

## Youth Empowerment and Participation in Mental Health Care

Throughout the 25-year history of the Research and Training Center on Family Support and Children's Mental Health (RTC), our work has focused on supporting parent and caregiver voice in creating family-driven services for families and their children who are or may be affected by mental, emotional or behavioral disorders. Over the last ten years, our commitment to understanding services and systems from the "user" perspective has led us expand our focus.

As an expression of this commitment, the RTC will be hosting the first National Youth Summit on Youth Voice in Mental Health Systems on June 22, 2009. Forty young leaders, ages 15 to 25 will be attending this youth-led event. Participants will collaborate together through activities,

*"I think that youth should be better informed about what kinds of trainings there are out there to get more involved in order to reshape our system."*

*—Youth survey respondent*

conversations, and brainstorming sessions to identify how to improve a variety of youth services in their communities.



Much of the planning for this day has been led by a Youth Advisory Board. (See Strachan article, p.22 ). However, as we were working to select the topics to be addressed during the Summit, we decided that it was important to hear from a broader spectrum of young people. This led us to create an online survey to see what sorts of changes in children's mental health young people with mental health conditions are most eager to see.

A list of potential topics was created, beginning with recommendations drawn from local- and state-level youth summits (or equivalent events). Additional items to be included in the survey were solicited from the Summit's Youth Advisory Board. Then two staff members narrowed down these recommendations to 28 items that were grouped into five categories: (1) *Medication and Treatment*; (2) *Therapy Relationships*; (3) *Youth Advocacy, Peer Support, and Peer-to-Peer Services*; (4) *"Aging Out"/ Tran-*

*sitions*; and, (5) *Specific Settings/Systems*. These items were then edited into more "youth-friendly" language.

Through RTC email lists and viral forwarding of our survey announcement, participants were invited to take our survey. At the outset, respondents were asked to identify themselves as being 26 years old or younger (youth) or over the age of 26 (adults). A total of 73 youth and 193 adults completed the survey.

*"I think that having more peers work with young people is important because when I was younger there were no peer educators and so I had no idea that people could get better."*

*—Youth survey respondent*

### Results

**Youth Responses.** When asked to rate how important each of the topics was to address at our Youth Summit, the most common topics identified by youth as being "a top priority" were *the importance of life skills training for youth (70%), the lack of support for young adults tran-*

sitioning out of social service systems (68%), mental health training for juvenile justice workers (67%), the lack of training and education youth need to get meaningful employment (63%), and the need to fund youth advocacy organizations (62%). The majority of these topics identified as being top priorities pertain to youth opportunities and supports (Table 1).

Although not rated within the top priorities, medication- and treatment-related issues were still a “top priority” for about half of the young people, and several of them made comments to clarify their ratings of these items:

*“The overuse of labels and diagnoses by counselors should be a priority. People don’t understand the long-term effects that follow youth around after being labeled. Some jobs and careers*

*are forever closed to youth who have specific diagnoses.”*

*“I don’t think staff should be calling us by our diagnosis or symptoms. We are not those; we are people.”*

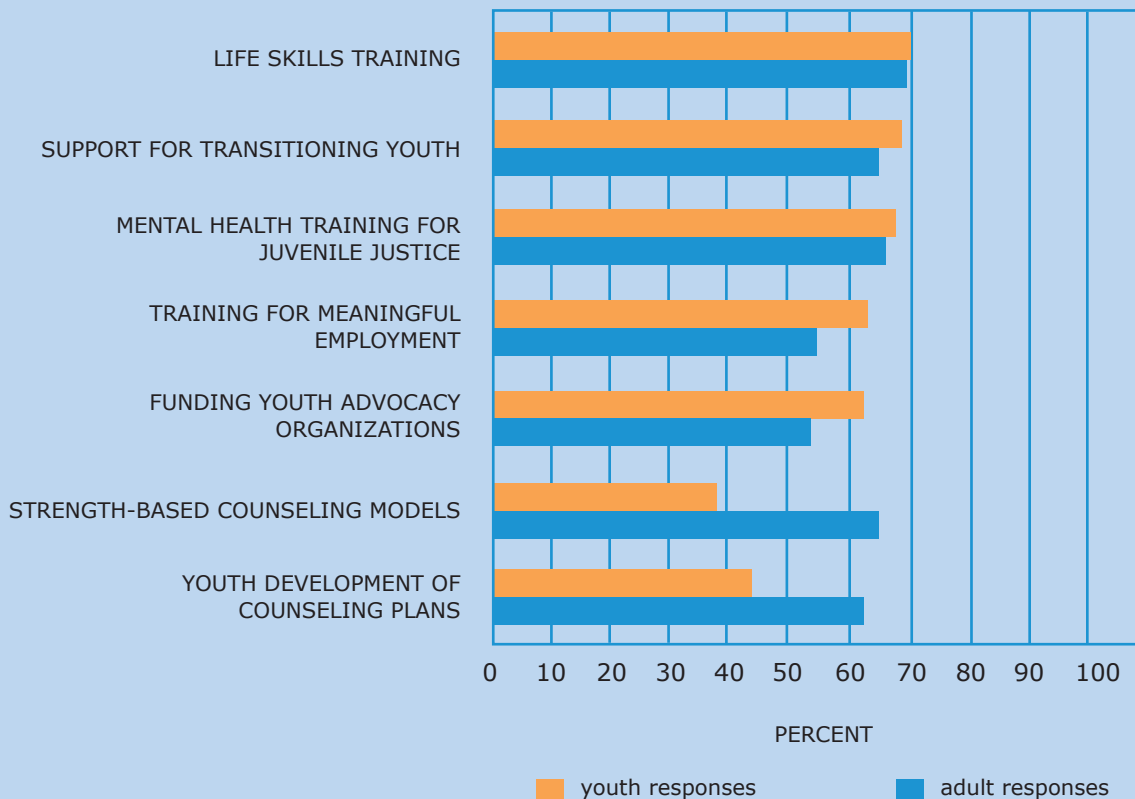
*“Providing youth with healthy, researched alternatives to medication is so important. Taking medication comes with too many labels and brings to the forefront the issue of control. Who is controlling you? How are you being controlled? Often being affected by a mental illness makes control all the more important in life. Alternative treatments such as therapy, massage, herbal/alternative medications, etc. bring that control back into one’s life. These options can always be*

*combined with medication, but they need to be heard and seen as options.”*

**Adult Responses.** The topics most commonly identified as top priorities by adults were the importance of life skills training for youth (69%), mental health training for juvenile justice workers (65%), the lack of support for young adults transitioning out of social service systems (64%), the importance of strength-based counseling models (64%), and the involvement of youth in developing their own counseling plans (62%). In other words, three of the top five priorities identified were the same for youth and adults.

Although there is significant overlap between the top priorities identified by the youth and adults, it is important to note that they are not identical. Among the top priorities that were not the same in the

**TABLE 1. TOP PRIORITIES TO ADDRESS AT THE NATIONAL YOUTH SUMMIT**



two samples, youth were more likely to focus on “real world” experiences—skills to get jobs and support-

*“I think it is important to teach youth the appropriate ways to request a different therapist/therapy and communicate their needs.”*

– Adult survey respondent

ing youth advocacy organizations, whereas adults leaned towards prioritizing issues related to treatment and counseling (strength-based counseling models and youth involvement in counseling). Differences such as these point to the importance of including youth perspectives when working to improve services for young people with mental health conditions.

### Youth Creating Change

This issue of *Focal Point* includes a series of articles that describe how youth are active in shaping mental health services and systems. One article (p. 13) describes two interventions, Achieve My Plan! and My Life, that are designed to support young people in taking a lead role in creating and carrying out plans for their treatment, education, and future. Preliminary

data show that these interventions increase youth empowerment and improve outcomes. A series of articles on peer mentoring (p. 27) highlights how youth can support other youth in achieving their goals as they transition to adulthood. The article on digital storytelling (p. 11) demonstrates how youth voice can be transformed into a powerful multi-media presentation to be used for education, advocacy, and empowerment. In articles by the Youth in Focus team (p. 6) and Youth n Action (p. 18), we hear how youth are involved in research, and as a direct result, have an impact on how communities and organizations respond to the needs of young people. Finally, you can read about how

*“Avenues for youth to give feedback to mental health programs and systems are important.”*

– Adult survey respondent

Youth MOVE National brings young people together to advocate for youth voice and rights in mental health (p. 25). Although most issues of *Focal Point* include articles written by young people, this issue has a greater proportion of articles authored or co-authored by youth.

*“It’s important for caregivers not to doubt the capabilities of the youth they are working with.”*

– Youth survey respondent

While these articles highlight a number of successful and innovative efforts to promote youth voice and youth empowerment, these kinds of approaches are still few and far between. New approaches, and wider implementation of existing approaches, will be needed if we are to transform systems and services so that they will be truly youth guided. Investment in these approaches has the potential to pay large dividends.

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