BRINGING YOUTH TO THE TABLE IN SYSTEMS OF CARE

As the result of nearly two decades of family advocacy, today, we acknowledge the expertise of the family when it comes to their children’s needs. We must now learn to value and support the youth voice in this same way when it comes to their services and needs. Who better knows the effects of services than those who are receiving them? Who better knows what needs are being met or left unmet by our systems and providers than the youth themselves? We must have youth involvement at every level of children’s mental health service design and delivery, the way that we now require family involvement. Youth must always be at the table.

The Technical Assistance Partnership for Child and Family Mental Health is working with the grantees of the federal Center for Mental Health Services’ Comprehensive Community Mental Health Services for Children and Their Families Program to get youth to the table. The Partnership is working to:

• support, enhance, and disseminate the youth programs that are already up and running in the grant communities;
• help facilitate the implementation of youth programs where they do not yet exist; and
• model, on the national level, the importance of involving youth.

As part of this effort, The Technical Assistance Partnership is hosting a new listserv 1 for youth and adults working with youth in the grant communities, to facilitate the sharing of ideas and information and to help build a national community of youth leaders. The Partnership will also be hosting a youth page on its website (www.air.org/tapartnership) which will contain resources for youth programming, and information on current youth projects in the grant communities. With its youth initiative, the Partnership will emphasize the importance of training adults who are working with youth, and providing youth with the necessary skills and resources to be effective advocates and leaders.

The Partnership recognizes that to respond to the needs of youth, there must be a spectrum of programs available. There must be programs that 1) allow for youth involvement in their services and System of Care; 2) provide opportunities for peer-to-peer learning; and 3) provide youth with training and needed resources. There are already many exciting programs underway in the Comprehensive Community Mental Health Services for Children and Their Families Program grant communities that represent this spectrum.

In King County, Washington, a group of young people ages 13-20 are involved in a program called Health In Action that focuses on how young people share their knowledge gained from their experiences with child-serving agencies in the system of care. The group of youth in Health in Action designed their own vision and mission statements for the project. Their goals are to:

• recruit youth interested in making changes in the system
• increase youth participation in planning and development committees
• develop mentoring for youth in the system
• support youth leadership training and participation
• sustain a community of youth who are leaders and participants in the system

The group is planning a Teen-Health Summit on May 5, 2001. They believe that it will be the first health summit by and for youth.

At the Tennessee Voices for Children initiative in Nashville, Tennessee, youth participate in a Youth Council designed to help them inform and educate themselves about their rights and what services and supports might be available to them, as well as to educate themselves about their rights and what services and supports might be available to them, as well as to educate...
other youth and adults about issues related to youth with mental health needs. This group is currently working on a newsletter and public service announcement, which will be funded in part by a youth empowerment grant won by one of the youth members.

At Nebraska Family Central in Kearney, Nebraska, over 750 youth take part in Youth Congress programs which give youth an opportunity to empower themselves and make positive changes in their schools and communities as well as in their own lives. The diverse group of youth who participate in the program range in age from seven to twelve. Youth selected for the program might not already be leaders, but have leadership potential. The youth provide mutual support, and work together through shared leadership to develop an action plan which they take back to their schools to be implemented with the support of a school counselor.

An adult from one grant community, when asked what the biggest challenge in partnering with youth was, replied “Keeping up! The youth are really ready to work.” The youth in all of our communities are ready to be involved and they have a lot to say. We need to make the commitment to work with youth and involve youth to the fullest if we are to provide effective mental health services for them, and if we are going to help them find the resources and opportunities needed to empower themselves. The question that remains is, If we are going to make this commitment, can we keep up?

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Resources
National Youth Development Information Center: http://www.nydic.org/

National Network for Youth: http://www.NN4Youth.org/

The Milton S. Eisenhower foundation has documented What Works in Youth Development: http://www.eisenhowerfoundation.org/frames/main_frame.html

Also, the Oakland Men’s Project has participated in the development of materials related to violence prevention among youth:


Paul Kivel and Allan Creighton. Making the Peace: A 15-session Violence Prevention Curriculum for Young People.

To contact the Oakland Men’s project: 510-835-2433

Footnote 1 If you are interested in subscribing to this listserv, please send an email to lstevenson@air.org

Lauren Stevenson, Interim Youth Coordinator for the Technical Assistance Partnership for Child and Family Mental Health at the American Institutes for Research. Dedicated to social change work with youth for many years, one of her accomplishments includes co-founding City of Peace Inc. in Washington, DC, an organization for youth that uses the performing arts as a tool for social change.

On Youth Involvement: Education
The most recent reauthorization of the Individuals with Disabilities Education Act (IDEA) requires youth input beginning at age 14. At this time, the Individualized Education Plan (IEP) must contain information regarding a student’s course of study including: planning for transitions regarding employment, postsecondary education or training, independent living, and community/recreational participation. This law strengthens the involvement of youth in the special education system, and should bring about new initiatives to provide students with more information about their strengths, needs, and the resources available to them. Hopefully, there will be self-advocacy training or objectives written into their service plans. With this emphasis occurring in their education program, youth voice can then carry over into individual service plans within the system of care.

We need to examine who the consumers really are—the youth and their families. Without the youth involved, and accepting of the supports, it is only words on paper. Whenever the child is included in their planning meetings, it adds an entirely different dimension to the content. Their voice should be heard above all.

—SANDRA KEENAN, SENIOR EDUCATION ADVISOR

On Youth Involvement: Juvenile Justice
The youth voice is a critical component in planning for and evaluating a system of care. Just as it would be ludicrous to design and evaluate a system of care without family involvement, it would be equally ludicrous not to have youth involvement. Through popular media, talk shows and other venues, many myths are perpetuated about youth attributes and trends. In regards to juvenile delinquency, popular media would have one believe that youth crime is on the rise, yet it is and has been on a significant downward trend. Hearing from youth directly, including youth in community leadership and involving youth as equal partners does much to clarify the strengths and challenges of young people.

—SAM BAUMAN, SENIOR JUVENILE JUSTICE ADVISOR

The Technical Assistance Partnership’s Vision
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Developing A National Agenda

Participants: Brandon Fletcher, Logan Stickney, CeCelia Nation, Janaea Bellows, Kimberly Walker, Kendra Wooden, Mario Benavidez, Terrell Williams, Jill Schalansky, Minal Kode, Stephanie Lane, Angelique Harris

On September 18 and 19, the Surgeon General’s office convened a major national conference on children’s mental health in Washington DC. The purpose of the conference was to engage families, professionals, and scientists in a meaningful dialogue about issues involved in identifying, recognizing, and referring children with mental health challenges for appropriate, evidence-based services. Presenters and participants represented a broad cross-section of mental health stakeholders, including pediatrics, education, juvenile justice, psychology, social work, psychiatry, nursing, and public health. During the conference, breakout sessions identified commonalities across the diverse professional, scientific and family perspectives. Points of agreement and recommendations will be included in a final report on the conference, which will form the basis of a Surgeon General’s Call to Action. Conference organizers invited ten young people from around the country to attend the conference. During the conference, the youth met together to develop a statement that would communicate to the Surgeon General and the conference attendees their knowledge about the services they receive, their needs, and their vision for change in these services. They made points in two areas: obstacles to effective and successful services, and recommendations for overcoming those obstacles. On the last day, when the leaders of all the conference breakout groups reported to the Surgeon General and attendees the results of their groups’ work one of these youth joined them on the stage. CeCelia Nation, a young woman from Alaska delivered the following message (written collectively by the youth) to the conference.

- We are young but need to be treated as human beings and not as a problem or a disorder. We are prototypes, not to be treated as stereotypes.
- School officials and health care providers must be trained to recognize and understand mental illness and its effects on us. The ignorance of the people who don’t understand hurts us. For example: Sometimes teachers who don’t understand that mental illness is not just a behavior problem say that we “choose” to act that way. Some professionals only take (or only have) a few minutes to deliver a diagnosis and “figure the whole thing out.”
- People who are supposed to be helping end up hurting us because they are not prepared and their training (and our lives) have not been made a priority. They contribute to the stigma of mental illness which is perhaps one of the biggest barriers to our service. It hurts even more when a doctor or teacher rejects you than when a peer does.

- Now, I’m sure many of you are thinking that you would never do this to us, or that you are not ignorant in this way, so it’s not your concern. We tell you from our own experience of the professionals out there that are ignorant in this way that it is your concern—because it’s not going to change unless the system changes. And at least we hope that systems change is why you are all here.
- Too often, once we get services (after fighting for them, or hitting a breaking point, or waiting for months), our services are hurried and disrespectful, and they don’t respond to who we are as people, who we are in the context of our families and communities, and who we will one day become. Let’s not forget that a lot of this is about who we will become and whether or not we will be able to dream and achieve our dreams.
- I want to tell a story that one of us shared.

I had two friends—doing something that took them before a judge. One was sentenced to a detention center and one to a rehabilitation center (I don’t know why there was this difference). Six months later they both came back and it was amazing to see the differences. The one who went to the detention center got worse, surlier, and more troublesome. The other one came back transformed and really made a change in his path. Why are we so comfortable devoting resources to locking youth up, and so reluctant to put money toward treatment? Treatment is cost effective and beneficial for all of us. If you lock someone up at a young age with others who are like them (or more hardened) without people to really help them, they will get worse.

- Young people will live up to or down to the expectations of adults, teachers and professionals in their environment. Providers and systems must highly value and expect the best from us.
- We need early prevention, better training for our parents, teachers and professionals, more awareness about mental health so that youth with mental health issues are not stigmatized and thrown away.
- We need systems that can and do work together. Families, schools, and health care providers must collaborate in a collective effort to mobilize and train our communities to work together.
- We need accountability with checks and balances. Services goals should be developed by youth and families—before services are delivered. Services must be evaluated according to how these goals are achieved. For example—has the provider established a connection with us that we can trust? Are we being treated like an ordinary person rather than a disability?
- You can do all the research you want, but if you forget who we are and what we need as people, and if you don’t respond to our needs in the system and in our individual treatment, you will fail, the system will fail, and we will bear the burden as we do now. You must include youth, bring us to the table and when we show up, you must listen. LISTEN.