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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, 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”/Transitions; 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

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

<table>
<thead>
<tr>
<th>Priority</th>
<th>Youth Responses</th>
<th>Adult Responses</th>
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<tbody>
<tr>
<td>Life Skills Training</td>
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<td>Support for Transitioning Youth</td>
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<tr>
<td>Mental Health Training for Juvenile Justice</td>
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<tr>
<td>Training for Meaningful Employment</td>
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<tr>
<td>Funding Youth Advocacy Organizations</td>
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<tr>
<td>Strength-Based Counseling Models</td>
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<tr>
<td>Youth Development of Counseling Plans</td>
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Regional Research Institute for Human Services, Portland State University. This article and others can be found at www.rtic.pdx.edu. For reprint or permission to reproduce articles at no charge, please contact the publications coordinator at 503.725.4175; fax 503.725.4180 or email rtcpubs@pdx.edu.
two samples, youth were more likely to focus on “real world” experiences—skills to get jobs and support-

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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Sacramento’s LGBTQ Youth: Youth-Led Participatory Action Research for Mental Health Justice with Youth In Focus

Youth-led participatory action research (YPAR) provides a way for young people to advocate for themselves and their communities, and for organizations to engage youth in the effort to bring about social and environmental justice. Youth In Focus (YIF), a nonprofit based in northern California, fosters the development of youth, organizations, and communities by supporting Youth-Led Research, Evaluation and Planning (Youth REP). Our work is based on the belief that youth can effectively partner with adults to address social and institutional challenges, and that these partnerships are crucial to achieving just, democratic and sustainable social change. Currently YIF emphasizes three main themes through our Health Justice, Education Justice, and Community Justice Initiatives. Nancy Erbstein has described how YIF contributes to the emerging frameworks of Community Youth Development and Social Justice Youth Development (see box). This article describes YIF’s Health Justice Initiative and illustrates our approach to youth-led participatory action research with an example of a needs assessment by lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth in Sacramento, California.

Youth-Led Participatory Action Research for Health Justice

With support from YIF, young people and adult allies investigate disparities and advocate for greater justice in fields such as health, juvenile justice, education, and community planning. YIF supports young people to utilize research methods such as interviews, focus groups, surveys, observation, photography, and video to draw out and present community knowledge. YIF’s youth-friendly curriculum structures research as a series of eight “Stepping Stones” from team building and initial planning of a research project through research design, data collection, analysis, findings, recommendations, public presentation, and dissemination, leading to direct action and advocacy. YIF has experienced successes and challenges in using participatory action research methods in fields (e.g., health) that, in our experience, are not traditionally receptive to research not grounded in experimental methods.

For example, through our Health Justice Initiative, YIF projects have expanded definitions of health to revolutionize advocacy for some of the most marginalized populations of youth who are often overlooked or ignored by health systems. YIF’s Health Justice Initiative envisions a world where the voices of underrepresented youth, including queer youth, youth of color, foster youth, and homeless, immigrant and low-income youth are engaged in all aspects of health policy that affect their lives. Since 2005, YIF’s Health Justice Initiative has supported over 30 YPAR projects to make space for youth voices on issues such as food and nutrition, physical activity, access to health care, mental health, environmental justice, sexual health, and reproductive justice. Previously called the “Adolescent Health Initiative,” YIF’s work in the health field began in 2002 and focused on improving school wellness centers while addressing issues such as stress, drug use and sexual health. In 2005, YIF redefined and renamed the initiative “Health Justice” to especially amplify the voices of those youth who are often the most marginalized due to sexism, heterosexism, racism, poverty, violence, HIV/AIDS and STIs, drugs and alcohol, and other such issues affecting young people’s well-being.

Because YIF sees all health justice work as interconnected, YIF’s Health Justice Initiative continues to expand to include food justice, environmental justice, and mental health. For example, when youth-led research reveals that homeless queer youth in San Francisco report that a lack of access to fresh fruits and vegetables affects their mental health as much as a lack of affordable healthcare, we see that food justice is intimately connected to prevention and early intervention of mental health issues. Adapting the Health Justice Initiative to meet the needs of communities is a key part of our success, seeing both systemic and personal change as integral to our work. One project that demonstrates the power and impact of YPAR on young people and on the health field is a multi-phase project conducted with the Sacramento Gay and Lesbian Center.
LGBTQ Youth Mental Health

In Sacramento, the sprawling capitol city at the heart of California’s Central Valley, LGBTQ youth confront daily challenges to health and spirit. More so than their heterosexual peers, LGBTQ youth are often on their own in seeking support, resources, positive relationships and safe spaces. Since 2007, Youth In Focus has been promoting and supporting youth-led participatory action research with LGBTQ youth in Sacramento, particularly regarding mental health needs. Sacramento has a growing number of youth-serving agencies, too many of which seem to lack the consciousness, skill and sensitivity to work effectively and respectfully with the LGBTQ youth community. YPAR projects are creating a stage for LGBTQ youth to discuss their needs and demands for mental health services, thereby gaining the attention of gatekeepers and service providers from the city, county, and Central Valley region.

Through a partnership among Youth In Focus, the Sacramento Gay and Lesbian Center, and adult allies in local Gay Straight Alliances, LGBTQ youth in Sacramento are acquiring skills in self-advocacy, civic participation, and research. Over the course of the project the research team included 25 young people ages 13 to 22 who had connections to the Sacramento Gay and Lesbian Center, and three adults. Participant numbers from this transitory population fluctuated as participants self-selected, but there was a core of five. This team of LGBTQ youth had many questions as they initiated the research. The broad question, “What are the needs of LGBTQ youth in Sacramento?” stood out as the one the youth research team wanted to tackle, having otherwise lacked opportunities or spaces to do so. To begin the research process, youth vocalized ideas and concerns they believed to be pressing for their peers. They articulated the effects of homophobic society: their narratives of abandonment, depression, anxiety, homelessness and suicide reiterated the strong need for action regarding the mental health of LGBTQ youth.

The group felt that it was imperative to get a general sense of LGBTQ youth experiences in Sacramento and that a needs assessment could provide insight on what strategies might support LGBTQ youth throughout the city. With help from Youth In Focus, the youth researchers created a survey concerning LGBTQ youth needs, with an emphasis on mental health.

Following YIF’s Stepping Stone process through team building, research design and data collection, youth were then ready to conduct their data analysis, formulate findings, and make recommendations, opening up many windows on this oft-silenced community of young people. Many of the youth researchers expressed a sense of solidarity in struggle with survey participants they had not even met. The survey, distributed directly to peer networks and more broadly by counselors and gay-straight alliances at high schools, elicited key issues and suggestions for improved programs and activities. Of the 100 LGBTQ youth surveyed, 70% agreed that coming out in an unwelcoming environment heightened their experience of depression and anxiety, 72% agreed that there is a lack of support for LGBTQ youth to come out, 48% said the pressure of identifying* as LGBTQ is the biggest challenge in coming out, and 54% felt that mental health is the biggest issue for their LGBTQ peers.

The data analysis phase gave the youth research team insight for formulating recommendations and strategies to meet these great needs. Prioritizing prevention and early intervention, the team recommended the following:

- Increase mental health services for LGBTQ youth and increase visibility of providers who have skills to work with this population. Services should be affordable and accessible, consist of strong outreach to community centers and schools, and provide transportation.
- Train schools and institutions to build their capacity to create systems for working with LGBTQ youth. Connections with such institutions as the Sacramento Gay and Lesbian Center can help bring this information to other neighborhoods and communities. Trainings should be available for teachers and youth service providers, particularly for those from rural and conservative areas.
- Increase awareness and understanding of the transgender community, identity, and experience, by encouraging more trans visibility, and conducting workshops and trainings such as Trans 101 from the Transgender Law Center of San Francisco.
- Increase LGBTQ-specific programs, such as LGBT Big Brother/Big Sister, gay-straight alliances in high schools, parent support programs and organizations, LGBTQ sex education, and LGBTQ-specific youth activities.

With an overwhelming sense of both need and optimism, the youth research team developed its strategy...

* In the context of this research, “identifying” was defined to mean choosing to identify with a particular LGBTQ label or labels.
to be not only an informative process but also an exercise in advocacy for the many who are silenced by homophobia.

The project’s significance has been underlined by support and enthusiasm from various organizations. In the spring of 2007, the Sacramento Gay and Lesbian Center YPAR project attracted attention from the University of California, Davis’ Center for Reducing Health Disparities and the National Institute for Mental Health. The Community Health Program Manager at the Center for Reducing Health Disparities, Katherine Elliot, Ph.D., MPH, connected YIF and the youth research team to a county-wide research project investigating the needs of under-represented communities throughout the Sacramento region. The youth research team shared key information with the university for publication.7 YIF, in turn, received an invitation to participate with the Sacramento County Mental Health Services Act (MHSA) Steering Committee. The youth research team’s recommendations continue to inform the collective efforts of LGBTQ youth of Sacramento, Youth In Focus, the Sacramento Gay and Lesbian Center, the UC Davis Center for Reducing Health Disparities, the MHSA Steering Committee, and the LGBT Mental Health Collaborative of Sacramento. In 2008-09, YIF and the Sacramento Gay and Lesbian Center youth culminated their research by filming a documentary8,9 to gather and share the narratives and needs of LGBTQ youth throughout Sacramento, with the goal of educating and attracting attention from local service providers and putting human faces on the research project data.

**Funding for the documentary project was provided to Youth In Focus through a REACH grant from Sierra Health Foundation.

Summary

Youth In Focus’ twenty years of experience has demonstrated that YPAR is a powerful tool for marginalized youth to transform not only their own lives and community, but also the ways in which youth voices are heard by adults and policy makers. YPAR challenges the narrow definitions of what is considered legitimate research in the public health field. These methods have proven capable of quantitatively and qualitatively assessing youth health needs and outlining effective, efficient, youth-friendly strategies for action. For the youth involved in YPAR projects, research becomes a means for young people to connect as agents with their community and policy makers rather than merely as clients, recipients of services, or subjects of study. YPAR can be a key tool for prevention and early intervention in the health field and beyond. Service providers, public health officials, and others involved in the health field can engage YPAR as a transformative process that allows agencies to more effectively reach youth and start to truly address the critical mental health needs of marginalized young people.

References


Authors

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The Met Students’ Action Research Project with Youth In Focus

Youth in Focus staff members Jesús Sánchez and Alyssa Nelson interviewed Chris B. about the experiences and challenges of being involved in an action research project.

What was your youth-led participatory action research project?

The Met Sacramento charter school recently wrapped up a youth-led action research project with Youth In Focus. Our research question was: What types of information do students at the Met need to help meet their various needs? The goal of the project was to create a resource center at our school where students could get information about internship programs, community service projects, higher education, and health. The process took about 10 months to complete and was coordinated by Jesús Salas Sánchez, Project Manager at Youth In Focus.

How were you involved in the process?

The process started when Jesús came to the Met to work with my class to devise our research project. I was not one of the original students on the project, but since I had obtained an internship with Jesús at Youth In Focus, I was still able to join the process at its beginning stages. The student research team met bi-weekly with Jesús and started figuring out the proper steps to get the project rolling. Jesús helped us develop our thoughts and ideas about the process. We created our research question and questions for a student survey so that we could learn which resources students at the Met wanted. I was also part of the group of students that collected student surveys from different classes at our school. We worked closely with the teachers so that we could administer the surveys during class time. Out of 140 students in the school, 96 took our survey. While students were taking the survey, our research team was there to make sure that students understood the survey and could ask any questions about it. After we looked at the data, I became part of the core group that carried out the planning for creating the resource center.

What were some of the project’s challenges?

We first started this project as a class but quickly realized that the majority of the students were not as engaged as was needed. Many of the students in our class didn't take the project seriously, so Jesús decided to lead a smaller group of students who were really inspired and motivated to finish what we started. The group consisted of Seetha Ream-Rao, Jolene Duren, Maria Farinias, and me.

At one point we had a summer break in the middle of the data collection phase. It was kind of chaotic. The original surveys we administered before summer break had to be administered to our school’s incoming students so that we could get their point of view, too.

Another challenge came when we started to analyze the data. When
we looked over the survey results, we worried that about half of the students were not taking the survey seriously. We knew this because a lot of the students told us that they did not care about the survey and that they didn't fill them out properly. We felt this was a major roadblock in our project because the resources that were going to be brought into the resource center were going to be based on the survey results. Despite this concern, we used all the surveys when we analyzed our results and we believe our research gave us an accurate sense of what students wanted to see in the resource center.

*How did the research help you understand what your peers wanted?*

Even though some students didn't take the survey seriously, there was still the data analysis piece to carry out. Based on our analysis of the surveys, we concluded that students mostly wanted information on internships, health services, and higher education. Based on those findings we provided flyers and pamphlets on those three subjects, and established community connections in those three areas. Currently, a new group of students is continuing the resource center work by creating more relationships with community organizations and getting more information from students about how the resource center should function.

**How well do you feel the project achieved the goal of developing the resource center?**

The resource center has been promoted well and runs successfully. In February 2009 the resource center was also turned into the Student Store. The Student Store has been very profitable for our school. Students feel so much more comfortable getting information from a space on campus, especially when looking up information on higher education, internships, and health services. Overall, the Met Sacramento is a better school due to the Resource Center/Student Store. It was challenging at times but overall very beneficial to be a part of the creation of the center.

*What were some other youth accomplishments?*

A fellow project member, Seetha Ream-Rao, wrote and received a grant of $5,000 from the Grants Advisory Board for Youth* to make the resource center both attractive and functional. Recently, faculty members have benefited from the resource center, using information and resources to link students to various service providers. Lastly, my fellow project member, Jolene Duren, took the lead on developing a short documentary** about our process of creating the research project and the resource center. It was a great way to wrap up our work and create a fun final product.

*Author*

Chris Barrick is a high school junior at The Met Sacramento High School.

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* The GABY program is made possible through a partnership of Sacramento Region Community Foundation and Sierra Health Foundation: http://gaby.sacregcf.org/ (last accessed 4/29/09).

** Funding for the documentary project was provided to Youth In Focus through a REACH grant from the Sierra Health Foundation.
Digital Story Telling

Everyone has a story to tell, and sharing those stories is a powerful form of connection. Personal stories can be a key tool for education and advocacy; the authenticity of the first-person perspective can inform and move others in a unique, unfiltered way. Shaping one’s personal narrative can also be therapeutic; reframing struggles with personal challenges—disability, illness, failure—as overcoming obstacles can make a person feel stronger and even be central to the therapeutic process. Digital Storytelling (DST) is a process and a product that serves therapeutic, educational, and advocacy purposes. We present three linked pieces that share experiences with DST; a youth participant, her mentor, and a DST producer each share pieces that share experiences with DST.

Victor Damien

There is nothing more powerful than hearing the stories of youth in their own words, in their own light, and in their own expression. Now imagine not only hearing these stories, but seeing them too. DST allows youth to capture their stories using visuals, photos, videos, and music, so they and other people can watch and experience parts of the lives of our youth. Not only does DST help youth heal, express themselves, and build community; it also enables them to find the internal strength needed to move forward in life and transform themselves into something better. I have heard one therapist say that he learned more about his client in a three-minute digital story than he did in three years as his therapist. As a provider, I personally feel that the 24-hour workshop experience of cre-
at a conference I attended when I was working with a violence prevention initiative. I saw the Center for Digital Storytelling’s presentation, and immediately DST made sense to me from so many angles. As soon as I could, I applied for a grant and received funding for training in DST.

More than anything, I really saw how effective creating a space for young people to tell their stories using this multi-media tech could be. The workshop process is a great way for youth to find their own voices. The goal of these workshops is to help youth find the resources within themselves to find their own voices. It’s an opportunity young people don’t have very often; it’s very empowering and gives them perspective. It reminds them how they got through those difficult moments in their lives and lets them know that they are going to get through future difficult moments. The process is truly transformational for the storytellers.

DST is a healing experience because it allows people to talk about their experiences and to project their voices. Their stories come from psychological and spiritual spaces. What makes these stories so unique is that they use the participants’ own words. There is no one in between to interpret them like a journalist or a filmmaker. There is no outsider perspective. These stories come from the people who have actually lived the experiences, sharing what they are like.

The Center for Digital Storytelling works with advocacy organizations and constituencies who want to get their voices heard—domestic violence survivors, foster youth—as well as general community health workers. I’ve done a lot of work with young people, but about 80-90% of my work is with adults. Some people want their stories simply to reflect their personal experiences; others want them to be transformational for the viewers. Sometimes digital stories are created for educational purposes, or to spur community action. One group, No More Funerals, is using its stories as part of a curriculum for a peer-led youth violence prevention program. I believe DST is one of the most effective educational techniques because it connects people to people. DST shows how people respond to experiences in a deeper way than what is possible through documentaries, reporting, research—it combines a lot of elements to make it work on many different levels. It connects the storytellers to those who may not have a full appreciation of their experiences or even know about them.

DST also can be used for professional trainings. In one case, Youth Connection (a group of foster youth) documented their experiences using DST and shared them with social workers for trainings on transition-aged youth. They vividly illustrated what their experiences were like, and how they could be better supported.

DST also can be used to change policy. Youth Connection also showed their stories to key decision makers in Sacramento [California’s state capitol]. There is a lot of legislation coming out of our state capitol to support these young people, and it’s getting bipartisan support. I think the digital stories helped expedite this process.

**Authors**

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**Reference**

Y
oung people with serious mental health conditions are at high risk for experiencing poor outcomes as they grow into adulthood. Compared to peers without such conditions, these young people are more likely to drop out of school, experience chronic unemployment and underemployment, have contact with the judicial system, and be disconnected from their communities.8

Schools and agencies that serve these youth often create treatment, service or transition plans that are intended to help the young people make a successful transition into adulthood. Unfortunately, these plans are typically created for youth, with little input or buy-in from the young people themselves. For example, federal legislation requires that schools provide transition planning—via an individualized education planning (IEP) process—for high-school age youth who receive special education services. Despite this mandate, it seems that most students do not participate meaningfully in the IEP/transition planning process. Many do not even have a transition plan, and many students who attend their IEP meetings do not participate at all.9

The failure of schools and agencies to engage young people in planning for their futures represents a lost opportunity. Properly implemented, an individualized planning process can provide young people with the kinds of experiences that directly contribute to increases in self-determination, empowerment and self-efficacy. People who have higher levels of self-determination, empowerment, and self-efficacy have confidence that, through their own decisions and actions, they can reach goals that are personally meaningful. What is more, these people actually are more successful in reaching their goals. Overall, they also tend to have better general mental health and well-being, and cope better with stressful circumstances. Existing research strongly supports the idea that young people with serious mental health conditions who have higher levels of self-determination, empowerment, and self-efficacy are more likely to have successful transition outcomes.9

This article describes two research studies that are underway at Portland State University. Both studies are testing interventions designed to increase young people’s self-determination, empowerment and/or self-efficacy by supporting them to take an active, leading role in their own treatment, care, or transition planning. While both of these studies are still underway, initial data is showing positive results.

Achieve My Plan! (AMP)

Achieve My Plan! (AMP) is an intervention that is being developed at the Research and Training Center on Family Support and Children's Mental Health at Portland State University. One of the most unique aspects of AMP is that the intervention and related materials were developed in collaboration with an advisory board that includes youth, caregivers and service providers. (See Thorne article, p. 17.)

AMP is designed to be used in any context where a young person with a mental health condition is involved in a team planning process. Human service and educational agencies and systems often convene teams to work collaboratively on plans for serving young people as they approach the transition into adulthood. This is particularly true for youth who are involved with multiple systems or who are felt to be in need of intensive intervention. These kinds of planning teams include IEP (Individualized Education Plan) teams, wraparound teams, foster care Independent Living Program teams, transition planning teams, youth/family decision teams, and other teams that create service, transition or treatment plans. AMP is designed to have an effect both at the level of individual youth and at the level of the agencies that serve the youth.

Youth-level intervention. The intervention with youth begins with a series of individual sessions with a designated “AMP coach.” The coach helps the young person work through a series of structured exercises and activities that lead up to the first “AMP meeting.” During the AMP meeting, the youth takes an active role in leading portions of the meeting and shaping the content of the team plan. The AMP meeting is not a separate meeting from the regular planning meetings, and it does not result in a separate plan. Instead, it is the same meeting and the same plan; however, there are differences from typical planning meetings in that both the plan and the planning process are somewhat adapted to reflect the youth’s participation and goals.

The youth’s initial preparation before the first AMP meeting takes...
approximately three hours, and is typically divided into three sessions at one-week intervals, though this schedule is flexible and can be tailored to meet individual needs. In the first two sessions, the coach facilitates a process that begins with the youth exploring his/her long-term goals and dreams. Gradually, the focus is brought into the shorter and shorter term, until the young person is able to identify a small number of concrete, short-term activities that he/she sees as important first steps in moving toward a long-term goal. At least one of the activities must be connected to academic or vocational goals, and another connected to behavioral/mental health. The coach and the youth also develop and implement a plan for sharing the activities with the youth’s parent or other caregiver prior to the AMP meeting, and gaining the caregiver’s support for the activities.

The third coaching session focuses on preparing the youth 1) to present the activities to the team during the AMP meeting, and 2) to participate effectively in other aspects of the meeting. The youth learns about how the meeting will be structured and who will be there, how to communicate positively and how to manage his/her stress, anxiety or other emotional reactions. The youth also has the opportunity to review items placed on the agenda by other team members, and to prepare his/her input for those items.

The coach attends the AMP meeting to support the youth’s participation. After the first AMP meeting, the youth and coach meet to debrief and develop strategies to ensure that team members follow through on their commitments for the plan. Youth preparation and follow up for subsequent team meetings is less intensive, but coaching continues to work with the youth as needed.

AMP coaching can be done by people who have a variety of other roles with the agency. The coach can be a therapist or care coordinator, but the coach may also be a young person who is a peer or near-peer of the youth who receive services.

**Agency-level intervention.** In addition to focusing on individual youth, AMP focuses on the agencies that provide treatment, care or transition planning. A basic level of training and consultation is provided to all agency staff. This training focuses on the importance of encouraging youth to take an active role in developing and carrying out the plans. The training also provides information demonstrating that including youth with serious mental health conditions in planning is both feasible and beneficial.

More intensive training is provided to agency staff who have key roles on planning teams and/or who participate on multiple planning teams. This intensive training teaches the adults how to create planning meetings that will support youth participation. The training provides examples of common things that go wrong in meetings and that discourage youth participation. The examples are drawn from video recordings of real team meetings. Participants learn how to recognize these common problems, and learn strategies for avoiding and remediating them. Follow up consultation is provided to these staff members during the early months of AMP implementation.

**Evaluation.** To date, AMP, has been tested with youth in a wrap-around program and with youth in a high school/day treatment program. Despite the relatively small sample size, the data show positive results. Several of these positive findings come from data gathered from youth prior to AMP and afterwards. These data show significant increases in youths’ perceptions that they were involved in preparation for their planning meetings and that their teams were more accountable to the plan. The data also show significant increases in youth empowerment as assessed with the Youth Empowerment Scale-Mental Health (YES-MH, see page 17). After AMP, youth described themselves as more confident both in managing their own mental health and in working with service providers to optimize their services and supports. Their overall empowerment scores also increased.

On the basis of these positive initial results, the researchers and advisors working on AMP are currently seeking funding for a larger-scale study that also examines outcomes in areas such as mental health, education/employment and service continuity.
My Life

Among youth in foster care, serious mental health conditions are extremely common. In the Casey National Alumni Study, more than half of young people who had exited foster care had mental health challenges, with 25% experiencing post-traumatic stress disorder and 20% experiencing major depression.6 Foster youth in general tend to experience relatively poor outcomes as they age out of care. In comparison to their same-age peers in the general population, youth emancipated from foster care are less likely to have stable housing, to be connected to a caring adult, to graduate from high school, to go to college, or to be employed.1, 6, 5 Youth in foster care who also have mental health conditions appear to face even higher levels of risk as they reach the age of emancipation and leave the foster care system. For example, research by Smithgall and colleagues showed that only 16% of foster youth in special education with a primary disability classification of emotional disturbance graduated from high school; even more worrisome, they found that 18% left school because they were incarcerated.7

Transition planning within the foster care and special education systems is intended to serve as the youth’s roadmap from school to adult life, ensuring that services and supports are in place as the young person moves towards his/her goals for the future and self-sufficiency. However, a study by Geenen and Powers (2006)3 found that the transition plans of foster youth with disabilities were poor in quality, both in absolute terms and in comparison to the plans of youth in special education only. Many of the foster youths’ plans were developed without a parent advocate or educational surrogate, documented limited expectations for the foster youth, did not specify accountability for plan implementation, and reflected little to no collaboration between the child welfare and special education programs. The findings from this study highlight the need for student-directed, individualized and collaborative transition planning for youth in foster care and special education, and serve as an impetus for a pilot study entitled My Life.4

My Life is the first study investigating the benefits of a self-determination enhancement intervention for youth in foster care and special education. Sixty youth, age 17, were randomly assigned to either a comparison group that received typical services and supports, or to an intervention group that participated in the My Life intervention. The intervention lasts for approximately 12 months and the youth’s self-determination and transition outcomes are measured before they begin, at the end of the intervention, and 12 months after the interven-

1. Identify dreams and set transition goals: Youth identify their dreams for the future (graduate from high school, apply to college, get a driver’s license).

2. Share dreams and goals with others: Youth learn how to share their dreams and transition goals during individual discussions with foster and biological families, important peers, and professionals.

3. Identify steps and supports to reach goals: After youth identify their broad transition goals, they identify specific steps they can carry out and supports needed from others to achieve them.

4. Formalize planning objectives: Youth present their goals and proposed steps and supports needed in a formal transition planning meeting.

5. Agree on responsibilities and time-frames for carrying out plans: The youth and other team members formulate specific plans for goal achievement, clarify responsibilities, and define monitoring procedures to ensure progress.

6. Problem-solve strategies to achieve goals: Youth learn to apply problem-solving and planning strategies to overcome barriers to goal achievement.

7. Carry out plans: The youth carry out the strategies to achieve their selected goals, regularly evaluate their success, and use problem-solving to address new barriers.

8. Monitor and manage support for achieving goals: Youth learn and apply steps for building partnerships and managing help from others.

9. Celebrate success and resilience: Youth learn how to self-monitor
and celebrate their goal achievement and resilience to barriers (e.g., frustration and discouragement by others).

Outcomes being measured include youth self-determination; involvement in transition planning; employment; educational participation and achievement; and quality of life. Data are still being collected at one-year follow-up so findings are only preliminary at this point. However, initial findings suggest the intervention is having a positive impact in several areas:

- **Self-determination:** Youth in the intervention group reported significantly higher levels of self-determination following intervention and one year after intervention, in comparison to youth in the control group. Differences between the groups appear to be widening over time.

- **Transition planning:** Youth understanding and involvement in transition planning meetings and related activities are higher for youth in the My Life intervention than youth in the control group; the difference between the groups widens further at one-year follow-up.

- **Quality of life:** Youth completed a quality of life measure with four domains. Overall, youth in the intervention group reported significantly higher quality of life than youth in the control group, both following intervention and one year later. Intervention youths’ scores on three of the four domains are significantly higher (Scores on the fourth domain are higher but not statistically significant).

Youth who participated in the My Life intervention also appear to have better outcomes in terms of employment (particularly at one-year follow up) and placement stability.

**Conclusion**

The initial findings from the AMP and My Life interventions suggest that it is quite possible to increase the extent to which young people are involved and engaged in making decisions and carrying out plans for their futures. The findings also indicate that youth who take this active role experience gains in empowerment or self-determination. Ultimately, both of these interventions aim to have an impact on other outcomes, such as education, employment, and mental health. The current AMP study is preliminary and so has not examined these types of outcomes; however, the My Life study appears to be having just these sorts of effects. More generally, these findings support the idea that youth-driven planning is a feasible and effective strategy for promoting better outcomes for young people as they move into early adulthood.

**References**


**Authors**

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Developing a New Intervention: 
Reflections of a Youth Advisor

Nathan, age 20, along with his mom, Sonja, have been dedicated members of the Achieve My Plan! (AMP) advisory board for the past three years. Nathan has dealt with mental health issues all of his life, and has been involved with various treatment, education and counseling services for nearly as long. During his treatment and education planning meetings, Nathan remembers “never feeling like my opinion mattered or was important to anyone…. People just spoke for me. I never realized it should have been the other way around.”

Nathan recalls that several years ago his mom received an email inviting her and Nathan to become advisors for a project that was working to increase youth participation and engagement in their treatment, education and transition planning. (The project was later named AMP.) Although his mom was unsure, Nathan talked her into going, mainly because it paid more than he could make working. Nathan describes the AMP advisory board meetings he has attended as an opportunity to be heard by a group of researchers, caregivers, professionals and other youth. “People in the meeting actually cared about what I thought and what I had to say. Now I know that my opinion matters.” Nathan remarks, regarding his experience in helping to shape the AMP intervention and related materials. Over the years as an advisor, Nathan has not only shaped AMP materials, but has also presented with members of the research team at a number of conferences. However, Nathan’s favorite activity has been acting in role plays that were taped for various AMP trainings and social marketing videos.

Nathan believes strongly that the work he is doing on AMP is important. He thinks that AMP can “give youth a sense of self-confidence, and help them to feel more independent.” Being an advisor to the AMP project has also affected Nathan in a positive way. Nathan admits that while his motivation to become an AMP advisor in the beginning was “mostly about the money,” he says that it has become about much more than that. “Before all of this [AMP],” Nathan reports, “I didn’t know what I wanted to do…. I wanted to be an archaeologist, but there isn’t much demand for that.” Now, Nathan sees himself walking a new path. “I want to become a spokesperson for people with mental health issues, and help them get the most out of life. Before being on the board, I never talked. Now, I want to make a career out of it!”

- by Elizabeth Thorne, AMP Project Manager, based on an interview with Nathan Tanner

The Youth Empowerment Scale-Mental Health (YES-MH) is a new measure designed to assess young people’s feelings of confidence and efficacy with respect to managing their own mental health condition, managing their own services and supports, and using their experience and knowledge to help peers and improve service systems. The YES-MH has 20 items and takes less than five minutes to complete. It provides an overall empowerment score as well as scores for empowerment in each of the three areas noted above: self, services and system.

The properties of the YES-MH were investigated in a study that is about to be published. In the study, young people from around the country completed the YES-MH as well as a series of other measures, and provided information about themselves and their experiences with mental health services and systems. Results from the study provide evidence of the measure’s reliability and validity.

More information about the YES-MH can be found online at:
http://www.rtc.pdx.edu/PDF/pbCompleteSurveyPacket.pdf

Youth ‘N Action: For Youth, By Youth!

Youth Involvement in Washington State

Delaney, 16, is living with her grandparents due to parental abuse and neglect. She's angry from the trauma she experienced and does not look to her classmates for support, as she fears they will view her situation negatively. She tries to isolate herself and falls under the radar because she feels no one cares. Her teachers and peers perceive her as disconnected and uninterested. Where can she go for support? Where can she go to be heard? Where she can meet people who understand her situation?

Sean, 20, struggles with depression. When he moved into a neighborhood filled with drugs and violence about five years ago, he joined a gang to protect and support his family. He didn’t want to join a gang but felt there were no other options. He knew gang life wasn’t for him after seeing friends and family die, fall into addiction and go to jail. Two years ago, a friend told him about a local youth organization that wanted to hear his voice and give him opportunities he couldn’t find in his neighborhood or gang. He checked the program out and found it focused on his strengths and talents and not the poor choices he’d made by joining a gang. That was important because he had not thought anyone would understand him. The program gave him a chance to remove himself from the lifestyle of his neighborhood and get involved in positive and productive activities with his peers. It also provided him resources to help deal with his depression, which he was self-medicating with drugs and alcohol. He got help with his addiction and became involved in a supported employment program. He now works full time and serves as a leader in the organization. He shares his experiences with other youth who are undergoing challenges in their life, so that they may create resiliency in their lives like he did. Where did he go? What organization would accept a “gang” member?

Gio, 17, has a mental health diagnosis. School becomes increasingly stressful as he fears the stigma of mental illness will fall upon him if people find out his diagnosis. His mother knows he needs to have a positive social connection and be around people who will not judge him for his challenges. She speaks out about it in a parent support program and they connect her to a youth organization that combats stigma. Gio joins the program and realizes for the first time that, not only is he not alone, but also he has nothing to be ashamed of. He can now help people who go through what he went through and do something positive with peers like himself. What is this program that helps young people turn their “problems” into strengths?

Policy makers and service providers can’t figure out why their multimillion dollar pilots are not working and why youth continue to spiral down in their lives and “fail” programs. They’ve brought in consultants from all over the nation; they’ve reviewed all their data and notes and finally, they realize they have never heard from the youth themselves... Where can they go to get youth voice? Who will support these youth?

Answer: Youth ’N Action. The young people in Youth ’N Action have had different experiences, but their goals are the same: to make life better for youth in Washington, and
Youth ‘N Action is a unique program that supports youth voice. Youth are the experts in their lives and their recoveries. Youth ‘N Action brings youth voice to public policy and empowers at-risk youth ages 14-24 to make positive differences in their lives, their communities, and systems that serve youth. YNA is a youth-driven organization surrounded by youth-friendly adults and professionals who provide support to the youth to help them create the positive outcomes they desire.

YNA provides youth with a variety of opportunities to make a positive difference. For example, in Eastern and Western Washington, YNA holds regional monthly meetings where youth get together and talk about the positive differences they’d like to see in their lives, communities and the systems that serve them. Additionally, youth receive education about programs and services available to them to help them reach their life goals.

YNA also provides youth with opportunities to advocate and educate. Youth bring their voices to important state-level venues such as the Washington State Community Transformation Partnership, a coalition of consumer advocacy organizations, and the Prevention Policy Summit, held in May of 2008, where over 260 mental health stakeholders identified Washington State’s priorities in the area of mental illness prevention. At the national level, YNA members trained psychiatrists on youth-directed care at a psychiatric conference in New Orleans, presented study results on the needs of transition-age youth at the Research and Training Center’s Building on Family Strengths Conference at Portland State University, and participated in other conferences sponsored by Georgetown University Institutes and the Federation of Families for Children’s Mental Health.

Youth ‘N Action also provides many avenues to encourage leadership and positive youth development, such as Spokane’s YNA Student 2 Student program (a peer support program in a local high school) and the Youth Stigma Reduction Speakers Bureau. A developing pathway is in the area of artistic expression. YNA leaders are currently producing a play titled, ‘Life is Not a Game,’ designed to give a real-life view of the issues youth in transition face in regard to mental health, family, peers, social lives, education, and employment.

As the collaboration between Youth ‘N Action and SAFE WA continued to develop, members realized they held widely different perspectives regarding youth involvement within the youth to help them create the positive outcomes they desire.

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As the collaboration between Youth ‘N Action and SAFE WA continued to develop, members realized they held widely different perspectives regarding youth involvement within
YNA. They came to believe that an evaluation process would assist them to more clearly identify a philosophy for the benefit of the youth, their families and the state of Washington.

A Youth-Driven Evaluation Process

In the spirit of being youth-driven, youth made the key decisions in every step of the evaluation. Adult partners were available as a resource, not a force, and offered their partnership and support throughout the project. To start out, YNA leaders developed the Youth ‘N Action program logic model. The logic model helped them to form their draft focus group questions. Subsequently, they finalized the focus group questions, created ground rules for the focus groups, and edited a pre-focus group questionnaire for participants to complete. When this hard work was done, they celebrated with other YNA members at a billiards and arcade restaurant.

Youth co-facilitators from Eastern and Western Washington were trained in focus group facilitation through discussion and role playing.

Thirty-three youth ranging in age from 14 to 24 participated in the focus groups. The sample was 58% male and the mean age was 17.1. The majority of participants were European American (46%), with 24% African American, 6% Native American and 24% multiracial. Five of the 33 participants had children. Other background information is provided in Table 1.

On the questionnaire, youth were provided a list of diagnoses and asked to check if they self-identified with and/or had ever been diagnosed with any of them. ADHD and other disruptive behavior disorders, learning disabilities and anxiety were the three most frequently identified diagnoses. Frequencies of self-reported diagnoses are shown in Table 2. The range of diagnoses was from 0-7, with a mean of one. It is noteworthy that 49% of the youth did not check any diagnoses.

Interviews were conducted in a youth-friendly manner and environment. Youth were given the opportunity to participate in one-on-one phone interviews or attend focus groups. Youth were met in their local areas, provided with transportation through volunteers and project staff, paid $40 for their participation, and provided with a meal. Youth were happy with how the focus groups were conducted and thankful for the opportunity.

Focus groups were audio taped, professionally transcribed and edited. After this, a group of key youth and adult stakeholders met to review focus group transcripts and highlight trends. Once again, youth took leadership, since their familiarity with youth culture and typical peer situations would allow them to make more subtle and accurate interpretations of the focus group data.

Highlights from the Results

What were your first impressions of Youth ‘N Action?

• Empowerment:

I liked it because everybody spoke their mind but also listened at the same time.

• Acceptance and felt no stigma:

My first impression of the group was that it was a good, fun place to come hang out and not have to hide who you are. You can hang out with different races of people and not worry about anything, not worry about being judged or anything like that.

• Opportunity:

For opportunity, I thought this could take me places, places to where I can get what I think and how I feel off of my mind and off my chest.

• Good environment and non-religious:

My first impression of Youth ‘N Action was, I came to one of the meetings and I really enjoyed the fact that it was a youth group that wasn’t based on any particular religion, because usually that is what youth groups focus on.

• Educational:

My first impression was good. I mainly did the educational things about it, so I think it is a good program.

• Fun, cool and FOOD:

The first time I went to a Youth ‘N Action meeting, you know, it was cool. It had food there, but that wasn’t it. You all trying to do some real stuff trying to set up a little fund raiser and stuff, a little concert and stuff… You all had former NBA star Joe Pace. It was crazy when I seen that, Joe Pace, hey a basketball player. I was like, “OOOH!!!”

• Community service:

My first impression was that it looked like a lot of fun and it looked kind of interesting to get involved in. A lot of things like how to help our community in different ways. So our community can be a better place.

• Meeting new people:

When I first came I thought it was pretty cool. I would like to be doing this on a regular basis. It taught me a lot about tolerance and I guess not judging, just accepting people regardless of their faults.

How has Youth ‘N Action affected you personally?

• Life, professional and leadership skills:

It has helped me with a lot, I think you call it intrapersonal skills, like
Leadership, advocacy, youth voice and empowerment:
I think that Youth ’N Action taught me a lot more about myself, trying to help other people. Guidance, growth, support and motivation.

Once I got involved in the program I quit stealing, because when I went to the meetings and we talked about our problems that helped me out. If Youth ’N Action were to disappear my life would probably change. If I didn’t have Youth ’N Action I probably would have kept on stealing. If Youth ’N Action were to disappear my life would probably change. I’d probably go back to my shyness a little bit, maybe. That’s about it.

Final Thoughts

I [Tamara] started this evaluation as a youth leader in Youth ’N Action who was motivated and thankful for all the opportunities, encouragement and support Youth ’N Action had provided me. I felt that if we did this evaluation it would show people how valuable this program is to youth and how it can touch so many lives and create change in the community. All it took to turn my life around was someone who cared and someone who listened and now I’m able to help so many other young people than myself.

Authors

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For more information see the following websites:

Youth ’N Action:
www.YouthNAAction.org

Statewide Action for Family Empowerment:
wwwSAFEwashington.org
It is Saturday morning. Nine young people from Oregon, Massachusetts, California, Texas, and New York have gotten out of bed, picked up their phones and dialed the 1-800 conference call number. What motivates them to spend two hours of their Saturday this way? They are all members of the 2009 Portland National Youth Summit Advisory Board. These youth, who have never met face to face, are working together with adult allies and the Portland State University Research and Training Center on Family Support and Children’s Mental Health (RTC) to build a youth-driven event from the ground up. All their monthly Saturday planning meetings and email communications will come together this June in Portland, Oregon for the 2009 Portland National Youth Summit. There they will meet with 30 peer leaders from around the country to share unique stories about their own experiences with mental health challenges, foster care placements, homelessness, the juvenile justice system, and residential treatment placements; and to identify common themes and areas for improvement within services for youth.

The Youth Summit Advisory Board

The Youth Summit was intended to be a youth-driven event, and so the first step in the planning process was to hire a young adult who had personal experience with mental health services to act as the Youth Summit Coordinator. The Coordinator, with support from RTC staff, led a process to recruit “systems-experienced” young people to join the Youth Summit Advisory Board and plan the Youth Summit event. This Advisory Board was appointed to identify specific goals and intended outcomes for the Summit, initiate recruitment for youth and young adult participants, oversee the creation of a participant application process, and plan the Summit agenda.

Recruitment of Youth Summit Board members began with a request circulated nationally to youth leaders, youth coordinators and adults connected to systems of care. Identified and interested young people submitted resumes and cover letters stating why they wanted to become a part of the Youth Summit planning team. Young people were then selected based on their experiences as youth leaders, their passion for making improvements within youth services, and their ability to commit time. Board members were also expected to be leaders during the event, and to take part in presenting outcomes from the Youth Summit during the following Building on Family Strengths Conference. In return for their involvement, individuals would receive compensation for time spent on conference calls, funds to travel and stay in Portland and attend the Youth Summit and Building on Family Strengths Conference, and a stipend upon completion of the event.

The Summit Coordinator was committed to creating an atmosphere where young Board members felt heard and valued, and where decision-making was transparent. Board members received meeting agendas and relevant documents before each conference call, and were invited to send any comments or request changes. Members were encouraged to lead team-building exercises at the beginning of each call to facilitate relationships. During the first conference call, members voted on which day of the week and time of day future calls should take place. Because members of the Board had many existing commitments, such as school, work and volunteering, they also received reminders about conference calls through emails, individual phone calls and text messages one or two days before each call. For those youth who could not attend certain calls but could communicate electronically, a group website was created through Google Sites to facilitate comments on planning and application materials, as well as to provide access to previous meeting agendas and minutes. Most importantly, youth were encouraged...
to speak up if the language being used through any communication avenue was not youth-friendly or clear.

**Challenges**

Despite the above efforts and dedication, it was at times a challenge for the Coordinator to encourage participation and completely let go of the steering wheel. In his 1997 book *Children’s Participation: The Theory and Practice of Involving Young Citizens in Community Development and Environmental Care*, sociologist Roger Hart identified eight levels of youth involvement, outlined into a “Ladder of ‘Youth Participation.’” Each sequential rung of Hart’s participation ladder (Figure 1) facilitates more youth participation and therefore, more youth empowerment. The goal of meaningful youth involvement is facilitation of mutual adult and youth decision-making, initiation and action. In the process of planning the Youth Summit, the Advisory Board hovered in between the fifth and sixth rung: The Board was consulted on and included in many decisions, but more often than not, youth were informed and asked to give input on decisions and actions initiated by adult allies.

Many of the Youth Advisory Board members, though well intended, did not follow through with planned attendance on conference calls, or respond to requests to review documents with edits and ideas. As a result, the RTC Coordinator became less comfortable assigning tasks to board members, given the time constraints of planning the Youth Summit. Some youth did not have easy or consistent access to the Internet; therefore, communication was often done primarily by phone, and collaborating on documents electronically was a challenge. When initiating phone correspondence, time zones had to be considered as well as school and work schedules. At times, individual Board members understandably needed to focus on managing their own mental health in addition to dealing with life difficulties such as homelessness, providing child care, and obtaining social service support. As participation from some members began to wane, Board members collaborated with the Coordinator to create participation expectations and outcomes. The Coordinator, youth allies, and other board members strived to be supportive of and flexible with each member’s level of involvement when creating membership expectations. However, a handful of youth were not able to complete their obligations, and Board membership dropped from nine active members to six.

**FIGURE 1. HART’S LADDER OF YOUTH PARTICIPATION**

1. **Manipulation:** Youth appear to be included, but really they have little or no choice in how they participate in adult-initiated projects
2. **Decoration:** Youth are used to help with adult-initiated projects in an indirect way
3. **Tokenism:** Youth appear to be included, but really they have little or no choice in how they participate in adult-initiated projects
4. **Community Youth Boards:** Youth are assigned project roles by adults and are informed how and why they are being included
5. **Youth Advisory Councils:** Youth provide feedback on projects that are initiated and run by adults
6. **Participatory Action Research:** Adults initiate projects, but decision-making is shared with youth
7. **Youth-Led Activism:** Youth initiate and direct projects while adults are in the supportive role
8. **Youth/Adult Partnerships:** Youth initiate projects and decision-making is shared with adults

(Adapted from “Ladder of Participation” from “The FreeChild Project Youth Voice Toolbox” www.freechild.org)
Meaningful Youth Participation

As mentioned, Youth Summit Board members were selected partly based on their involvement with many other youth service organizations. Seventeen-year-old Chelsea Garcia, from Houston, Texas is a youth board member with three additional organizations. As a part of the statewide initiative Youth On Board, Garcia and other young people work with nonprofits and government organizations to create more youth-friendly spaces on planning committees and other decision-making bodies. To Garcia, the thing that really drives her to be a part of these groups is the fact that she feels her ideas and words are really valued. “It makes such a difference when the people in suits ask you your ideas, listen, and then put them into action. Once you see you are putting yourself out there and they are going to listen, it makes you feel like more than just the ‘token youth.’ You are an important part of making the changes happen.”

Martin Rafferty, age 22, of Eugene, Oregon, is also very active in his community as a youth board member. In addition to serving on the 2009 Portland National Youth Summit Advisory Board, he is a part of the Oregon Family Supports Network, the Leadership Education Adventure Direction program in Oregon, and the Resources, Education, and Assistance for Community Housing program in Kentucky. When asked what he believes is most valuable in encouraging youth voice as a part of board membership Rafferty replied, “Having at least two young people present makes a difference. It is much more comfortable for that young person to say ‘Hey can you repeat that?’ if another young person is present.” Rafferty and Garcia agree that board members must be ready to slow down for youth. “Not because youth can’t grasp the concepts,” Rafferty elaborates, “but because youth aren’t spending 40 hours a week around those concepts and ideas like most of the other members are.” Also, Rafferty believes it is helpful to have an advocate there who can speak up if an adult-dominated board is veering away from “youth-friendly language” or is using unclear acronyms. “You would be surprised how many times a young person or ally speaks up because they need something explained, and other adults are relieved ‘cause they don’t get it either,” laughs Rafferty.

Something else to consider when inviting a young person to be involved with an organizational board is to make sure that young person feels like part of the group. Taking the time to build relationships facilitates youth investment and leadership. “It is really nice when each person in the room goes around the table to introduce themselves and say what they do,” Garcia explains. “It takes a lot of the intimidation away when you realize ‘Hey these are people just like me.’ It also makes you feel more a part of the process when you can say what you do and see that they respect your experience.” Garcia and Rafferty both believe it would have been helpful if the Youth Summit Board could have met as a group in person for their planning conference calls. “It just makes such a difference to be able to see body language,” Rafferty says, “You also eliminate so much talking over each other that you get when you are only hearing voices on the phone. That is why I am a big fan of web cams if they are possible. Having that eye contact makes all the difference.”

Including a youth in service assessment and planning through organizational board membership not only benefits that young person, but it greatly benefits the organization’s ability to hear from the population they serve. By making a few small adjustments, organizations can ensure that their programs are taking steps “up the ladder” towards youth participation and empowerment.

TIPS TO MEANINGFUL YOUTH BOARD INVOLVEMENT

• Take time to have team-building exercises. Whether it is an all-day activity or a quick icebreaker, it creates healthy working relationships and gets energy up.
• Use acronyms sparingly, or include a key that lists acronym meanings.
• Have a “youth ally” available to meet with youth in between meetings, review concepts, and speak up for youth if non-youth-friendly language is being used.
• Include at least two youth seats on the board for a more comfortable setting.
• Consider the school or work schedule of the young people involved.
• Include youth in voting and other decision-making processes.
• Wear name tags the first several meetings so everyone can be identified by their first name.
• When you ask a young person their thoughts, take them into serious consideration and follow up with youth on the progress of their ideas.
• And in the words of Chelsea, “When all else fails, bring brownies!”

Reference

Author
Rebecca Strachan is a graduate student of social work at Portland State University and the Youth Summit Coordinator with the Research and Training Center on Family Support and Children’s Mental Health at Portland State University.
Youth Motivating Others through Voices of Experience (Youth MOVE) National is a youth-led national organization devoted to improving services and systems that support positive growth and development by uniting the voices of individuals who have lived experience in various systems including mental health, juvenile justice, education, and child welfare.

The youth movement began years ago when youth coordinators and youth across the country were advocating for national involvement. Their passion and determination continued on until 2003 when the National Youth Development Board was formed with the support of a diverse group of youth coordinators from communities across the county.

The National Youth Development Board existed in an advisory capacity in the early years. In 2007, the Board took the first step toward becoming an independent organization. Members of the Board asked the National Federation of Families for Children’s Mental Health to consider acting as Youth MOVE's fiscal agent. The family movement—and the National Federation itself—has had over 20 years of experience in empowering families and creating positive system change. Board members thought that it would be of great benefit for Youth MOVE National to learn from this experience. This relationship would also allow for professional mentoring of Board and staff, and would have the added advantage of providing office space in the National Federation’s home office, which is close to both SAMHSA (the Substance Abuse and Mental Health Services Administration) and our nation’s capitol. The conversations led to Youth MOVE becoming a subsidiary of the National Federation of Families.

In October 2007, with start-up funding from SAMHSA, the National Youth Development Board transitioned into a national youth-led advocacy organization known as Youth MOVE National. With this start-up funding, Youth MOVE National was able to hire a full-time Director, Carl Yonder, and part-time administrative assistant, Brian Campbell. Moving forward in January 2008, Youth MOVE National was officially incorporated to become Youth MOVE National, Inc.

Today, Youth MOVE National's main goals are:

- To assist in developing the Youth Leadership program at meetings
- To create youth movement principles and policies
- To develop training tools, guides and other documents
- To unite the voices and causes of youth
- To act as consultants to youth, providers, families, and other adults
- To create youth movement principles and policies
- To provide national youth leadership representing youth served by mental health and other youth-serving systems
- To coach others in the area of authentic youth involvement

Youth MOVE National is working to become a model of successful youth involvement in consultation and policy work at the national level. With members from around the country—from Montana to Florida,
New York to Hawaii—the board of Youth MOVE National is a diverse group. One board member is a former gang member, while others were involved in foster care for their entire lives. Board members bring their own personal beliefs and values, yet all are committed to using their personal success on behalf of Youth MOVE National.

This diverse coalition has already achieved positive work within the mental health system. For example, one of Youth MOVE National’s early projects was to develop a definition of what it means to have a youth-guided system of care. Youth-guided means that young people have the right to be empowered, educated, and given a role in making decisions, both about their own lives and about the policies and procedures governing care for youth in the community, state and nation.

Creating this definition was important to the work of building systems of care, and board members charged forward with passion to create more tools to inspire change through youth involvement. Youth MOVE National board members had the unique opportunity to travel and learn of the youth movement occurring in our neighboring nation, Canada. From this relationship, the project Dare to Dream was brought to the United States by Youth MOVE National. Based on the successful Dare to Dream Program from Ontario, Canada, the U.S. program promotes positive mental health by providing funding to youth (23 years of age and under) to facilitate awareness-raising and stigma-reduction projects in local communities. Between 2008 and 2009, Dare to Dream America, with startup funding from SAMHSA, has awarded 20 grants to youth across the country who demonstrated high interest and energy around unique and creative projects. The ideas of youth astounded Youth MOVE National, with concepts ranging from ad campaigns to creative theatre productions to a Battle of the Bands. This program has offered many youth the opportunity to improve the knowledge and understanding of each local community around mental health.

Beyond Dare to Dream America, Youth MOVE National provides several services such as serving as consultants on panels at the national, state and local levels; assisting in developing youth-guided programs and projects for improving services and systems; and providing youth speakers for conferences and workshops across the country. Board members have participated in high-profile opportunities such as the Georgetown Transition Policy Academy and the International Initiative for Mental Health Leadership, for which board members traveled to New Zealand and Australia! Other board members have presented to the American Association of Child and Adolescent Psychiatrists and served on the Council for Coordination and Collaboration. Youth MOVE National was fortunate to be able to participate in the first-ever Youth Coordinator Conference in Washington DC, where close to 80 youth coordinators met to discuss their work and the need for future collaboration to continue the youth movement. There is a lot of important work being done by youth coordinators across the country and Youth MOVE National is there to help support the positive change for youth-serving systems every step of the way.

How Can You Help?

There are several ways to help Youth MOVE National continue its work as an organization devoted to improving youth-serving systems and increasing authentic youth involvement in this process of change.

You can become an individual member of Youth MOVE National!

Your support of Youth Move National is valued and appreciated as your membership dues enable Youth MOVE to broaden its ongoing efforts to build programs and policies for positive youth involvement across the country. The Youth MOVE National board is eager to support and work with its members in order to bring about positive systems change. Please check our website, www.youthmove.org, as we will post updates on activi-
ties pushing forward the national youth movement. We are also in the process of creating an email listserv for all Youth MOVE National members.

You can create a Youth MOVE chapter!

Youth MOVE National is excited to offer the opportunity to youth groups around the country to become chapters of Youth MOVE and become part of a network of youth actively involved in creating positive systems change. Our chapters will be free to run in their own individualized way while carrying out the mission and vision of the national board. The Youth MOVE National board will serve as the connection to keep a tight relationship between national and local levels. The voice of youth at a community level will be proclaimed and addressed by our national organization while the chapters will serve as the eyes and ears of Youth MOVE National at the state and local level.

Collaborate with Youth MOVE National

Youth MOVE National realizes that we cannot do it alone. We need help and welcome the opportunity to collaborate with other organizations to further the mission and vision of Youth MOVE National and to work towards the day where positive system changes are a reality.

A Local Example: Youth MOVE Oregon

Youth from across Oregon are beginning to organize themselves to bring a strong and united youth voice in the design, implementation and evaluation of youth mental health services, organizations and systems. This work has gone on across the state with many different organizations and programs. The newly formed Youth MOVE Oregon (YMO) is aiming to unite these groups and bring a strong youth voice for improving all youth-serving systems.

Recently, at the Governor’s Wrap-around Initiative Youth Work Group meeting, youth from across Oregon met and decided it was time to join together and be formally recognized as Youth MOVE Oregon. The young people are organizing within the Oregon Family Support Network (OFSN, a chapter of the National Federation of Families for Children’s Mental Health) until they are ready to leap out on their own. Martin Rafferty, a youth leader in Oregon, has been assigned the role of Director for this newly forming organization. He says that “This work is about uniting systems. This work is about youth leadership.”

The group’s first statewide stigma-reducing activity is helping to plan Children’s Mental Health Day at the capitol in May 2009. Members of the group will also be participating in the national anti-stigma “BUST IT!” campaign. Our youngest youth member stated, “We’re going to have free t-shirts, dancing, food… oh, and legislators and stuff—it will be a blast!”

Serving youth with professionalism, respect, and commitment is YMO’s top priority. YMO members believe young people are a great asset to their communities and should be encouraged, supported and recognized for their contributions. They wish to support youth advocating for positive change. If you would like to get in touch with YMO please email Martin Rafferty at martinrafferty@gmail.com or call OFSN at (541) 342-2876. We look forward to Youth MOVE-ing into your area of the state and nation!

Authors

Carl Yonder is the first director for Youth MOVE National. Though he doesn’t always like speaking about himself, he feels his work in whatever form will.

Johanna Bergan, Youth MOVE National Board Member, is passionately dedicated to removing the stigma around mental illness and improving mental health awareness, especially in rural areas.

Laura Rariden strives to serve youth with professionalism, respect, and commitment.

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Young adults struggling with mental health issues can often feel different, isolated, and powerless. Unfortunately, this isolation can lead to negative outcomes such as withdrawal from the community, dropping out of school, and severing ties with friends and family. Additionally, a mental health diagnosis can leave young adults with the fear that the future is no longer bright and that hopes and dreams are no longer possible. Fortunately, the truth is that recovery is a real possibility and something that every young adult can achieve despite the challenges that come with a mental health condition.

TRACS (Transition Resources and Community Supports) is a program of South Shore Mental Health in Massachusetts that serves young adults ages 16-25 with mental health or co-occurring mental health and substance use disorders. Founded on principles of psychiatric rehabilitation, stages of change theory, and the transition to independence process, TRACS strives to facilitate the reconstruction of hope, purpose and meaning in the lives of the young adults served. One strategy used to meet this goal is hiring young adult peer mentors onto our staff and incorporating them into the team at TRACS.

Young adult peer mentors are individuals that offer their firsthand experiences of living with and overcoming mental health issues to support and assist young adults who come to the program. The peer mentors demonstrate by their simple presence that recovery is real and possible.

To promote recovery, TRACS offers an array of services from which young adults may choose, allowing them to select what will be most helpful and skip what might not be as good a fit. Current services include peer support groups, monthly social/recreational events (laser tag, trivia nights, casino nights, sports games, etc.) with young adults from other programs, Photovoice projects (using photography for social action), and open studio nights for artistic expression. TRACS also offers resource workshops, book discussions, and support groups for parents and caregivers. Lastly, TRACS offers 1:1 peer mentoring where mentors provide more intensive, community-based outreach and support to a young adult.

The 1:1 Mentoring Relationship

TRACS serves about 50 young adults in any given 6-month period. However, only about 10 participate in 1:1 mentoring in a given 6-month period. In 1:1 mentoring, a peer mentor is paired with another young adult to work together in the community for approximately six months, for 1-2 hours a week. Young adults coming for mentoring are provided a handout at the beginning to clarify the mentoring relationship. (See box.) At the start of the mentoring relationship, the young adult sets goals that will be addressed in weekly meetings. TRACS has found it very important to maintain a focus on goals rather than general, open-ended support. The risk with just offering support is that when the young adult moves on from the program, he/she is back to the same place he/she started. So TRACS prefers to focus on bridging that young adult with other, more natural and sustainable resources that will help him/her long-term. Mentors are encouraged to approach each mentoring relationship as an opportunity to effectively work themselves out of their jobs; that is, to facilitate the young adult moving forward in such a way that at the end of mentoring, the young adult no longer needs a mentor. Mentors are encouraged to be open about their illness and recovery experiences, to the point that they are
A Peer Mentor is ...  
- Someone you can go to for advice on things like how to get housing, get a job, enroll in college, etc.  
- Someone you can go to for support around things like making friends, dealing with problems at school, navigating job interviews, etc.  
- Someone who can support you and understand you from the perspective of having had similar experiences.  
- Someone who can tell you about his/her experiences with matters such as medication and help you with things like how to remember to take your medication, how to talk to your doctor about what you are experiencing, etc.

A Peer Mentor is Not...  
- A therapist.  
- A case manager.  
- A bank! Please do not ask your mentor to loan you money.  
- A crisis line... if you need emergency or 24-hr support, please contact your local crisis team, whose number is on the welcome sheet.  
- A doctor, which means that your mentor can not give you advice about what medication to take or whether or not to take it.

**Goal-Setting**

During the goal-setting process, young adults are encouraged to keep in mind areas of their lives that are often overlooked in more traditional services, such as spirituality, health, recreation and relationships. TRACS generally sorts goals into five categories: employment, education, independent living, wellness, and social network/community connections. Young adults can set as few or as many goals as they want, but each goal should be something feasible to work on together with a mentor. To track progress on goals, a goal sheet is developed after the initial meeting with the young adult and this is referenced often during mentoring outings. After about three months, a review meeting is held with the young adult, the peer mentor, the program coordinator and anyone else the young adult would like (family, case manager, friend, therapist, etc.). At this review meeting, the young adult rates each goal and objective as “achieved,” “partially achieved,” “not achieved at this time,” or “no longer applicable.” Discussion centers on what happened concerning each goal. Regarding goals not met, the young adult can choose whether to continue working on them or not. New goals may also be added during the meetings. A written summary accompanies the goal review sheet to explain each rating. A similar review process is used at the wrap-up meeting at the end of mentoring to assess further progress on goals. By doing this, both the young adult and the program are able to track where there has been success and where there is still room for more work.

Here are some examples of the goals that have been reached through 1:1 mentoring:

- Obtained learner’s permit and/or driver’s license  
- Enrolled in classes for and/or obtained G.E.D.  
- Started attending part-time college classes  
- Obtained part-time employment  
- Learned to use public transportation  
- Increased connectedness with others in the community  
- Learned relaxation techniques to use when anxious

**Table 1. Goals Achieved by Youth Involved in Peer Mentor Program**

<table>
<thead>
<tr>
<th>Goal Domain</th>
<th>Percentage of Goals Achieved or Partially Achieved at 3 Months</th>
<th>Percentage of Goals Achieved or Partially Achieved at 6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>100%</td>
<td>80%</td>
</tr>
<tr>
<td>Employment</td>
<td>67%</td>
<td>100%</td>
</tr>
<tr>
<td>Independent living</td>
<td>73%</td>
<td>75%</td>
</tr>
<tr>
<td>Social network/community connections</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Wellness</td>
<td>100%</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>69%</strong></td>
<td><strong>82%</strong></td>
</tr>
</tbody>
</table>
I believe that the peer model in treatment is important because of the support that it provides. The peer model helps young adults connect with their peer mentor on a more personal level. This level is a deep understanding of what young adults are going through. Since I have already gone through a similar situation, as a peer mentor I can show other young adults that mental illness does not have to control their lives. More importantly, I show that an individual can recover from a mental illness and be a productive part of society. The other helpful part is that, as a peer mentor, I have had the chance to interact with these young adults in their community. This way the young adults have a chance to start their recovery within their community and not outside of it. I believe this helps promote a higher chance of recovery and stability for them. Overall, I believe the peer model helps show young adults that recovery is possible; however, it takes time and a helping hand.

Being a peer mentor has benefited me in many ways. I feel the most important change I have seen in myself since starting this position is that I am more outgoing and open. Before starting this job, I was a shy and introverted person. This job challenged me to be more extroverted. This change, however, has not only been seen in my work as a peer mentor but also in my school, personal, and family settings. This job has also challenged me to travel out of my comfort zone. For example, some of our young adults do not know how to use public transportation. This job has challenged me to learn different forms of public transportation and to not only use it but also to show and teach other young adults how to use it as well. Overall, this job has changed how I look at my own treatment going forward and how I can benefit both myself and other young adults.

— Justin Drakos
TRACS Peer Mentor at South Shore Mental Health

- Increased comfort being around other people
- Increased confidence in ability to form social relationships
- Increased comfort opening up to other people
- Used a planner effectively to manage time and keep track of appointments and schoolwork independently

Program Evaluation
TRACS receives positive feedback from young adults, their family members and other members of their treatment team about the impact of mentoring in their lives. Staff are also able to see the progress, but more attempts have been made recently to quantify the impact and learn where there is room for improvement.

To directly assess progress on goals, TRACS monitors the goal review process described above. Table 1 shows the percentage of goals by domain that were obtained over a nine-month period by eight young adults who were involved in our peer mentoring program over a six-month period. Please note that some goals are only worked on between the three- and six-month reviews, while others are worked on for the entire six-month mentoring period.

To assess the more global impact that mentoring is having on a young adult’s recovery, young adults are now asked to fill out the Recovery Assessment Scale (RAS) at the start and end of mentoring. This scale, developed with input from mental health consumers, is designed to look at recovery in a broad context rather than just evaluating presence and absence of symptoms. Young adults rate their agreement with statements on a 5-point scale (strongly disagree – strongly agree). The RAS includes subscales measuring the domains of:

- Personal confidence and hope (e.g., I am hopeful about my future)
- Willingness to ask for help (e.g., I know when to ask for help)
- Goal and success orientation (e.g., I believe that I can meet my current personal goals)
- Reliance on others (e.g., Even when I don’t care about myself, other people do)
- No domination by symptoms (e.g., Coping with my mental illness is no longer the main focus of my life)

While the RAS is a helpful indicator of overall recovery, it still does not capture all the nuances that are part of the mentoring relationship, so TRACS developed an additional short survey that is given at the end of mentoring to further evaluate impact. Survey questions are rated on a 7-point scale from “got much worse” to “got much better,” and young adults are provided space to comment on each question. Questions on the survey were developed based on feedback staff received about ways mentoring was helping young adults that were often not captured on a goal sheet. They include how mentoring influenced participants’ comfort around other people, levels of independence, sense of hope, and interest in achieving goals.

Evaluation using the RAS and the internal survey is still in process, but preliminary data has been very positive. An effort has been made to administer as few surveys and ask as few questions as possible to maintain the integrity of responses and not frustrate young adults who come for services, not forms. Nonetheless, the feedback is extremely helpful and is incorporated into ongoing quality im-
Final Remarks

Young adults challenged by mental health issues face an array of potentially overwhelming experiences. By partnering with them to infuse a sense of hope, build resiliency and promote recovery, TRACS hopes to steer young adults away from potentially detrimental outcomes and onto the path of positive, purposeful futures. The use of young adult peer mentors facilitates this process by ensuring that recovery is real, visible and tangible for young adults still in the throes of illness. Peer mentors not only provide a model of what is possible but also coach young adults on how to make that possibility a reality. By supporting young adults in the process of reaching even small goals, TRACS hopes to teach young adults skills that they will be able to use on an ongoing basis after mentoring is over. As with any program, ongoing evaluation and improvement is crucial to ensure that the program is actually accomplishing what it intends. As such, we look forward to continuous developments and improvements in the program.

References


THE TWO-WAY BENEFIT OF PEER MENTORING

I have been diagnosed with bipolar, anxiety, and PTSD. I have been in recovery from these mental health conditions for about four years. I attribute much of my recovery to being a young adult peer mentor since early 2006. I find this position to be very rewarding and empowering. It is great to have a job that has meaning and allows me to help others using my past experience. I went through something that may have been negative but I was able to get through it and come out a stronger person in the end. My experience can help other young adults going through similar situations now who want support from people who have experienced it themselves.

For most of my life I felt that I was unheard and had to struggle with my illnesses alone, making it much more difficult to recover. Since working with young adults through mentoring, I now see that many feel the same way that I did while going through this period in my life. I feel that because I share similar experiences with my peers we are able to connect on a much deeper, more personal level than, say, a psychiatrist or therapist who has not had the lived experience of a mental illness.

I remember feeling like people did not understand what I was going through. I felt judged—people made assumptions about me because of what I was dealing with. The young adults that I have worked with tell me they feel this way too and that they feel more comfortable talking to someone who is on the same level as them, rather than an adult who is much older because this can be intimidating. They know that when they go out with me one-on-one that I am not judging them, trying to prescribe them medication, or evaluating their behavior.

I have worked with a couple of young adults who, after a few weeks of meeting with me, seem much happier than when we were first introduced. This position allows me to take young adults out into the community and accomplish a set of goals that they created during the intake process. In some cases the young adults do not have someone they feel comfortable talking to or they just do not get out much, but the mentoring program gets them out and allows them to talk with someone around their age about common experiences. Mentoring connects them with another young adult who is in recovery from a mental health condition and this is proof to them that recovery is possible. They have the opportunity to learn that they do not have to go through this alone and that they can be a stronger, happier person.

—Liz Pepin

TRACS Peer Mentor at South Shore Mental Health
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