

Supports for Young People with Mental Health Conditions and Their Families in the Transition Years: Youth and Family Voices

Pauline Jivanjee and Jean Kruzich

Young people aged 17 to 24 with mental health conditions face significant obstacles in obtaining services and supports as they negotiate the transition from adolescence to adulthood. For many of these young people, results of an “unsupported transition” include high rates of unemployment, homelessness, and incarceration, as well as substance abuse, unplanned pregnancy, and engagement in high-risk behaviors. In general, families want to be supportive, but they struggle to understand the unique needs of their children and to be involved in their treatment. This article reports on a qualitative study of the experiences and perceptions of transition-age youth and their parents of using mental health services and informal supports. Findings indicate that youth and parents appreciated service providers who were compassionate, well trained, and responsive to needs, and that they appreciated family and peer support. Participants complained about ineffective and unhelpful staff, the lack of relevant services, and youths’ loss of eligibility for services at age 18. Ideal supports include families; peer support and leadership development groups; accessible, appropriate services; and responsive, compassionate service providers. Optimal supports and services will be more likely when young people and families are included in service planning and delivery.

Keywords: youth in transition; young adults with mental health conditions; family support; peer support; mental health services

Pauline Jivanjee, PhD, is a research associate at the Research and Training Center on Family Support and Children’s Mental Health at Portland State University in Portland, Oregon. Jean Kruzich, PhD, is associate professor in the School of Social Work at the University of Washington in Seattle. This research was supported by the National Institute on Disability and Rehabilitation Research (U.S. Department of Education), the Center for Mental Health Services, and the Substance Abuse and Mental Health Services Administration (U.S. Department of Health and Human Services, Grant No. H133B040038). The content does not necessarily represent the views or policies of the funding agencies. The authors wish to thank Lyn Gordon, Jan Lacy, Lacey Vankirk, Cathy Callahan-Clem, and Cynthia Brothers for their assistance and our project participants for sharing their experiences and perspectives.

The transition from adolescence to adulthood is marked by role transitions such as finishing education, beginning full-time employment, and forming adult relationships. In the transition to adulthood, young people also begin to develop responsibility for themselves, make independent decisions about their own beliefs and values, and move toward achieving financial independence and relationships with parents as equal adults (Arnett, 2000, 2001). Some young people also take on additional responsibilities as parents. At the same time, parents experience their own transitions as they redefine family relationships and renegotiate rules and limits as their children move toward greater degrees of independence (Blacker, 2005; Preto, 2005). However, for young people with serious mental health conditions, the transition years are fraught with challenges resulting from their struggles with symptoms; from the prevalence of stigmatizing attitudes among teachers, service providers, peers, and others that affect their integration into the community; from their difficulties in accessing appropriate mental health and other supportive services and community supports (Vander Stoep, Davis, & Collins, 2000); and from the bewilderment of their ill-prepared parents (Harden, 2005). Many of these difficulties are even more profound for culturally diverse youth in communities where stigmatizing attitudes are common and options for obtaining help are more limited (Dialla et al., 2000; DiCerbo, 2000; Fox, Becker-Green, Gault, & Simmons, 2005; Lindsey et al., 2006).

While the developmental processes of transition occur gradually and are linked with cultural expectations, institutional transitions are “abrupt, arbitrary changes in status” linked to changes in legal status and eligibility for services, often related to age (Davis, Green, Beckstrom, & Wing, 2005; Davis & Koroloff, 2007; Vander Stoep et al., 2000, p. 6). Many youth with mental health difficulties are ineligible to receive services from the adult mental health system because of “arbitrary distinctions between the nature of serious mental health conditions in minors versus adults,” and for those who are eligible, there are few specialized services available (Davis & Hunt, 2005, p. iv). Frequently, when young people lose coverage under their parents’ insurance policies, they are required to apply to different providers and meet different eligibility criteria (Podmostko, 2007), and they may fail to gain access to public or private services (Davis et al., 2005), resulting in many “falling through the cracks.” The lack of access to appropriate mental health services is compounded by the lack of availability of transition services for this population (Davis, Geller, & Hunt, 2006).

Estimates of the number of youth and young adults aged 16 to 25 with a mental health disorder vary between 2 and 6.5 million, of whom a small percentage, estimated to be between 6 and 33 percent, receive mental health services (Vander Stoep et al., 2000). These young people encounter barriers to community integration related to the prevalence of stigmatizing attitudes (Gowen & Walker, 2009) and are at risk of a range of negative outcomes, including dropping out of school, unemployment, homelessness, involvement in criminal activities, substance abuse, and early pregnancy (Armstrong, Dedrick, & Greenbaum, 2003;

Blackorby & Wagner, 1996; Kortering, Braziel, & Tompkins, 2002; Newman, Wagner, Cameto, & Knokey, 2009; Podmostko, 2007; Vander Stoep et al., 2000; Zigmond, 2006). While the prevalence of mental health disorders increases in young adulthood, due to the later age of onset of some disorders, studies have revealed “precipitous decline” in mental health service utilization after the age of 18 (Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008, p. 373). This finding may be associated with young people losing access to school-based mental health services.

While only a small proportion of young people with serious mental health conditions receive services, even fewer receive services that they perceive as helpful. When asked about their experiences with transition services, both young people with mental health conditions and parents have been critical of their limited involvement in planning services and of the relevance and helpfulness of services provided (Davis & Butler, 2002). Most families want to be helpful but lack skills to assist their young adult children with mental health conditions. Often they are “deskilled” in their interactions with mental health professionals, some of whom implicate families in “causing” the mental health condition (Harden, 2005, p. 216). These difficulties are compounded after the child has legally become an adult (at age 18, or younger for some types of health-related decisions), when parents are excluded from the treatment relationship and service providers are unwilling to share information about the child’s diagnosis and treatment because of confidentiality laws (Davis et al., 2005; Vander Stoep et al., 2000). It may be especially difficult for culturally and linguistically diverse parents to be involved in planning for transition services for their children because of language and cultural factors. Providers may fail to reach out to diverse parents, interpreting their constrained involvement as lack of interest (Geenan, Powers, & Lopez-Vasquez, 2001).

In summary, the literature indicates that young people with serious mental health conditions face significant hurdles in their journey to adulthood, that they encounter barriers to community integration, that supportive services are lacking, inadequate, or difficult to access, and that their primary support system, namely their family, is deliberately excluded from services. With few exceptions, there is little research to suggest how families and peers can best support these young people; additionally, there are few firsthand reports from the perspectives of young people and parents, and those that do exist focus on the shortcomings of policies and services. This article reports on findings from separate focus groups with a sub-sample of pairs of transition-age youth with mental health needs and their parents, focusing on their experiences and perceptions of receiving formal mental health services, as well as family and peer support and the ways that these types of supports enhance young people’s sense of community integration. The sample was part of a larger study that examined community integration across a wide range of domains (Jivanjee, Kruzich, & Gordon, 2007, 2009). Throughout the article, “transition-age youth,” “young people,” “youth,” and “youth and

young adults” will be used interchangeably to indicate young people age 17 to 24 who have a mental health condition. “Parents,” “family members,” and “families” will be used to refer to parents or other adults who are primary caregivers or parent figures for youth in this study. All young people who participated in the study had received mental health services and/or were referred to participate by mental health professionals who viewed the youths’ mental health needs as interfering with their daily functioning.

Methods

At each research site in two northwestern cities, advisory groups were developed that included ethnically and racially diverse young adults with mental health conditions and family members of young people with mental health services involvement. Advisory board members provided consultation at all stages of the project, including the development of recruitment materials, pre-focus group questionnaires, and focus group questions. Focus groups were selected as the major method of data collection because individuals are less likely to feel vulnerable in a group than in a one-to-one interview and are more likely to feel a greater degree of control over how much they wish to contribute to the discussion (Farquhar, 1999; Jarrett, 1993). Focus groups also have the benefit of not discriminating against people who have difficulty reading or writing (Owen, 2001). Given the sensitivity of the topic, the researchers also recruited, hired, and trained young adult research assistants who had experience using mental health services and used family members to assist with recruiting participants and facilitating focus groups.

Youth research participants were recruited through contacts with local mental health agencies, youth advocacy/support groups, colleges, alternative schools, and youth employment organizations. Parents were recruited through their membership in family support organizations. Project staff distributed brochures, flyers, and electronic bulletin board announcements inviting young people aged 17 to 24 with mental health difficulties and families of such youth to participate. The research team made deliberate attempts to seek ethnically and racially diverse participants with some limited success. In total, twenty focus groups were held, of which twelve were with youth and young adults and eight with parents. Most youth participants were not related to the parent participants; however, approximately one third of the entire sample was parent-child pairs who participated in eight separate focus groups, four with young people and four with parents. These participants comprise the sample for this analysis. While the larger sample was quite diverse in terms of race, ethnicity, and social class, the sub-sample of parent-youth pairs described here was less diverse.

Participants

Participants of this sub-sample were sixteen young people and their eighteen parents (both parents of two youth took part). Fourteen of the sixteen youth

participants were male with an age range of 17 to 23 and a mean of 19.4 years. Responses to the demographic questionnaire indicated that fourteen were European American, with one Native American and one Pacific Islander. Thirteen youth participants reported that they were living with one or both parents, while two were living with extended family; one youth checked "living alone or with room-mates." Seven youth participants indicated that they had graduated from high school or obtained their GED; six had not graduated and two reported that they were still in high school. While five youth reported that they were in full-time or part-time school or employment, six reported that they were unemployed and three that they were unable to work; two reported that they were participating in supported employment or vocational rehabilitation.

Sixteen of the eighteen parents in the focus groups were female and the age range was 37 to 60 years of age (mean 46.3, *SD* 7.4). Most participants were mothers, with two fathers, one aunt, and one grandmother who were primary caregivers. Sixteen family members reported that they were European American, plus one Native American and one Hispanic. The most frequently reported youth diagnoses were: bipolar disorder (8), depression (6), learning disabilities (6), attention-deficit disorder (3), behavioral disorder (3), obsessive-compulsive disorder (2), and post-traumatic stress disorder (2); other diagnoses were endorsed by one participant and many participants reported multiple diagnoses for their child. Table 1 summarizes youth participants' self-reported use, need, and access to mental health services.

Data Collection

Parallel versions of the same focus group questions were used with parents and young people, with questions focused on the meaning of community integration for transition-age youth with mental health needs; barriers and supports to their community integration; hopes, goals and dreams for youths' futures; and advice to other parents and youth with similar concerns. Prior to each focus

Table 1 Youth Report of Current Use, Need and Access to Services by Percent (*N* = 16)

Service	Currently receiving	Needed, but not received	Offered, but could not access
Medication	10	1	1
Individual counseling	3	0	1
Case management	7	1	1
Mentoring	1	2	1
Employment support	2	3	1
Support group	3	1	1
Drop-in center	1	1	1
Group counseling	2	1	1
Wraparound	2	1	1
No services	1	NA	NA

group, participants also completed parallel versions of a two-page questionnaire that included questions about demographics; youth living arrangements; involvement in school and work; and need for, access to, and use of mental health services. Focus groups were held in a range of community settings. Based on the assumption that participants would be more comfortable talking with someone who had shared similar experiences (Jarrett, 1993; Morgan, 1988), youth focus groups were facilitated by a youth research assistant and family focus groups by a family member; in each case one of the principal investigators or the project manager acted as a co-facilitator. Refreshments were provided and each focus group lasted about 90 minutes; participants were paid \$30 in appreciation for their time. Focus group discussions were tape recorded (with participants' consent) and transcribed.

Data Analysis

Questionnaire responses were entered into SPSS and descriptive statistics were computed. Focus group transcripts were entered into N6 qualitative analysis software (QSR International, 2002). With the assistance of the software, all team members participated in data analysis, following instruction in the constant comparison method, originally developed by Glaser and Strauss (1967) and updated by Charmaz (2005). Team members read transcripts and completed preliminary independent coding for categories and themes using the original questions to guide their analysis of participants' definitions of community integration, barriers and supports to community integration, goals, and advice for others in a similar situation. After this preliminary analysis, team members met and compared the categories and themes they had inductively derived. In a series of negotiations, the individual coding lists were combined into a shared coding map and then team members coded two transcripts and added additional codes as they emerged. In further team meetings, the team engaged in intensive reviews of these coded materials and reconciled codes. Finally, after team members had reached a satisfactory level of consistency in coding, they coded the remaining transcripts independently. More detailed descriptions of the team-based interpretive data analysis process are provided in Jivanjee, Kruzich, and Gordon (2007, 2009). Categories of participant comments that emerged during analysis were usually situated in specific contexts and relationships. The report of findings that follows is focused on participant reports of experiences with mental health services and support from families and peers.

Findings

As recorded in table 1, these young people and family members reported only limited use of mental health services. In the report of qualitative findings that follows, youth and parent responses regarding positive experiences with services are presented first, followed by challenges related to services. Following these sections,

we present youth and family perspectives on family support for youth, and peer support for both youth and families. In each section of findings, we first present youth perspectives and then family perspectives.

Positive Experiences with Mental Health Services

Both youth participants and parents expressed appreciation for helpful services, with youth making positive comments about service providers' responsiveness while families emphasized practical supports and providers' willingness to communicate with them.

Youth Reports Several young people reported helpful experiences with counseling, particularly where service providers were responsive to their needs, taught them useful skills, or gave them hope for a better future. A young man reported:

I had counseling. I had it once a week. It was pretty fun. It helped me a little . . . just talking to them helps me do better during the week. It made me look at what I did during the week and what I could change if I did something bad, to make it better.

Another young person described a counselor's assistance:

He had good advice on how to calm myself down, gave me some things called cognitive thinking skills that I started using . . . basically, some tools to use to calm myself down and get my mind straight and things like that.

One young man appreciated his counselor's responsiveness and availability: "He was . . . cool. Whenever I needed to talk, he would be there. He would come by. It was like 4:00 in the morning and he would come over and talk to me." Other young people described service providers who had been especially helpful; as another young man commented, "She helped me a lot through a lot of this stuff, and she is still helping me. I don't know, she just gives me that little glimmer of hope and that's cool."

As shown in table 1, over half of the youth participants were currently using medications, and several young people reported that medication was helpful in managing their symptoms. One young man appreciated his psychiatrist's approach: "My psychiatrist has been willing to try all sorts of different medications . . . [and] not over-prescribing."

Family Reports Parents tended to emphasize the value of practical help and resources, including wraparound services, respite care, appropriate medication, and providers' willingness to collaborate with and support them. One parent was pleased with a case manager's activities to help her son reintegrate into the community and his willingness to consult with the family: "He was also open to hearing his dad's and my thoughts on what we thought would be especially helpful for —." Similarly, one parent reported that a psychiatrist partnered with the

122 *Best Practices in Mental Health*

family: “What also worked for —— was having a psychiatrist that asked for input and accepted our input, our observations.” Several families had received wrap-around services and they were generally enthusiastic about this support. For example, a parent commented on the power of the wraparound team to meet her son’s needs:

One of the biggest pieces for him was to have a mentor. Wraparound team, thank you! That also mandated the school to get more involved, I think, too, because there was then an expectation that the district was part of that team.

Parents who had worked with a wraparound team reported that they felt supported; as one mother put it:

It is kind of like a support group . . . that wraparound team helps me know how to continue to be in his life in appropriate ways and where to draw lines with him, that kind of thing. It really has helped my parenting skills.

Another parent described the help she received from the wraparound team and a parent partner (a parent with experience navigating service systems on behalf of a youth or young adult with a mental health condition, and trained and hired to support other parents):

[It] made it possible for me not to have all the answers . . . what she said is, “You no longer need to be his doctor, his therapist, his nurse, his playmate, his interpreter, his counselor, whatever professionals there were. You don’t need to do that. All you have to do is be his mom.”

Respite care was mentioned positively as a support to families. In-home respite care enabled one parent to keep her job:

It allowed me to keep my professional life separate from my personal life, I guess is what I am saying . . . he was getting what he needed and I got a chance to kind of regroup before I had to go home to him.

Challenges Related to Inappropriate or Unavailable Services

In contrast to the positive reports, there were many descriptions of inaccessible and inappropriate services and unhelpful providers. Both youth and parents recounted stories of youth, who were unable to get appropriate mental health or school-based services, being referred to the juvenile justice system, which in turn resulted in more challenges for them.

Youth Reports Youth reported that their inability to find appropriate mental health services was related to the lack of service providers who really understood them, providers’ pessimistic attitudes, and the use of ineffective or problematic medications. One participant was critical of psychiatrists and other providers who did not take the time to get to know him: “A lot of the time they are wrong and

don't know the patient, because they are not willing to listen." Several youth wanted to find helping professionals and peers who had shared their experiences and would understand them, but they were discouraged because they could not find such people. For example, one young man commented, "It is hard to find people who have kind of gone through the same thing or understand and can support you." Similarly, a young man who had experienced an extended period of inpatient treatment said:

The hospital . . . it held me back because the mindset of a hospital is really pessimistic and they give out a lot of pessimistic prognoses. They try to refute any sort of objectives that I had personally, like go to college. . . . They tell me things like, "You are going to be on meds the rest of your life. . . . You are going to be in and out of hospitals, in and off the streets."

While medications were helpful to some participants, others reported that they were ineffective. A young man said, "I've been on just about everything up until recent years, ever since I was a kid. They all worked to some degree for a while and then I would start getting immunities to them, and they would stop working." Some young people described their dislike of medication side effects; others were wary of medications and suspicious of the motives of physicians prescribing drugs. For example, one youth was critical of physicians who prescribe "a lot of medications that someone doesn't need or prescribing therapies that people don't need, just so that they can get the money."

Family Reports Many parents were upset and angry about restrictive eligibility rules that excluded their children from services, particularly the loss of services when youths turned 18. They also complained about their children's lack of access to appropriate treatment and service providers' ineffectiveness in working with their children. One mother commented on the lack of understanding of her son's illness and the absence of support for him:

My kid runs everybody off. We have gone through Big Brothers, so it gets really frustrating. I have even had counselors just throw their hands up going, "This kid is way over my head." I have had school counselors bail out. So it gets frustrating.

A grandparent reported that she had been told her grandson's difficulties were too serious for him to respond to treatment:

Do you know what they say about kids like mine? "They are too severe for the program . . ." I have had mental health professionals working with my son walk away and say, "I am concerned for my own safety, so therefore I can't help your child." I am like, "Aren't you trained to work with kids like him?" I don't know why these people are being paid to serve kids like ours. They are judgmental. They are mean.

124 *Best Practices in Mental Health*

Other parents complained that they could not access needed services, usually because of budget cuts or restrictive eligibility rules. One mother described her frustration because of such barriers:

Every time I try to get him help, even with respite care, they always say, "We don't have the funding for it." "We don't have this." "We don't have that." "He doesn't meet the criteria." "He is not severe enough." He just keeps falling through the cracks and they just keep pushing me away.

A mother reported the financial impact on her family of obtaining appropriate treatment:

We went broke back then, because there were not community services in the state . . . at the level he needed, so we had to go private insurance and had an advocate to help us so we could access any insurance we could.

Several parents said that their children lost eligibility for health benefits or Social Security benefits when they turned 18, even though their conditions had not improved. One parent said her son would have no coverage after he lost his health insurance on his nineteenth birthday. Another parent said, "He just got declined by SSI. We have always been in private insurance, so we have no resource through the state or anything like that for him. He won't be able to get his medications." Another parent whose son had a developmental as well as a mental health disability described the lack of logic of his being denied Social Security:

I just got the denial letter. . . He just turned 18 and they told me that he no longer qualified. I asked them why. They told me. I said, "He hasn't changed." . . . But the system has changed. I just need an opinion that says that his behavior is a direct result of his low IQ instead of his low IQ a direct result of his behavior.

Family Support

Both youth and family members talked at length about the assistance and support that family members had provided and continued to provide even after they turned 18. This sub-sample of pairs of parents and youth may not be representative of the wider population of transition-aged youth with mental health difficulties and parents of such youth. Because they both participated in the separate focus groups, they may be assumed to have closer and more supportive relationships than other young people and their parents, and their comments yield insights into the benefits of these supportive relationships. Parents also described their ongoing concerns about their children's well-being and their desires to support them, while also encouraging their independence as young adults.

Youth Reports Several youth participants talked about positive support they received from their parents. For example, in response to a question about where youth participants received support, one young man responded, "Nowhere. My

parents.” Another youth gave a more detailed response of his mother’s efforts to assist him:

My mom has helped me a lot. My mom has been a really big supporter of me trying to achieve my goals. She has been helping me out, because I want to move out. I turn 18 in like two weeks, and I want to move out and live on my own, but it is going to be hard for me because once I turn 18, the supports that I have, some of them are going to disappear. . . . I am going to have to be able to deal with my issues on my own and find other supports. My mom has been helping me out with figuring that stuff out.

A young man reported on his appreciation of the assistance his parents provided even though he was legally an adult:

My parents have been a pretty big support, too. I’m 19, so I can’t get support like I did when I was under 18, so my parents had to still kind of stay in there and help me through all the legal troubles and helped guide me through programs, support groups. They really helped me out and kind of gave me motivation to go out and get jobs and help me fill out the applications.

Another young man appreciated the support and advocacy on his behalf that his parents had provided throughout his illness:

Family support was a big help for me when I was in the hospital. I probably would have stayed in there a lot longer if it wasn’t for them. I know the hospital was planning on sending me to a group home once I turned 18. Actually they were going to send me to a group home until I turned 18, and then they wanted to send me to the adult ward in the hospital. But my parents stepped in and they really argued with them and they told him they would take me in, and they would help out. They would let me stay in their place, which I think is very fortunate for me, because a lot of people didn’t have family support. . . . That was a big help for me in comparison to the other people in my predicament.

Family Reports Parents reported wanting to assist their children and the challenge of finding a balance between supporting their children and encouraging their adult development. For example, a parent commented, “As parents you wonder what is the fine line between enabling your child or helping them.” Another parent described her efforts to achieve a delicate balance of support and encouragement for her son’s moves toward independence after a difficult adolescence in which he was hospitalized with a diagnosis of schizophrenia:

Somebody with schizophrenia tends to rely on their family a lot and having common interests so you are not always thinking about bad stuff, you are focusing on the good things. Sometimes that takes planning and thinking through to make those things happen, and all the time trying to find ways to

126 *Best Practices in Mental Health*

push him out, encourage that, always letting him know that he has a choice. It is really okay to go and be with your buddies instead of come here.

Another parent described her offers to be as helpful as she could be to her son:

I told [name of son], "If you need me in there, you need to voice that. I can't say it for you and I can't ask to go in. So if it is something that you need me sitting there, just for your security or whatever, you say, 'I am not doing this without my mom present or my father.'"

Peer Support

Not surprisingly, given that the families who participated in these focus groups were members of family support organizations, they eagerly described the support they had received from other parents who had also raised a child with a serious mental health condition. Similarly, some youth participants appreciated receiving support from other young people.

Youth Reports While some youth participants reported mixed experiences with support groups they had participated in, they noted that groups had been helpful when the members and leaders were similar in age, shared experiences with mental health services, and included activities focused on leadership development. One youth contrasted youth-oriented groups with typical adult-oriented ones:

There were a couple of groups that I have been to that were really cool, actually. Everybody in there was like 20. It is like the trials and errors of going through high school . . . things that we can relate to, going through what we have been through and trying to make it in life with all these obstacles. . . . Not just like, "Back in Nam, I blah, blah, and I started doing heroin," and they are like 85 years old now.

As a result of positive support group experiences, some of these participants were willing to help other youth who were struggling. For example, a young man said he was thinking, "What can I do to aid in this now? Where we could get together as people who are in the same position as me and form some sort of mentoring?" Some youth participants had become involved in a youth leadership development organization and they reported gaining skills as well as support networks of peers.

Family Reports Parents saw the benefits of their children's involvement in receiving and providing support and engaging in advocacy activities. For example, a parent reported that her son had found a new community by becoming involved in a youth leadership program: "[Name of program] . . . is a supportive group of people that do the same thing for him that we do for each other, and that is make them feel . . . they are good people with a difficult childhood." This parent elaborated on the benefits of this group:

The youth are learning to be leaders in the community. My son is the vice president of the ——— movement here in the state. That is the only thing that I really feel that has ever really given him any kind of purpose. It is just amazing. . . . He really understands the importance of the role . . . that he is talking about system design and designing it for youth like himself. . . . Your son may not want a therapist, but if he could connect with another youth . . . that could say, "Are you really thinking about what you are doing before you are doing it?" That is way more powerful than a lot of the paid professionals that run away from our kids because they are afraid of them, or say they are too extreme to meet criteria, or they are not extreme enough.

This parent talked about her son learning from observing her acting as an advocate for families and emulating her behaviors: "He will call me with people that he has met who need help and he knows how to access everything."

When asked what had been helpful to them in dealing with their child's illness, parents were enthusiastic about the support they received from other parents, especially through family support organizations. As one parent commented, "What helps me is the support that I feel from other families." Parents reported many benefits from their participation in a family support organization:

We have a great family organization structure here that is helpful for resources, information, training, and support. We also do peer supports, and it helps us as parents to have that extra support, too. It is just an awesome thing.

As mentioned earlier, several parents appreciated the assistance they had received from parent partners supplied by wraparound teams. One mother captured the critical element of empowerment offered by this support:

Peer mentorship that has occurred for parents . . . has been so successful, because actually when you empower a parent, it really does help us to change and see our children differently and do things differently for them.

Connections to other parents were described as a key to overcoming the shame that many parents felt:

One of the things that I think has been so helpful for us as parents to heal and not feel shame and guilt about our kids has been our support in our community. It is our [name] parent group . . . which is where a core group of parents got together for many, many years, going through the adolescent years with our kids. That has been the saving grace for us, to know that we are not bad parents. We are parents doing a difficult job with difficult kids.

Discussion

Focus group findings provide firsthand accounts of the struggles of young people with mental health conditions and their families to maintain supports for

successful transitions to adult roles and preferred levels of community integration. While this was a small study with a sample of youth and family participants that cannot be assumed to be representative of all youth with mental health conditions and their families, we believe the findings provide much-needed first-person perspectives on the needs of transition-age youth. Caution must be used in considering the applicability of our findings to other youth and family populations, particularly since our sample was not very diverse, although it is instructive to link our findings with other research on related issues. Most youth participants were male and living with their parent(s), and most parent participants were female. Therefore it may be assumed that these young people's relationships with their parents were closer than youth living apart from family. Because of the overrepresentation of mothers and sons, further research will be needed to gain information about whether daughters and their fathers have had similar experiences. These parents were also actively involved in family support organizations, and as a result, they (and their children) were probably better connected with both professional and peer support systems, including advocates, than other similar families who are not members of family support organizations. Given the extent of challenges they reported, it is likely that other families would encounter even more difficulties accessing appropriate mental health services for their children. Ideally, we would have reported the comments of matched youth-parent pairs; but because of our open-ended questioning format, specific youth and parents did not necessarily address the same topics, resulting in our adopting a reporting format across groups.

Both young people and their parents recommended improving access to well-trained, compassionate service providers, and youth participants expressed appreciation for service providers who were responsive, available, hopeful, and focused on meeting their needs. This finding reflects findings from another study in which young people reported on the characteristics and behaviors of mental health service providers that were most acceptable to them, including "positive personality traits" ("friendly and nice . . . patient"), "active listening," and being "understanding" ("someone cares and can relate to what you are saying") (Hyman, Manion, Davidson, & Brandon, 2007, pp. 266–267).

While some youth and families spoke of positive experiences with mental health services, many of their accounts document difficulties in accessing appropriate services and skilled service providers, especially after age 18. Other researchers have recommended that to improve mental health services, it will be necessary to eliminate the discontinuities between child and adult systems and to use definitions of disability based on functional impairment, regardless of age (Davis et al., 2005). The creation of developmentally appropriate supports (Davis & Hunt, 2005) is also integral to such improvement and is a key element of the evidence-supported transition model proposed by Clark and associates (Clark et al., 2002; Clark & Hart, 2009).

Families reported their commitment to assisting their young adult children, and they lamented the constraints on their helping roles resulting from being

excluded from services due to confidentiality rules. Young people expressed appreciation for the support and assistance they received from their families, even after they reached legal adulthood. There is a need for interventions to support parents during the transition years. Successful transition planning is based on mutual respect between professionals, youth, and families and is characterized by open and honest communication, a solution focus, knowledge of resources, and empowerment of youth and parents (Hitchings, Natelle, & Ristow, 1999). As noted by parents in this study and recommended by Preto (2005) and Leggatt (2007), connecting parents with other parents is vital to reducing families' feelings of isolation in their distress and gaining reassurance from those who have experienced the same or similar situations. There is a need to balance parents' desires to be involved in their children's care with young people's rights to confidential care (Fox & Limb, 2008).

Youth participants in our study were strengthened by peer support and opportunities to participate in youth leadership activities and assist other youth. A youth-led study specifically recommends creating opportunities for youth to use their experiences in helping others, as well as for family involvement in transition services (Federation of Families for Children's Mental Health [FFCMH] & Keys for Networking Inc., 2001). Literature suggests that peer support can take a variety of forms (Solomon, 2004). Peer support groups have been found to be an effective intervention for youth and family members dealing with a range of health problems, including Asperger's syndrome (Weidle, Bolme, & Hoeyland, 2006), traumatic brain injury (Hibbard et al., 2002), and HIV in adolescents (Funck-Brentano et al., 2005). Nascent research on peer-provided services versus standard services, albeit primarily with adults, has found improved outcomes for individuals with serious mental health conditions on a range of measures including alcohol use, empowerment, confidence, and functioning (Resnick & Rosenheck, 2008); lower rates of hospitalization (Lawn, Smith, & Hunter, 2008); and significantly increased consumer perceptions of motivation, knowledge of mental illness, confidence, and hope (Salyers et al., 2009).

Conclusion

As reported by youth with serious mental health conditions and their families, the fragmented system that youth must navigate as they attempt to transition to adult roles and achieve their preferred levels of community integration is fraught with challenges that compound the difficulties resulting from their diagnoses. Findings from this qualitative study provide consumer perspectives on improving mental health services for transition-age youth and their parents and strengthening family participation in services. Participants' comments also suggest the benefits of peer support for both parents of transition-age youth and youth themselves. These topics deserve to be examined further in future research designed collaboratively with young people and their families to address questions that are of concern to them and with more ethnically diverse samples that also include

greater representation of fathers and daughters. Youth transitions to adulthood and a fulfilling life in the community will be improved by the creation of a seamless mental health system serving all ages, with effective service providers who understand and have compassion for young people and a willingness to collaborate with them and, when appropriate, with parents. As the voices from this study attest, youth and families want service providers to ask them what would be helpful and to act on their recommendations. They want access to peer support to normalize their experiences and provide practical strategies for better futures. With such supports, challenges to successful transitions can be overcome, and young people can engage positively with their communities.

References

- Armstrong, K. H., Dedrick, R. F., & Greenbaum, P. E. (2003). Factors associated with community adjustment of young adults with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders, 11*, 66–76.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469–480.
- Arnett, J. J. (2001). Conceptions of the transition to adulthood: Perspectives from adolescence through midlife. *Journal of Adult Development, 8*, 133–143.
- Blacker, L. (2005). The launching phase of the life cycle. In B. Carter & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.) (pp. 287–306). New York: Pearson Educational.
- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*, 399–413.
- Charmaz, K. (2005). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed.) (pp. 507–535). Thousand Oaks, CA: Sage.
- Clark, H. B., Belkin, M. T., Obradovich, L. D., Gagnon, R., Caproni, P., Deschennes, N., & Casey, R. E. (2002). The transition from school to community: Navigating rough waters. In K. L. Lane, F. M. Gresham, & T. E. O'Shaunessy (Eds.), *Interventions for children with or at risk for emotional or behavioral disorders* (pp. 299–316). Boston: Allyn & Bacon.
- Clark, H. B., & Hart, K. (2009). Navigating the obstacle course: An evidence-supported community transition system. In H. B. Clark & D. K. Unruh (Eds.), *Transitions of youth and young adults with emotional or behavioral disorders: An evidence-supported handbook* (pp. 47–113). Baltimore: Paul H. Brookes.
- Davis, M., & Butler, M. (2002). *Service system supports during the transition from adolescence to adulthood: Parent perspectives*. Washington, DC: National Association of State Mental Health Program Directors and National Technical Assistance Center for State Mental Health Planning.

- Davis, M., Geller, J. L., & Hunt, B. (2006). Within state availability of transition-to-adulthood services for youths with serious mental health conditions. *Psychiatric Services, 57*, 1594–1599.
- Davis, M., Green, M., Beckstrom, T., & Wing, S. (2005, February). *The collision of institutions and individuals during the transition to adulthood*. Plenary presentation at the System of Care Community Meeting, Collaborative Approaches to Successful transition for Children, Youth, and Families within Systems of Care, Dallas, TX.
- Davis, M., & Hunt, B. (2005). *State efforts to expand transition supports for young adults receiving adult public mental health services*. Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.
- Davis, M., & Koroloff, N. (2007). The great divide: How mental health policy fails young adults. In W. H. Fisher (Ed.), *Community-based mental health services for children and adolescents, Vol. 14* (pp. 53–74). Oxford, UK: Elsevier Sciences.
- Dialla, C., Muntaner, C., Walrath, C., Nickerson, K. J., LaVeist, T. A., & Leaf, P. J. (2000). Racial differences toward professional mental health care in the use of services. *American Journal of Orthopsychiatry, 70*, 455–464.
- DiCerbo, P. (2000). Risking a future: How do we keep Hispanic youth in school? *On the Move with School-Based Mental Health, 5*(1), 1–6.
- Farquhar, C. (1999). Are focus groups suitable for 'sensitive' topics? In R. S. Barbour & J. Kitzinger (Eds.), *Developing focus group research: Politics, theory, and practice* (pp. 47–63). London: Sage.
- Federation of Families for Children's Mental Health (FFCMH) & Keys for Networking Inc. (2001). *Blamed and ashamed: The treatment experience of youth with co-occurring substance abuse and mental health disorders and their families*. Alexandria, VA: FFCMH.
- Fox, H. B., & Limb, S. J. (2008). *State policies affecting the assurance of confidential care for adolescents*. National Alliance to Advance Adolescent Health, Incenter Strategies, Fact Sheet No. 5.
- Fox, K., Becker-Green, J., Gault, J., & Simmons, D. (2005). *Native American youth in transition: The path from adolescence to adulthood in two Native American communities*. Portland, OR: National Indian Child Welfare Association.
- Funck-Brentano, I., Dalban, C., Veber, E., Quartier, P., Hefez, S., Costagliola, D., et al. (2005). Evaluation of a peer support group therapy for HIV-infected adolescents. *AIDS (London, England), 19*, 1501–1508.
- Geenan, S., Powers, L. E., & Lopez-Vasquez, A. (2001). Multicultural aspects of parent involvement in transition planning. *Exceptional Children, 67*, 265–282.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Gowen, L. K., & Walker, J. S. (2009). Stigmatization. *Focal Point: Research, Policy, and Practice in Children's Mental Health, 23*, 3–7.
- Harden, J. (2005). "Uncharted waters": The experience of young people with mental health problems. *Qualitative Health Research, 15*, 207–223.

- Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., et al. (2002). Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *The Journal of Head Trauma Rehabilitation, 17*, 112–131.
- Hitchings, W. E., Natelle, B., & Ristow, R. (1999). Parents, professionals, and the transition process. In P. Retish & S. Reiter (Eds.), *Adults with disabilities: International perspectives in the community* (pp. 77–102). Mahwah, NJ: Lawrence Erlbaum Associates.
- Hyman, S. I., Manion, I., Davidson, S., & Brandon, S. (2007). “Youth-friendly” characteristics in mental health settings. *Vulnerable Children and Youth Studies, 2*, 261–272.
- Jarrett, R. (1993). Focus group interviewing with low-income minority populations: A research experience. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 184–201). Newbury Park, CA: Sage Publications.
- Jivanjee, P., Kruzich, J., & Gordon, L. J. (2007). Community integration of transition-age individuals: Views of young adults with mental health disorders. *Journal of Behavioral Health Services and Research, 35*, 402–418.
- Jivanjee, P., Kruzich, J., & Gordon, L. J. (2009). The age of uncertainty: Parent perspectives on the transitions of young people with mental health difficulties into adulthood. *Journal of Child and Family Studies, 18*, 435–446.
- Kortering, L. J., Braziel, P. M., & Tompkins, J. R. (2002). The challenges of school completion among youth with behavioral disorders: Another side of the story. *Behavioral Disorders, 27*, 142–154.
- Lawn, S., Smith, A., & Hunter, K. (2008). Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service. *Journal of Mental Health, 17*, 498–508.
- Leggatt, M. S. (2007). Minimising collateral damage: Family peer support and other strategies. *The Medical Journal of Australia, 187*(7 Suppl), S61–S63.
- Lindsey, M. A., Korr, W., Broitman, M., Bone, L., Green, A., & Leaf, P. (2006). Help-seeking behaviors and depression among African-American adolescent boys. *Social Work, 51*(1), 49–58.
- Morgan, D. (1988). *Focus groups as qualitative research*. Newbury Park, CA: Sage Publications.
- Newman, L., Wagner, M., Cameto, R., & Knokey, A. M. (2009). *The post-high school outcomes of youth with disabilities up to four years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)* [NCSE 2009-3017]. Menlo Park, CA: SRI International.
- Owen, S. (2001). The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of Advanced Nursing, 36*, 652–8.
- Podmostko, M. (2007). *Tunnels and cliffs: A guide for workforce development practitioners and policymakers serving youth with mental health needs*. Washington, DC: National Collaborative on Workforce and Disability for Youth, Institute for Educational Leadership.

- Pottick, K. J., Bilder, S., Vander Stoep, A., Warner, L. A., & Alvarez, M. F. (2008). US patterns of mental health service utilization for transition-age youth and young adults. *Journal of Behavioral Health Services and Research, 35*, 373–389.
- Preto, N. G. (2005). Transformation of the family system during adolescence. In B. Carter & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.) (pp. 274–286). New York: Pearson Educational.
- QSR International. (2002). *N6 qualitative analysis software*. Melbourne, Australia: QSR International Pty. Ltd.
- Resnick, S. G., & Rosenheck, R. A. (2008). Integrating peer-provided services: A quasi-experimental study of recovery orientation, confidence, and empowerment. *Psychiatric Services, 59*, 1307–1314.
- Salyers, M. P., Hicks, L. J., McGuire, A. B., Baumgardner, H., Ring, K., & Kim, H. (2009). A pilot to enhance the recovery orientation of assertive community treatment through peer-provided illness management and recovery. *American Journal of Psychiatric Rehabilitation, 12*(3), 191–204.
- Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27*, 392–401.
- Vander Stoep, A., Davis, M., & Collins, D. (2000). Transition: A time of development and institutional clashes. In H. B. Clark & M. Davis (Eds.), *Transition to adulthood: A resource for assisting young people with emotional or behavioral difficulties* (pp. 3–28). Baltimore: Paul H. Brookes.
- Weidle, B., Bolme, B., & Hoeyland, A. L. (2006). Are peer support groups for adolescents with Asperger's syndrome helpful? *Clinical child psychology and psychiatry, 11*, 45–62.
- Zigmond, N. (2006). Twenty-four months after high school: Paths taken by youth diagnosed with severe emotional and behavioral disorders. *Journal of Emotional and Behavioral Disorders, 14*, 99–107.