the meeting was to bring diverse youth and family participants together with Network members to develop a guiding framework, vision, and goals for involving youth and families at all levels of Network activity. NCTSN centers were selected based on their organization's commitment to including youth and family members in their programs at a variety of levels—on advisory boards, in treatment planning, program development, and evaluation.

For two days the group worked on developing a vision and principles related to youth and family involvement for the NCTSN; on setting goals; and on developing strategies, tools, and processes for family involvement. This document represents the best thinking and ideas from that meeting.

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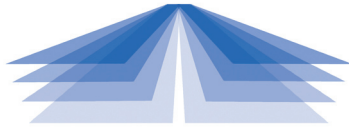
Since the 1970s, three national family organizations have significantly influenced mental health service delivery through advocacy, family support, research, and public awareness. They are the National Alliance for the Mentally Ill (NAMI), the Federation of Families for Children's Mental Health (FFCMH), and the National Mental Health Association (NMHA). NAMI serves families of adults with chronic mental illness. FFCMH serves children and youth with emotional, behavioral, or mental disorders. NMHA serves a broad base of family members and other supporters of children and adults with mental disorders and mental health problems. Although these groups developed in response to different areas of concern, they have in common the following emphases: addressing stigma, preventing discrimination, promoting self-help groups, and promoting recovery from mental illness (Frese, 1998).

Notably, the FFCMH is credited with advancing the causes of family participation and support in systems of care, access to services, and decision-making about child mental health care. This work represents a major shift in service delivery.

Since 1998, there has been an increasing impetus on the part of the U.S. government to involve youth and families at the program, administrative, and policy decision-making levels in children's mental health. This impetus is reflected in legislation, such as the Individuals with Disabilities Education Act (2004) and state mental health services comprehensive plans, as well as in government research, evaluation, initiatives, and reports.

The *Surgeon General's Report on Mental Health* (1999), the final report of the President's New Freedom Commission on Mental Health (2003), and SAMHSA's reports on the transformation of mental health care (2005, 2006) all make the case that a transformed mental health system will be family- and consumer-driven. *Achieving the Promise: Transforming Mental Health Care in America* (2003) 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 . . ." The report also explains that transformation will not be easy, and will require an "unparalleled commitment" on the part of governments, communities, public and private sector providers, consumers, and family members to work together toward a single vision.

Most NCTSN providers understand that involving youth and family in the design and provision of services makes those services more responsive, culturally sensitive, and effective. In addition, including youth and family in decisions about their services improves access to services, increases public awareness, and strengthens outreach

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efforts to other families who might need services. Meaningful family involvement is a value emphatically promoted by SAMSHA and is required of its grantees. However, some Network centers may perceive that involving youth and families in center activities may threaten their privacy and reexpose them to their trauma. Furthermore, some Network centers may find it difficult to create an organizational environment and culture that welcomes youth and families' ideas and sustains their involvement.

How do clinicians' attitudes change when families become equal partners?

"When a client and therapist disagree, it is not uncommon for a clinician to say, 'It's client resistance,' or 'The client is unhappy because I confronted them on something they don't want to face.' If you look at your client as your partner, the way you give feedback and address issues is different. We're putting resources towards consumer-oriented training for our staff because some clinicians know how to empower their clients, and others need help in shifting their attitudes." —*Kris Buffington**

"And peer support might be an important way to help some families in treatment. At last year's ANM [All Network Meeting], Judy Cohen [Judith Cohen, MD, medical director, Center for Traumatic Stress in Children & Adolescents, Allegheny General Hospital] brought a mother and adolescent daughter who'd received TF-CBT [Trauma-Focused Cognitive Behavioral Therapy]. And the young woman said that she really wished that when she'd started she'd had someone who had been through the treatment already who could just tell her what to expect. It can be so important when someone is just entering treatment for a peer to say, 'I've been through treatment here, and this is how it helped me, and this is what it's going to be like, and if you're afraid about anything, you can call me.'" —*Rachel Buehrer**

*Excerpted from an interview—conducted in 2007 by National Center Product Development Consultant Deborah A. Lott— with Cullen Center Former Project Director Kris Buffington, MSW, LISW, and the Cullen Center's Coordinator of Research, Advocacy and Community Programming, Rachel Buehrer, FLE. In it they describe about how the Cullen Center has forged partnerships with youth and families to improve quality of care, and offer advice for other NCTSN centers.

Human service providers, administrators, and advocates, are familiar with the barriers that impinge on youth and family involvement, both in clinical treatment and at the broader organizational level. Many of these barriers to care and to increased involvement in the service system are well documented and include:

✦ **Poverty.** Many caregivers live in poverty, function as single parents, and face myriad life stresses.

✦ **Caregiver trauma.** Intergenerational trauma may make the healing process challenging because of caregivers' own trauma reminders that can interrupt the treatment process.

✦ **Access.** Caregivers may have jobs that do not permit taking time off from work for anything other than illness or emergencies. They may not have access to affordable transportation to appointments and meetings, or to child care for their other young children.

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✦ **Stigma.** Shame about mental illness and misconceptions about trauma sometimes deter people from seeking treatment, and from talking about treatment with others in ways that might advance youth and family involvement in mental health care. Trauma, in particular, may evoke feelings of shame, blame, and embarrassment.

✦ **Poor prior mental health care system experience.** Many families have had prior experiences in the mental health care system that make them wary of seeking help for trauma.

✦ **Challenge of addressing the trauma.** Traumatic events often involve challenging interpersonal issues and emotions—such as grief, fear, betrayal, anger, suicide and death, sexual abuse, thoughts of revenge—that are difficult to acknowledge and share, even with a trained professional. It takes courage on the part of youth and families to engage in active trauma treatment.

Youth and families who successfully participate in clinical treatment may face additional barriers to broader agency participation:

✦ They may be concerned about losing their privacy and having to share details of their experience or treatment in more public venues.

✦ They or their therapists may be concerned about reexposure to traumatic events or information.

✦ They and/or their therapist may believe it will be easier to move on if they sever ties with the agency.

✦ They may lack transportation, resources, or the necessary skills to participate in some agency activities.

✦ They may not feel welcomed, supported, and heard by agency staff.

All of these barriers—along with the seriousness of the presenting problems, complexity of the social situation, and reliance on an expert-driven system—hinder adequate youth and family participation in child traumatic stress treatment and in broader agency planning and tasks.

Research supporting family involvement in their children's mental health, however, overall reflects that:

✦ Family participation promotes four changes in the way children are served: 1) increased focus on families, 2) provision of services in natural settings, 3) greater cultural sensitivity, and 4) a community-based system of care (Knitzer, 1993).

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- Family participation improves the process of delivering services and their outcomes. For example, Koren, et al. (1997) found that for children with serious mental health problems, the more the family participates in planning services, the better family members feel, because their children's needs are being met.

- Youth involvement gives young people opportunities to learn about research and evaluation (Checkoway, & Richards-Schuster, 2003). Youth have been involved in evaluation as subjects, consultants, and partners. Young people have served as co-evaluators and directors, and have organized their own research projects to study a problem of their choice.

- Participation in service planning also helps service coordination. Curtis and Singh (1996) and Elling, et al. (1997) found that family involvement in services was a determinant of the level of parental empowerment, that is, how much control parents felt they had over their children's treatment.

Additionally, research specifically related to child trauma reflects that family involvement in treatment has improved outcomes for youth and family members. The following illustrates research related to outcomes for child trauma:

- In children who have been sexually abused, involving family in trauma-focused treatment through parent components and parent-child sessions focused on trauma led to decreases in PTSD symptoms, decreases in acting out behaviors, and greater improvement in depressive symptoms for child and parent; and improvements were maintained over the year after treatment ended (Cohen, Deblinger, Mannarino, & Steer, 2004).

- Involving family in burn pain management reduced the child's experience of pain and assisted with longer-term compliance with treatment and healing (George & Hancock, 1993).

- Studies of children exposed to various types of trauma have shown that when parents experience less distress and there is more familial support, the negative impact of trauma on children is mitigated above and beyond whatever treatments are directly provided to the child (Laor, Wolmer, & Cohen, 2001; Kliewer, Murrelle, Mejia, de Torres, & Angold, 2001).

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Some centers are concerned about breaching confidentiality or violating boundaries in asking former clients to remain involved. Do you have any advice?

"Many professionals feel uncomfortable engaging current and former clients in partnerships to evaluate, develop, and implement services. For many professionals and organizations this is a new and unknown experience, and the unknown can be a little scary. Very often in our college education and ongoing in our field training experiences, we are not provided with perspectives and practical tools that guide us on how to develop these partnerships. We are often trained to think of the professional and client relationship as hierarchical, and with the perspective that we are the experts and our clients need to defer to our expertise. It is quite a transformation, a very needed transformation, to begin to look at youth and families as experts and equal partners.

"One of the things that helped my organization to move forward was to tap into the expertise of colleagues and families in other organizations and systems that have a good track record of consumer and professional partnerships. Here in Toledo, we have the Wernert Center, a member of the Ohio Advocates for Mental Health, a site that provides peer-to-peer services. Their members are consumer survivors who've been trained to mentor others in the mental health system. Many of the members of the Wernert Center are quite articulate about their needs and what works for them. The members of the Wernert Center lead the design and implementation of all of their programming and services. We continue to learn about successful roles and engagement of youth and families as partners from others. Every community has successful partnerships that we can all learn from.

"Participation in program development or other activities doesn't mean that families have to go through reexposure to their trauma. They don't have to tell their own trauma stories; we're clear when we ask for their views on how to better do A or B, that we don't expect them to talk about their own traumatic experiences. If they do share them, we take the time to ask, 'How are you doing with that?'"

—Excerpted from an interview with Cullen Center Former Project Director Kris Buffington.

There are numerous benefits, therefore, that come from active youth and family involvement including:

1. Increased participation of youth and families with diverse cultural perspectives strengthens the relevance and cultural competence of agency services.

2. Participation of youth and families in Network center planning and evaluation strengthens their sense of ownership in Network activities and further empowers them to create change.

3. Ongoing input from youth and families enables Network centers to continually improve quality of information and services related to child trauma and its treatment.

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4. Including youth and families supports the formation of a movement that works toward increasing public awareness of child traumatic stress and advocacy for better policies and services.

5. Youth and families can be powerful agents for spreading the word about services to others who need help. They can also serve as wonderful mentors and examples to their peers.

Trauma often has the effect of silencing its survivors. Some may avoid discussing anything that reminds them of the trauma. Having come through unspeakable events, trauma survivors may feel unable to speak about the experience. One goal of trauma treatment is to restore the survivors' voices, so that they can speak not only of what has happened in a way that gives meaning to the events, but also can speak up on behalf of their own interests. Having a voice in shaping treatment decisions can be therapeutic, as it helps survivors regain their voices. They begin to feel less helpless and vulnerable, and more competent and in control.

Following treatment, trauma survivors may find meaning in sharing with others what they have learned from their experience, and in speaking up with and for others. By working with trauma service organizations and providers, the survivors help restore the social order—the sense of safety and protection—that traumatic events undermine. Some of an agency's strongest advocates can be adults who were traumatized themselves as children; caregivers who remember the toll that childhood trauma took on the lives of someone in their family; and youth who spent their childhoods in foster care and wish to improve the lives of other children enduring similar experiences. By involving and educating the entire family about traumatic stress and seeking solutions to manage its impact, providers can involve families in contributing to the long-term solution.

"At the Cullen Center, we've also used our Family Perspective Survey (a satisfaction-with-services survey) to help recruit families to participate in focus groups and program development. This recruitment takes place only with clients who have completed services and their families. However, I think it is important to ask families about their readiness, rather than assuming that those still in treatment aren't ready and that those who have completed treatment are ready. Youth and families will know what they can handle. I don't consider myself 'recovered' and yet I still do a lot of speaking out and telling of my own story, but I am able to do this because I have the right supports in place. There is no rule; it's a case-by-case decision."

— Excerpted from an interview with Cullen Center Coordinator of Research, Advocacy, and Community Programming Rachel Buehrer.

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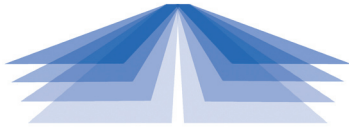
How to Use This Document

Each NCTSN site brings unique strengths and challenges to this initiative, and an assessment of organizational capacity is an important first step. Organizations can begin by: 1) holding meetings with key personnel to identify intended areas of focus; 2) gathering information about perceived strengths and weaknesses; 3) determining who will complete the *Pathways to Partnerships* assessments and how information will be summarized; 4) focusing on what resources the organization has for meeting its goals; and 5) making an action plan in response to information learned through the assessments (Ahsan, & Cramer, 1998). The action plan can draw and expand from the objectives and activities provided in the *Pathways to Partnerships* document.

Self-Assessment Tools

In the following pages are two self-assessment tools, one that pertains to clinical practice and one that pertains to organizational/program practices.

The self-assessment tools are designed to generate discussion and identify target areas for further action. Self-assessment tools can be completed by individual staff or by teams. We suggest that group discussion follow the completion of each self-assessment to determine next steps. Next steps can be small tests of change. Every organization has a different set of structure and personnel variables, so there is no perfect score, nor are there changes appropriate for all Network centers.

Clinical Self-Assessment Tool. Integrating youth and families into NCTSN activities also requires changes in how clinicians work, and in how they conceptualize their partnerships with youth and families. We developed this self-assessment tool based on the *Clinician Guidelines for Core Components of Family-Based Assessment and Intervention for Child and Family Traumatic Stress* by William Saltzman, PhD, and Patricia Lester, MD. The associated objectives and activities are also based on this document as well as on input from the Partnering with Youth and Families Collaborative Group. Using the tool and the suggested activities that follow will aid Network centers in creating a plan to enhance youth and family involvement at the clinical/treatment level.

Organizational/Program Self-Assessment Tool. NCTSN used a self-assessment tool, *How Are We Doing? A Program Self-Assessment Toolkit for the Family Support Field,* developed by Ahsan and Cramer (1998), to measure youth and family involvement in agency planning and governance. Using this tool, which covers organizational level involvement, and the suggested activities outlined thereafter, centers can begin to develop a plan for strengthening youth and family involvement in their program.

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Goals and Activities. Following each of the self-assessment tools are several goals, along with objectives and suggested activities to meet the goals. The objectives and suggested activities were, for the most part, generated in discussions at the 2005 meeting in Virginia and in subsequent discussions with the Partnering with Youth and Families Collaborative Group. Many of the activities for the clinical objectives came from an earlier NCTSN Family Engagement Collaborative Group. The suggested activities are meant as jumping-off points for changes in your Network center; and we encourage you to let us know which ones are appropriate for your use and to send us your own suggestions for activities.

Building Your Plan for Change

Build on your strengths as you assess your organization and create your plan. How has your organization already successfully engaged youth and families? To keep the process manageable, start with implementing only a few activities. Over time, as your organization sees the positive impact of involving youth and families, the amount and depth of involvement will likely increase.

For the clinical self-assessment, you may wish to create a team composed of clinicians and administrators. If clinical practices vary among your staff, you may want individual clinicians to complete the assessment and then come together as a group to discuss their answers. Changing clinical practices may even require implementing new forms of organizational support for those changes.

For the organizational/program self-assessment, we suggest bringing together a team whose members have varied perspectives. Your team might include board members, program administrators, clinicians, paraprofessionals, and administrative staff. Also consider including family members and youth in the assessment process, as their viewpoints are critical. Do administrators and clinicians assess your current strengths and weaknesses in youth and family involvement in the same ways that family members do? A disconnect between the two might suggest a need to enter into further dialogue with the families served.

Developing Goals

Next you will probably want to develop goals. We have set ten goals for improving involvement of youth and families in the NCTSN: six pertain to the clinical level of change and four to the organizational/program level. For each goal, we have also developed objectives. For each objective, we have developed a list of suggested activities that can contribute to meeting the goal. We based these activities on a brainstorming event conducted at the October 2005 Family and Consumer Engagement Summit meeting. NCTSN centers and others are currently using some of these activities.

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Using Suggestions for Activities

✦ Decide which of the goals and objectives to focus on first, and then develop a list of activities that might be implemented at your organization. It is probably realistic to work on only a few key activities at once. To prioritize objectives and activities, you might want to use the same team that completed the self-assessment, or you might survey your staff.

✦ Create a timeline for implementing the highest priority objectives and activities. Without a timeline, activities can easily slide. Consider setting smaller milestones within the larger deadlines.

✦ Assess your resources for carrying out the plan. Seek help from family agencies and organizations in your community that might already be integrating consumers into their operations.

✦ Begin small, but begin. The most important actions are to make youth and family involvement a priority; to achieve buy-in from administrators, clinicians, and others in the organization; and to keep moving forward.

✦ In future versions of this document, we hope to be able to share the action plans created by Network centers with others.
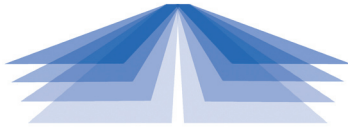
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Self-Assessment Clinical/Treatment Tool

Instructions: Each statement below concerns trauma assessment and treatment. Note the scale of 1 to 5 (1=Always, 2=Frequently, 3=Sometimes, 4=Rarely, and 5=Never), plus N/A. Assign a number to each statement that best reflects the level of work your organization does with children and families experiencing trauma.

After completing your self-assessment, you may wish to focus first on those areas you rated on the lower end of the scale.

Acknowledgment	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We acknowledge that family members are essential to supporting the child's recovery from traumatic events.						
We ask about a family's cultural norms as they relate to seeking outside help.						
We identify caregivers as experts on their child's functioning and well-being.						
We show respect for a caregiver's readiness to discuss the child's and the family's history of trauma.						
We ask about caregiver and child concerns regarding child and family functioning.						
We identify and acknowledge the level of the child's and the family's distress related to the trauma.						
We identify family strengths and challenges with regard to supporting both the child's and family's recovery.						
We identify a family's cultural norms as they relate to gender roles in the family and in the larger community.						
We acknowledge when the family has needs that cannot be met by the center.						
We listen to the youth's and the family's concerns with a nonjudgmental approach, and acknowledge their strengths.						

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Safety	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We assess violence in both the home and the community.						
We discuss the child's and the family's feelings of safety regarding participation in trauma-focused treatment.						
We address a safety plan with the child and family.						
We create ongoing plans regarding continued safety concerns in the home and/or in the community.						

Partnership	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We share assessment results with the child and family, and discuss treatment approaches and goals as a team.						
We have regular check-ins with the child and/or family to assure that there is agreement about where treatment is focused.						
We take the time to make sure that the child and family feel listened to and understood.						
We give the child and family information about all the services available.						
We share with the family ways that they can help support their child.						
We seek information regarding whether the child and family are satisfied with treatment.						
We use the results of the satisfaction surveys to modify care when appropriate.						

Peer-to-Peer Support	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We offer family members resources from other families who have previously received services.						
We offer a caregiver support group for family members.						
We offer a peer support group for children and youth.						

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Hope	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We explain how the services are helpful, and how other children and families have been helped by the trauma-focused treatment provided.						
We explore feelings with the child and family when the treatment does not appear to be "working."						
We identify and explore how the child and family's ethnic or cultural background make meaning of the trauma.						
We promote the view that caregivers can exert a positive influence on their child's functioning and adaptation.						

Psychoeducation	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We explain the benefits, risks, and treatment techniques that we use in our setting.						
We inform families about their right to request a different clinician.						
We explain how youth and family will be able to tell that the treatment is helping.						
We inform families about what their insurance will cover with regard to changing clinicians.						
We make sure the child and family understand the links between trauma reminders and the child's emotional or behavioral problems.						

Trauma Assessment & Treatment	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We do an initial screening of the child at the beginning of treatment.						
We use assessment tools that are developmentally informed.						
We identify cultural and ethnic beliefs that influence the treatment process.						
We collect the child's trauma history with a structured interview or measure.						
We assess the clinical process on an ongoing basis throughout treatment.						
We ensure that treatment strategies continue to be based on input from families.						

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Trauma Assessment & Treatment	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We adjust treatment strategies as different needs arise with the child and family.						
We use interventions that are based on evidence regarding trauma.						
We focus sessions on enhancing coping skills of the child and the caregiver.						
We assist caregivers with managing their distress during treatment.						
We develop a collaborative plan for ending treatment together with the child and family.						
We discuss with families resources for any future concerns or issues.						
We know through measurement whether children and families get better.						

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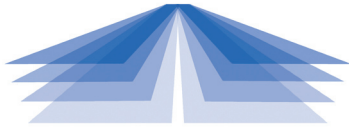
Clinical/Treatment Goals

1. Providers work with youth and families to address safety issues and concerns.

2. Treatment providers collaborate with youth and families to define needs and issues to be addressed in treatment and in ending treatment.

3. Treatment providers acknowledge the importance of partnering with youth and families to address barriers to youth and families' engagement in and completion of treatment.

4. During both the assessment and treatment processes, providers address and respect the role culture plays in youth and families' behaviors related to seeking help.

5. Providers use appropriate and effective trauma assessment and treatment practices.

6. Youth, families, and providers report that the youth and families are doing better.

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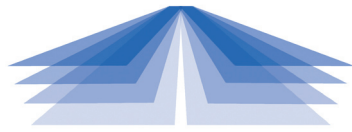
Clinical/Treatment Objectives and Activities

1. **Providers work with youth and families to address safety issues and concerns.**

   Objective A: Ensure that safety planning is an integral part of sessions.
   Activities include:
   - Acknowledge youth and family's needs for safety and protection.
   - Evaluate youth and family's current exposure to traumatic stressors (including evaluation of safety issues during home visits).
   - Provide access to booster sessions to help the youth and family cope with possible additional trauma exposure or reminders.
   - Refer youth/family to additional services if needed.

2. **Treatment providers collaborate with youth and families to define needs and issues to be addressed in treatment and in ending treatment.**

   Objective A: Youth and families are actively involved in identifying treatment goals.
   Activities include:
   - During the intake process in the first session, take time to help the youth and family tell their story about why they have come.
   - Explain the therapy process and anticipated outcomes in clear terms without professional jargon.
   - Engage youth and families in setting priorities for treatment.
   - Recognize and acknowledge youth and families as experts on their own experiences as well as on their needs and behaviors.
   - Ask youth and families how they might gauge the success of treatment. Explain the rationale for the measures of success you will use. Attempt to reach agreement on treatment priorities and outcomes.

Objective B: Youth and families are actively involved in treatment choice.

Activities include:

✦ Introduce service options (such as case management, mentoring, support groups, in-home services).

✦ Inform youth and families about therapy choices; provide full disclosure on treatments' strengths and weaknesses; and refer out for those treatments not offered at the center.

✦ Give youth and families information about providers' backgrounds, professional training, and expertise.

3. Treatment providers acknowledge the importance of partnering with youth and families to address barriers to youth and families' engagement in and completion of treatment.

Objective A: Families attend child's therapy sessions with support and leadership from agency staff.

Activities include:

✦ Acknowledge the family's role as decision-maker for the family.

✦ Acknowledge the family's stress and praise the family for getting help for the youth.

✦ Identify and problem-solve around barriers to help-seeking such as stigma and previous negative experiences with helping professionals.

✦ Allow for flexibility in scheduling of visits (including scheduling a second appointment sooner than the following week) and in length of sessions.

✦ Allow for flexibility with appointment time and treatment session locations.

✦ Focus on immediate, practical concerns (e.g., food, shelter, medical treatment, changing schools).

✦ Use phone engagement techniques prior to the first visit and throughout treatment.

✦ Address the issue of families' being advised by others not to seek professional help.

Objective B: Provider supports the family in making sure the youth attends sessions.

Activities include:

✦ Assist the family in negotiating with other systems to allow youth to attend appointments.

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◆ Assist the family in soliciting help from close friends and other family members to support attendance of youth and family in treatment (e.g., child care, transportation).

◆ Reinforce to the family the importance of youth attending treatment throughout the duration of treatment.

◆ Offer attendance incentives to both youth and families (e.g., food, donated gift certificates, graduation certificate/event).

4. **During both the assessment and treatment processes, providers address and respect the role culture plays in youth and families' behaviors related to seeking help.**

Objective A: Good therapeutic alliance is established and measured through an appropriate tool.

Activities include:

◆ Invite observations and feedback from youth and family on an ongoing basis.

◆ Create consumer satisfaction surveys that include questions about the level of comfort youth and families have when talking with the therapist, as well as questions about trusting the therapist.

◆ Avoid using terms such as *treatment resistant* and *noncompliant.* Avoid giving negative attributes to youth and families.

◆ Periodically during treatment, educate youth and families on their rights and options.

◆ Fully disclose to youth and families all mandated reporting, confidentiality issues, and exceptions.

◆ Support the youth's and the family's self-care efforts, especially those related to managing stress.

◆ Address the youth's and the family's fear of being judged or criticized for revealing information during sessions.

Objective B: Providers attempt to understand and respect the role culture plays in seeking help, understanding information, and relating to the provider and to other family members.

Activities include:

◆ Explore differences in race or ethnicity between the youth/family and the clinician.

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- ✦ Educate immigrant youth and families about the systems they will be involved in.

- ✦ Provide translators for youth and families who don't speak English. Make sure that youth and family have confidence in the accuracy of the information being translated.

- ✦ Explore how the youth and family's culture views home visits.

- ✦ Provide treatment in the language preferred by the youth and family.

- ✦ Ask youth and families how trauma would be treated in their indigenous culture. Explore how to incorporate some of those traditional approaches into treatment.

- ✦ Explore how spirituality can affect treatment for the youth and family.

5. Providers use appropriate and effective trauma assessment and treatment practices.

Objective A: Treatment plans reflect the use of evidence-based family interventions and practices.

Activities include:

- ✦ Participate in training and supervision in evidence-based interventions.

- ✦ Educate youth and family about trauma and evidence-based practices.

- ✦ Engage the youth and family in identifying and discussing trauma triggers, trauma reminders, and avoidance.

- ✦ Teach youth and family which cognitive reframing and behavioral responses are most effective.

- ✦ Give direct support and information to the family specific to managing the special needs and behaviors of their youth.

- ✦ Help the family understand the impact their own trauma exposures may have on their parenting behavior as well as on their reactions to the current traumatic event.

- ✦ Share with the family developmentally based information on trauma symptoms, reactions, and responses.

- ✦ Make sure the youth and family understand the links between trauma reminders and the youth's emotional and behavioral problems.

- ✦ Emphasize positive parenting skills including behavioral management.

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- ✦ Address and correct maladaptive cognitions of youth and families.

- ✦ Facilitate the creation of a conjoint trauma narrative.

Objective B: Standardized trauma-focused assessment instruments are used.

Activities include:

- ✦ Screen family members for their own trauma exposures/histories.

- ✦ Explain the assessment process and instruments to the youth and family, share assessment results, and check whether the assessment makes sense to the youth and family.

- ✦ Select assessment measures that have good psychometric properties, are clinically sound, and are appropriate for the youth's developmental profile.

- ✦ Assess youth using multiple responders (e.g., teachers, caregivers, child).

- ✦ Assess for functional impairments as well as symptoms.

- ✦ Reassess youth and family at completion of treatment.

Objective C: Assessments and treatment approaches acknowledge the strengths, challenges, and preferences of the youth and family.

Activities include:

- ✦ Identify the youth and family's outside supports.

- ✦ Identify the vulnerabilities the family faces in addition to trauma (e.g., unemployment, mental illness, substance abuse, isolation, poverty).

- ✦ Assess how the level of family members' distress and support are affecting the youth's recovery.

- ✦ Develop a clear understanding of how the youth and family functioned in multiple domains prior to the trauma.

- ✦ Help the family understand how they can be a positive influence on their youth, and how that will improve the youth's functioning and adaptation.

- ✦ Highlight resilient responses of youth and other family members.

- ✦ Identify and praise positive coping by the youth and family.

- ✦ Identify and address trauma/loss related to the adversities the family is facing (e.g., change in living arrangement, change of school, loss of income source).

6. Youth, families, and providers report that the youth and families are doing better.

Objective A: Increase the number of youth and families completing treatment. Leadership and agency mission should support staff to undertake the activities listed below.

Activities include:

✦ Approach youth and families who have already completed treatment about serving as mentors and encouraging youth and families to complete treatment.

✦ Provide alternatives when the family's insurance coverage is exhausted for the year.

✦ Revisit goals on a regular basis.

✦ Give regular progress reports to the youth and family. Seek feedback from the youth and family on their commitment to treatment.

✦ Be readily available to the youth and family, including by phone, throughout treatment.
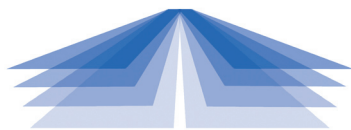
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Self-Assessment
Organizational/Program Tool

Instructions: Rate each of the following statements as it pertains to youth and family involvement in your organization. Note the scale of 1 to 5 (1=Always, 2=Frequently, 3=Sometimes, 4=Rarely, and 5=Never), plus N/A. Assign a number to each statement that best reflects the level of work your organization does with children and families experiencing trauma.

After completing your self-assessment, you may wish to focus first on those areas you rated on the lower end of the scale.

Supporting Involvement	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We compensate the family and community participants for their time, reimburse them for their expenses, and provide and/or arrange for their transportation to appointments and agency meetings and events.						
We provide or ensure the availability of high-quality, flexible child care that meets the needs of family members, allowing them to participate in agency meetings and other events.						
We create opportunities for youth and families to engage in peer networking and support with each other and with staff.						
We measure our program's success for evaluation and monitoring in part on the quality of youth and family involvement (e.g., intensity and meaningfulness of involvement).						
We devote resources, such as money and staff time, to youth and family involvement.						

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Communicating Clearly & Setting Goals	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We ask for regular feedback from youth and families about how welcome and comfortable they feel.						
We make sure that the information we share with youth and families is free of jargon and can be easily understood.						
We provide translations of written and spoken information to youth and families in their native language.						
We provide relevant information to youth and family participants in a timely manner so that they can prepare for meetings and other events.						
We collaborate with the family in setting specific and attainable goals for involving them in policy-making and decision-making aspects of our initiative.						
We set clear roles and expectations for participation by youth and families.						

Achieving Appropriate Representation & Recruiting Diversity	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We recruit and engage families who have not typically been involved in decision-making or other kinds of family involvement.						
We make sure that the youth and families involved are representative of the larger community in terms of race, culture, language, income, and education.						
We have strategies for promoting both youth and family involvement, so that they have a stake and a voice in areas important to them.						
Our initiative involves a variety of community members including representatives from the business, civic, education, and religious sectors.						
We are successfully involving males (fathers, grandfathers).						

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Going Beyond Token Involvement	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We have at least as many family members as professionals on decision-making bodies.						
We give full voting rights to youth and families on decision-making bodies.						
We enable youth and families to select their own representatives for decision-making bodies.						
We give youth and families an equal voice in the most important decisions we make including hiring staff, setting policy directions, and deciding how to spend money.						
We offer training sessions for professionals and youth and families, which are co-facilitated by participants and staff, on how to work collaboratively with each other.						

Participation Beyond Meetings	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We invite youth and families to participate in the ongoing evaluation and assessment of our initiative.						
We provide or make available training for youth and families on leadership and governance.						
We encourage and support youth and family involvement in community advocacy and leadership efforts beyond our initiative.						

Flexibility & Responsiveness	Always 1	Frequently 2	Sometimes 3	Rarely 4	Never 5	N/A 6
We offer opportunities for involvement at times and locations that are convenient for youth and families.						
We assure that our initiative responds with action to the concerns of youth and families.						
We use needs assessments that have been developed in collaboration with youth and families so that we can best address issues that are important to the community.						
We have a flexible involvement policy that allows youth and families to determine the level and intensity of their involvement.						

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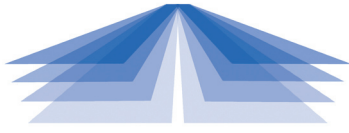
Organizational/Program Goals

1. Youth and families participate as partners at all levels of program design, development, and implementation. They are integral partners in the delivery and evaluation of services.

2. Youth and families help make decisions about the direction of the organization and are considered an integral part of program governance.

3. Youth and families take part in outreach activities, thereby raising awareness about child trauma services.

4. Programs addressing youth and families' involvement initiatives are culturally competent.

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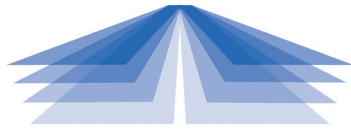
1. **Youth and families participate as partners at all levels of program design, development, and implementation. They are integral partners in the delivery and evaluation of services.**

   Objective A: Increased numbers of youth and families actively participate as partners in program design, development, and implementation.

   Activities include:

   ✦ Provide a menu of ways for youth and families to participate in program activities (e.g., review materials, review proposed goals and activities, do one-on-one outreach).

   ✦ Develop a tool or process to recruit, identify, and assess youth and families who are ready and capable of serving in this capacity in the organization.

      ✧ Ensure that consumer satisfaction surveys include a question asking, "Would you like to discuss a role with the organization such as . . . ?"

      ✧ Offer options for participation (e.g., mentoring, volunteering, co-training, reviewing of materials, serving as a buddy in the buddy system, sharing the trauma narrative, public speaking about child trauma issues). Explain about the training and financial support available for participation.

   ✦ Create a mechanism (such as a standing committee) for youth and families to contribute to the development and review of materials (e.g., brochures and newsletters) as well as to contribute to the review of information, evidence, evaluations of various programs, and clinical options).

   Objective B: Supports for youth and family participation are provided.

   Activities include:

   ✦ Provide adequate training to youth and families to participate in organization activities.

   ✦ Create incentives to encourage youth's participation in programs (e.g., staff may provide college references or job references; involvement may count toward community service hours).

   ✦ Provide formal recognition for the accomplishments of youth and families in the organization.

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✦ Create policies that allow budgetary funds to be used to provide stipends to support youth and family participation. Options include budget line items and flex funds.

✦ Assess family needs to maximize participation and provide concrete assistance that promotes youth and family participation (e.g., transportation, stipends, translators, child care, flexible appointment times and places).

✦ Cultivate donors to sponsor youth and family involvement (e.g., scholarship programs).

✦ Create a special support group for peer-to-peer mentors to share information and experience. The group could select delegates for leadership roles in the organization.

Objective C: Program evaluation includes feedback from participants.

Activities include:

✦ Conduct focus groups of youth and families who have participated in programs. Give families who participate an opportunity to assess the program and to make recommendations for improvement.

✦ Develop a mechanism for documenting and analyzing the effectiveness of youth and family involvement in the organization's activities.

✦ Create a standing committee that includes youth and families to review new interventions, the effectiveness of existing programs and interventions, and other programmatic decisions. Create a transparent process for decision-making in the committee by documenting conflicts and resolutions.

✦ Survey youth and families in treatment, as well as those who have completed treatment, about their experience with providers.

Objective D: Youth and families are provided with coaching, mentoring, and preparation on how to actively participate and co-lead meetings. Treatment providers empower youth and families to be equal partners in team meetings.

Activities include:

✦ Prepare youth and families for meetings ahead of time by providing coaching and training, and using various techniques such as role-playing.

✦ Encourage youth and families to come to meetings by offering mentoring and support. Review outcomes from meetings and any behaviors from meetings that youth and families have questions about.

✦ Avoid tokenism—make sure that multiple youth and families attend and participate.

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Objective E: Youth and families are more involved in training offered by the organization.

Activities include:

✦ Develop a mechanism to recruit youth and families for trainings offered by the organization.

✦ Develop training curriculum materials with youth and families.

✦ Develop coaching, mentoring, media training, and ongoing support programs for training youth and families, and include a discussion of risks and benefits.

✦ Submit proposals for training conferences that include sessions co-led by youth/families and providers.

2. **Youth and families help make decisions about the direction of the organization and are considered an integral part of program governance.**

Objective A: Organizations provide staff resources to support and maintain youth and family involvement.

Activities include:

✦ Create an organizational policy and protocol that supports the hiring of youth (if appropriate) and family members.

✦ Consider using youth and families in staff roles to increase youth and family involvement.

✦ Define staff roles and responsibilities to include recruiting, training, and supporting of youth and families.

✦ Recruit mentors and support group leaders, translators, and family advocates.

✦ Have youth and families help train clinicians.

✦ Include youth and families in the staff interview and hiring process.

✦ Include youth and families as partners to train staff on preferred practices for making home visits (if applicable).

3. **Youth and families take part in outreach activities, thereby raising awareness about child trauma services.**

    Objective A: Routinely conduct outreach activities that create greater awareness of and use of services.

    Activities include:

    ✦ Create (in partnership with youth and families) a variety of materials that can be disseminated in waiting rooms and community locations. Consider information such as "Tips on Trauma" and "What is Trauma?"

    ✦ Involve youth and families in exploring use of free communication and publicity methods (e.g., public service announcements, newspapers, radio, public access television).

    ✦ Involve youth and families in conducting regular information sessions for community partner agencies about trauma and services available for youth and families.

4. **Programs addressing youth and families' involvement initiatives are culturally competent.**

    Objective A: Participants in the youth and family involvement program represent the diversity in the community.

    Activities include:

    ✦ Make sure materials are translated into languages that are spoken in the community.

    ✦ Recruit and train youth and families who represent populations the agency is trying to reach (e.g., fathers, non-English speakers, lesbian and gay youth).

    ✦ Utilize the NCTSN Cultural Competence Guidelines to inform and affect work with various cultural populations.

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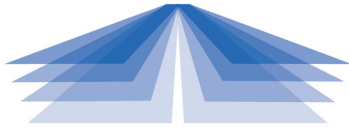
Next Steps

Evaluation. The Partnering with Youth and Families Collaborative Group is offering a mechanism by which sites can offer feedback about the effectiveness of this document. Once you've had a chance to implement the self-assessments and work with some of the suggested activities, please give us your feedback by completing the survey in Appendix C: Evaluating This Document.

After we receive your feedback, we will revise this document and distribute it throughout the NCTSN.

Assistance, Additional Resources, and Training. The Collaborative Group can provide technical assistance in using this document as well as offer additional suggestions and resources about how to involve youth and families in your work.

The Collaborative Group will be developing a technical assistance toolkit, which will include more models, examples, and vignettes on how to partner effectively with youth and families. If you'd like to share a vignette or a process that you've used in your organization, please contact your liaison.

The Collaborative Group hopes to plan a training event for interested NCTSN sites on how to effectively and respectfully partner with youth and families in all aspects of trauma work.

Contacting the Collaborative Group. For further information or if you are interested in joining the Collaborative Group, contact Vikki Rompala, the current co-chair, at vrompala@larabida.org.

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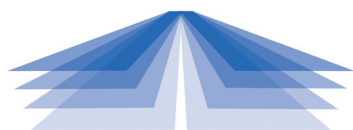
References

1. **Ahsan, N., & Cramer, L.** (1998). *How Are We Doing? A Program Self-Assessment Toolkit for the Family Support Field.* Chicago: Family Resource Coalition of America.

2. **Armstrong, M. L., Korba, A. M., & Emard, R.** (1995). Of mutual benefit: The reciprocal relationship between consumer volunteers and the clients they serve. *Psychiatric Rehabilitation Journal, 19*(2), 45-49.

3. **Brannan, A. M.** (2003). Ensuring effective mental heath treatment in real-world settings and the critical role of the family. *Journal of Child and Family Studies, 12,* 1-10.

4. **Chamberlin, J.** (1995). Rehabilitating ourselves: The psychiatric survivor movement. *International Journal of Mental Health, 24,* 39-46.

5. **Checkoway, B., & Richards-Schuster, K.** (2003). Youth participation in community evaluation research. *American Journal of Evaluation, 24,* 21-33.

6. **Chinman, M. J., Weingarten, R., Stayner, D., & Davidson, L.** (2001). Chronicity reconsidered: Improving person-environment fit through a consumer-run service. *Community Mental Health Journal, 37,* 215-229.

7. **Cohen, J. A., Deblinger, E., Mannarino, A. P., & Steer, R. A.** (2004). A multi-site randomized control trial for sexually abused children with PTSD symptoms. *Journal of the American Academy of Child & Adolescent Psychiatry, 43,* 393-402.

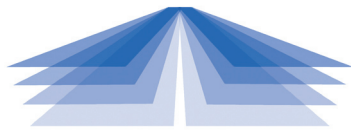8. **Curtis, J. E., & Singh, N. N.** (1996). Family involvement and empowerment in mental health service provision for children with emotional and behavioral disorders. *Journal of Child and Family Studies, 5,* 503-517.

9. **Davidson, L., Haglund, K. E., Stayner, D. A., Rakfeldt, J., Chinman, M. J., & Tebes, J. K.** (2001). "It was just realizing . . . that life isn't one big horror": A qualitative study of supported socialization. *Psychiatric Rehabilitation Journal, 24,* 275-292.

10. **Elling, R., Herman, S., Hulleza, C., Jurkiewicz, T., Lobb, C., & Thompson, L.** (1997). Pathways to family empowerment: Effects of family-centered delivery of early intervention services. *Exceptional Children, 64,* 99-113.

11. **Fallot, R. D., & Harris, M.** (Eds.). (2001). *Using Trauma Theory to Design Service Systems: New Directions for Mental Health Services.* San Francisco: Jossey-Bass.

12. **Federation of Families for Children's Mental Health & Keys for Networking, Inc.** (2000). *Blamed and Ashamed: The Treatment Experiences of Youth with Co-occurring Substance Abuse and Mental Health Disorders and Their Families.* Alexandria, VA: Federation of Families for Children's Mental Health. Retrieved February 10, 2008, from http://download.ncadi. samhsa.gov/ken/pdf/KEN02-0129/KEN02-0129.pdf.

13. **Frese, F. J.** (1998). Advocacy, recovery, and the challenges of consumerism for schizophrenia. *Psychiatric Clinics of North America, 21*(1), 233-249.

14. **George, A. & Hancock, J.** (1993). Reducing pediatric burn pain with parent participation. *Journal of Burn Care and Rehabilitation, 14*(1), 104-107.

40   Pathways to Partnerships with Youth and Families
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15. **Hodas, G.** (2006). Responding to childhood trauma: The promise and practice of trauma informed care. Retrieved February 10, 2008, from http://www.nasmhpd.org/general_files/publications/ntac_pubs/Responding%20to%20Childhood%20Trauma%20-%20Hodas.pdf.

16. **Jeppson, E., Thomas, J., Markward, A., Kelly, J., Koser, G., & Diehl, D**. (1997). *Making Room at the Table: Fostering Family Involvement in the Planning and Governance of Formal Support Systems*. Chicago: Family Resource Coalition of America.

17. **Kliewer, W., Murrelle, L., Mejia, R., de Torres, Y., & Angold, A.** (2001). Exposure to violence against a family member and internalizing symptoms in Colombian adolescents: The protective effects of family support. *Journal of Consulting and Clinical Psychology, 69*(6), 971-982.

18. **Knitzer, J.** (1993). Children's mental health policy: Challenging the future. *Journal of Emotional and Behavioral Disorders, 1,* 8-16.

19. **Koren, P. E., Paulson, R., Kinney, R, Yatchmonoff, D., Gordon, L., & 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,* 62-172.

20. **Laor, N., Wolmer, L., & Cohen, D.** (2001). Mothers' functioning and children's symptoms 5 years after a SCUD missile attack. *American Journal of Psychiatry, 158,* 1020-1026.

21. **Lefley, H. P.** (1997). Synthesizing the family caregiving studies: Implications for service planning, social policy, and further research. *Family Relations, 46,* 443-450.

22. **McCay, M. M., Hibbert, R., Hoagwood, K., Rodriguez, J., Murray, L., Legerski, J., & Fernandez, D.** (2004). Integrating evidence-based engagement interventions into "real world" child mental health settings. *Brief Treatment and Crisis Intervention 4,* 177-186.

23. **McKay, M. M., Nudelman, R., McCadam, K., & Gonzales, J.** (1996). Evaluating a social work engagement approach to involving inner-city children and their families in mental health care. *Research on Social Work Practice, 6*(4), 462-472.

24. **President's New Freedom Commission on Mental Health.** (2003). *Achieving the Promise: Transforming Mental Health Care in America.* Rockville, MD: President's New Freedom Commission on Mental Health. Retrieved on February 14, 2008, from http://purl.access.gpo.gov/GPO/LPS36928.

25. **Saltzman, W., & Lester, P.** (2005). *Clinician Guidelines for Core Components of Family-Based Assessment and Intervention for Child and Family Traumatic Stress Family Intervention Working Group.* Unpublished manuscript.

26. **Salzer, M.** (1997). Consumer empowerment in mental health organizations: Concept, benefits and impediments. *Administration and Policy in Mental Health, 24*(5), 425-434.

27. **Salzer, M. S., & Liptzin Shear, S.** (2002). Identifying consumer-provider benefits in evaluations of consumer-driven services. *Psychiatric Rehabilitation Journal, 25,* 281-288.

28. **Solomon, P.** (2004). Peer support/peer provider services: Underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27,* 392-401.

29. **Staudt, M.** (2003) Helping children access and use services: A Review. *Journal of Child and Family Studies, 12,* 49-60.

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30. Substance Abuse and Mental Health Services Administration. (2005). *Transforming mental health care in America: The Federal action agenda–First steps.* Rockville, MD: U.S. Dept. of Health and Human Services, Substance Abuse and Mental Health Services Administration. Retrieved February 14, 2008, http://purl.access.gpo.gov/GPO/LPS80210.

31. U.S. Department of Education. (2004). Individuals with Disabilities Education Act. Retrieved February 10, 2008, from http://idea.ed.gov/.

32. U.S. Department of Health and Human Services. (2006). SAMHSA Action Plan: Mental Health Systems Transformation. Retrieved February 10, 2008, from http://www.samhsa.gov/Matrix/SAP_mh.aspx.

33. U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General—Executive Summary.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

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Appendices

Appendix A. Web Resources

Consumers

1. Consumer-directed (self-directed) care
SAMSHA publication
http://nmhicstore.samhsa.gov/consumersurvivor/publications_sdc.aspx

2. Managed care
Feedback from consumers and family members
http://www.mhanj.org/News/samhsa.htm

Family

1. Family involvement, mental health, consumer empowerment
SAMHSA publication
http://mentalhealth.samhsa.gov/publications/allpubs/
stateresourceguides/florida01.asp

2. Federation of Families for Children's Mental Health
http://www.ffcmh.org

3. U.S. Department of Health & Human Services
Administration for Children & Families
http://www.acf.hhs.gov/index.html

Parents

1. Circle of Parents
Self-help groups led by parents—national network
http://www.circleofparents.org

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Research Organizations

1. American Institutes for Research

Includes education, student assessment, international education, individual and organizational performance, health research and communication, human development, usability design and testing, employment equity, and statistical and research methods.

http://www.air.org

2. Evaluation Research & Development (ERAD)

Evaluation research on children, youth, and families

http://cals-cf.calsnet.arizona.edu/icyf/index.cfm?page=margaret

Technical Assistance/Training of Volunteers

1. Harvard Family Research Project

A Guide to Online Resources on Family Involvement

http://www.gse.harvard.edu/hfrp/projects/fine/resources/guide/guide.html

2. National Mental Health Consumers' Self-Help Clearinghouse

http://www.mhselfhelp.org

Youth

1. American Psychiatric Foundation

Article from *Psychiatric News*—Youth-guided systems of care

http://pn.psychiatryonline.org/cgi/content/full/41/15/9

2. Innovation Center for Community and Youth Development

http://www.theinnovationcenter.org

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Appendix B. Tips for Talking with Youth and Families About Participation

✦ When asking a youth/family member for their help, provide full information about the request up front. Be clear about the time required, the actual work involved, and the available compensation.

✦ Provide a menu of possible ways to become involved.

✦ Provide a mentor (not the youth/family's therapist) who can give support and can help the youth/family member set limits on involvement.

✦ Youth and families who are involved in your organization do not have to be in public roles.

✦ Stigma may influence youth and family's decision about whether to become involved. Interfamilial abuse may limit a family's willingness to talk publicly about what has happened.

✦ If a family member is asked to participate and the response is "maybe," accept the answer and approach them at another time.

✦ Consider building a youth and/or family peer-support network within your organization.

✦ Remember that "meaning-making" is part of the healing process for many individuals.

✦ Remember that a good alliance is key to this process.

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Appendix C. The Cullen Center: An Interview—Partnering with Families to Improve Quality of Care

This interview was conducted in 2007 by Deborah A. Lott, National Center product development consultant, with Kris Buffington, MSW, LISW, the Cullen Center's former project director, and Rachel Buehrer, FLE, the coordinator of research, advocacy, and community programming at the Cullen Center. In it they tell how the Cullen Center has forged partnerships with youth and families to improve quality of care, and offer advice for other NCTSN centers.

How did your partnerships with families begin?

KB: When we established the Cullen Center, we wanted to offer the best possible trauma-focused care. I realized that in order to do that we had to have families and survivors guiding us, leading us so that our actions were in response to their needs. Professionals are only one piece of the puzzle; we miss out when we don't ask, 'What do you think really works? What can we do better?' and listen to what families say. We miss out when we don't regard families as full equal partners in care. Terry Gardner, a very outspoken advocate in Ohio, said to me, 'You really need to go with the philosophy in terms of families—*not about me without me.* No matter what you're doing—direct interventions, planning, evaluating—you don't do it without the involvement of the people who will be most affected by it.' That's changed the way I practice as a clinician.

We're still in the infancy or toddler stage of having really good consumer/survivor involvement in all aspects of what we do, but what may distinguish us is that we are really determined to do this.

RB: One of the things that made me realize how serious we were about partnering with families was when we put our intentions into our mission statement. Then it was obvious that this notion of involving families was an agency-wide priority. The Cullen Center mission is to develop mutually respectful and equal partnerships among consumers, trauma survivors, families, and professionals in order to provide evidence-based and best practice trauma-focused counseling, support, education, and outreach services.

What was the first step toward integrating families into your work?

KB: One of our first steps was to include consumers and survivors on our Advisory Board. The first person who joined us was an author who identified herself as a survivor when we worked together for a local child abuse task force. I met another of our members when she testified about her childhood trauma experiences at a public mental health hearing. At this point, about 35 percent of the board's membership is comprised of family members/survivors, and we're working to expand that.

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How did Rachel come to be so key to the Cullen Center's youth and family initiatives?

RB: In my cover letter when I applied to work at the Cullen Center, I explained my own history as a survivor of child abuse. This was part of what gave me passion to work in this field and part of my motivation for helping other children. I was originally hired to do intakes and coordinate the research evaluation, but as I began attending Advisory Board meetings, and learning how dedicated Kris is to partnering with families, my role has developed further into one of an advocate.

KB: Rachel has often spoken up when she felt that client rights weren't being respected.

RB: For example, when we were asking families to participate in our staff evaluation research, it hit me that we needed to have a way of explaining the purpose of the research to our families in accessible language, and in terms of what they would be asked to do, and how that would benefit trauma survivors across the nation. The tone of the brochure, which we created with families' help, communicates that we see them as equal partners in the study, and as bringing their expertise to making a significant contribution to other people.

KB: From a family perspective survey that Rachel helped design with families, we learned that adolescents in treatment felt that the kind of therapeutic activities we were using in TF-CBT made them feel as if they were being treated like children. They also felt uncomfortable with all the toys and young children's artwork that decorated our offices. We're developing an adolescent focus group to get more feedback on how to improve the treatment and the environment for them.

Some centers are concerned about breaching confidentiality or violating boundaries in asking former clients to remain involved. Do you have any advice?

KB: Many professionals feel uncomfortable engaging current and former clients in partnerships to evaluate, develop, and implement services. For many professionals and organizations this is a new and unknown experience, and the unknown can be a little scary. Very often in our college education and ongoing in our field training experiences, we are not provided with perspectives and practical tools that guide us about how to develop these partnerships. We are often trained to think of the professional and client relationship as hierarchical, and with the perspective that we are the experts and our clients need to defer to our expertise. It is quite a transformation, a very needed transformation, to begin to look at youth and families as experts and equal partners.

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One of the things that helped my organization to move forward, was to tap into the expertise of colleagues and families in other organizations and systems that have a good track record of consumer and professional partnerships. Here in Toledo, we have the Wernert Center, a member of the Ohio Advocates for Mental Health, a site that provides peer-to-peer services. Their members are consumer survivors who've been trained to mentor others in the mental health system. Many of the members of the Wernert Center are quite articulate about their needs and what works for them. The members of the Wernert Center lead the design and implementation of all of their programming and services.

In our community, we also have learned a lot from families of children with developmental and physical disabilities. For example, the Lucas County Early Childhood Collaborative is co-led by parents and professionals. The Lucas County Community Partnership has initiatives led by youth. The Federation for Children's Mental Health has branches nationwide and can serve as a resource. A lot of public organizations, such as our Child Protection Agency, have a requirement for a certain level of consumer participation on their boards and might be able to help identify potential participants. We continue to learn about successful roles and engagement of youth and families as partners from others. Every community has successful partnerships that we can all learn from.

RB: At the Cullen Center, we've also used our Family Perspective Survey (a satisfaction-with-services survey) to help recruit families to participate in focus groups and program development. This recruitment takes place only with clients who have completed services and their families. However, I think it is important to ask families about their readiness, rather than assuming that those still in treatment aren't ready and that those who have completed treatment are ready. Youth and families will know what they can handle. I don't consider myself 'recovered' and yet I still do a lot of speaking out and telling of my own story, but I am able to do this because I have the right supports in place. There is no rule; it's a case-by-case decision.

KB: Participation in program development or other activities doesn't mean that families have to go through reexposure to their trauma. They don't have to tell their own trauma stories; we're clear when we ask for their views on how to better do A or B, that we don't expect them to talk about their own traumatic experiences. If they do share them, we take the time to ask, 'How are you doing with that?'

Are there any steps you take to initiate consumers or prepare them to participate?

KB: You don't just throw people into a meeting on day 1. We begin by developing a mutual mentoring relationship. You take the time to really get to know each other, to state clearly what each of you needs and expects from the other. When you invite the person

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into meetings with others, you process what's going to happen at a meeting before the meeting, and afterward you process what's gone on at the meeting. That kind of supportive, empowering relationship can help in case there are some trauma triggers. It's got to be mutual mentoring, give and take, learning from one another. We also need to remember that it's not only consumers who experience triggers; professionals are also human beings who can experience trauma-related or other types of emotional triggers. It is important in all of our partnerships, committees, and institutions that we create a safe and empowering environment for all of us to do our work.

How have consumers been involved in the Systems Transformation Grant in Ohio?

KB: We've advocated that the Ohio Department of Mental Health's Child Trauma Task Force (part of the State's Transformation Grant process) include more consumers and survivors. We were the first to bring consumers and survivors with us to the Task Force meetings. One of the changes made is that the Ohio Department of Mental Health has agreed that for Phase II of the Task Force, each work group will be co-led by one consumer and one professional, and we will have a one- or two-day training for leaders of the work groups in how to set up a safe, respectful, appropriate environment.

RB: The state trauma forums were originally conceived as professionals educating policymakers about the impact of trauma on children's mental health. But at each of the forums, we've added a focus group luncheon, open only to consumers and survivors and led by one of their peers. We developed a survey to get an idea of what they thought were the weaknesses and strengths of the mental health system, and we'll be writing a report of everything we learned from all these wonderful survivors across the state of Ohio.

KB: We asked the survivors at the focus groups if they made a connection them-selves between their current mental health difficulties and the traumas they endured as children, and if the system recognized that relationship. In the Columbus group, a woman said, 'I've been through most of the traumas you talked about, and nobody ever told me it had anything to do with my depression and suicidal feelings.' We learned that a lot of adults who were sexually abused as children, who witnessed domestic violence, even had a parent murdered, never understood the connection to their current distress. They just thought they were crazy. And we were able to tell them there were effective treatments for them.

How do clinicians' attitudes change when families become equal partners?

KB: When a client and therapist disagree, it is not uncommon for a clinician to say, 'It's client resistance,' or 'The client is unhappy because I confronted them on something they don't want to face.' If you look at your client as your partner, the way you give

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feedback and address issues is different. We're putting resources towards consumer-oriented training for our staff because some clinicians know how to empower their clients, and others need help in shifting their attitudes.

RB: Another example might be a family that's going through a really rough time where there's a lot of chaos in their lives and they miss several appointments in a row. A clinician might conclude, 'Oh well, they don't want to come; I'm going to serve someone else who gets here.' I understand where the clinician's attitude is coming from, we only have so many available slots; but sometimes all it takes to keep a family in treatment is a clinician calling and saying, 'Why did you miss our last session? Is there anything I can do to help you work around the barriers that are keeping you from getting here?' Sometimes the difference can be as simple as your tone of voice when speaking to a client on the phone.

And peer support might be an important way to help some families in treatment. At last year's ANM [All Network Meeting], Judy Cohen (Judith Cohen, MD, medical director, Center for Traumatic Stress in Children & Adolescents, Allegheny General Hospital) brought a mother and adolescent daughter who'd received TF-CBT [Trauma-Focused Cognitive Behavioral Therapy]. And the young woman said that she really wished that when she'd started she'd had someone who had been through the treatment already who could just tell her what to expect. It can be so important when someone is just entering treatment for a peer to say, 'I've been through treatment here, and this is how it helped me, and this is what it's going to be like, and if you're afraid about anything, you can call me.'

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Appendix D. Evaluating This Document

Please give us your feedback about the effectiveness of this document by completing the survey, either online or on hard copy:

Online

Pathways to Partnerships Evaluation Survey

http://www.surveymonkey.com/s.aspx?sm=4ri_2f_2bClMHtlwLX29MSiF2g_3d_3dzs

Hard copy

Please print out the document that follows. Directions for submitting it
(by fax or mail) are on the last page of the evaluation.

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Pathways to Partnerships Evaluation Survey

1. What best describes your role?

◯ Administrator

◯ Mental Health Clinician

◯ Health Care Provider

◯ Family Member

◯ Youth

◯ Other: _____

2. Highest level of education you completed:

◯ High School

◯ Bachelor's

◯ Master's

◯ Doctoral

◯ Other: _____

3. Specialty: _____

4. Years of professional experience working with children and families: _____

5. I have reviewed the materials included in the *Pathways to Partnerships* document:

◯ YES

◯ NO

[Note: If you have not reviewed the materials, please do not complete the survey.]

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For the questions in table format, please circle the number that best reflects your level of agreement with the corresponding statement.

6. Materials	Not Applicable 0	Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5
The materials were of reasonable length.	0	1	2	3	4	5
The materials were well organized.	0	1	2	3	4	5
The materials covered the right amount of subject matter.	0	1	2	3	4	5
The format was easy to read.	0	1	2	3	4	5
The instructions were clear and easy to read.	0	1	2	3	4	5
The information on relevant research was helpful.	0	1	2	3	4	5

7. Specific Components	Not Applicable 0	Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5
The Self-Assessment Clinical/Treatment Tool was helpful.	0	1	2	3	4	5
The Clinical/Treatment goals, objectives, and activities were helpful.	0	1	2	3	4	5
The Self-Assessment Organizational/ Program Tool was helpful.	0	1	2	3	4	5
The Organizational/Program goals, objectives, and activities were helpful.	0	1	2	3	4	5

8. The most useful components of the *Pathways to Partnerships* were:

_____

_____

_____

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_____

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9. Target Audience	Not Applicable 0	Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5
Pathways to Partnerships can be useful for mental health organizations.	0	1	2	3	4	5
The Self-Assessment Clinical/Treatment Tool can be useful for mental health providers.	0	1	2	3	4	5
The Self-Assessment Organizational/ Program Tool can be useful for mental health providers.	0	1	2	3	4	5
The Self-Assessment Organizational/ Program Tool can be useful for administrators.	0	1	2	3	4	5

10. I would suggest the following changes be made to the *Pathways to Partnerships* document to make it more useful for specific target audiences:

_____

_____

_____

_____

_____

11. Overall Rating	Not Applicable 0	Strongly Disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly Agree 5
Pathways to Partnerships has helped raise awareness about ways to involve family and youth in my agency.	0	1	2	3	4	5
Pathways to Partnerships has helped increase youth and family involvement in my agency.	0	1	2	3	4	5
Overall, *Pathways to Partnerships* was user-friendly.	0	1	2	3	4	5

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12. Please specify why you would recommend *Pathways to Partnerships* to colleagues:

_____

_____

_____

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_____

13. Please specify why you would not recommend *Pathways to Partnerships* to colleagues:

_____

_____

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_____

14. Please provide any additional suggestions or feedback that would improve the quality of *Pathways to Partnerships*:

_____

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Thank you for your participation!

Submit your completed survey form to Vikki Rompala, co-leader of the Partnering with Youth and Families Collaborative Group: Fax (773) 374-6223, or mail to Vikki Rompala, 8949 S. Stoney Island, Chicago, IL 60617.

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