Community Integration of Transition-Age Individuals: Views of Young with Mental Health Disorders

Pauline Jivanjee, PhD
Jean Kruzich, PhD
Lynwood J. Gordon, MSW

Abstract

This qualitative study examines the perceptions of young adults with mental health disorders of community integration. Fifty-nine young men and women participated in 12 focus groups whose aim was to gain understanding of what community integration means to them. Focus group questions also explored barriers and supports for their community integration, as well as their goals for the future and advice to others facing similar challenges. Themes that emerged were reported within the multiple domains that participants used to describe their experiences of community integration (or the lack thereof). This study highlights the desires of these young people to achieve goals in education and employment and to have friendships. Participants identified a pervasive lack of understanding of mental health and prevalent stigmatizing attitudes as resulting in challenges to their community integration. Implications of the study discuss roles for behavioral health services in encouraging empowerment, choices, and connections so that young people with mental health disorders may achieve their preferred levels of community integration.

Introduction

For behavioral health service providers working with young people with mental health disorders, the concept of community integration broadens the focus of assessment and intervention. Moving beyond symptom management, a focus on community integration broadens the goals of services to optimizing the quality of life in all life domains for young people with mental illness. A focus on community integration is compatible with system of care principles

---

Address correspondence to Pauline Jivanjee, PhD, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751 Portland, Oregon 97207-0751, USA. Email: jivanjeep@pdx.edu.

Jean Kruzich, PhD, School of Social Work, University of Washington, Box 354900, 4101 15th Avenue, Seattle, Washington 98105-6299, USA.

Lynwood J. Gordon, MSW, Clark County Department of Community Services, P.O. Box 5000, Vancouver, Washington 98661, USA.

Journal of Behavioral Health Services & Research, 2007 © 2007 National Council for Community Behavioral Healthcare.

that have transformed the delivery of children's mental health services in the last two decades to be community-based, comprehensive, and family/youth-centered,[1] and it provides a framework for goals for successful functioning in important adult roles desired by young people. This article reports on the findings of a qualitative study of the perspectives of young adults aged 17–24 on community integration. The purpose of the study was to gain understanding of the ways that young people in transition to adulthood describe community integration, the ways that they strive to achieve their preferred levels of community integration, and the barriers and supports they encounter in the process. In this article, the phrases "young people" and "young adults" are used interchangeably to refer to the population of 17- to 24-year-old individuals.

Community integration is generally viewed as a multidimensional construct, including both objective elements (e.g., activities outside the household, contact with neighbors and others) and subjective elements (e.g., feelings about the meaningfulness of social contacts, attitudes about one's sense of belonging, availability of help, feelings of influence, and emotional investment in the community and community members).[2–4] Community integration has been linked with the concept of recovery.[2,5,6] The President's New Freedom Commission on Mental Health highlights objective aspects in its definition of recovery as a "process in which people are able to live, work, learn, and participate fully in their communities."[7, p.5] Salazar's[8] community integration framework links community integration with opportunities for increased community presence and participation and well-being and recovery. Whereas the intent of the current study was to examine community integration from the perspectives of young people with mental health difficulties, the researchers were guided by Aubry and Myner's[9] conceptualization of community integration as they initially formulated study questions. According to these authors, community integration refers to the ability of people with disabilities to fulfill activities of daily living (physical integration), to engage in social interactions with non-disabled community members (social integration), and to feel a sense of belonging in their communities (psychological integration). Whereas the integration of young adults with mental health disorders in the community has not been an explicit focus of research to date, research findings on community integration of adults with serious mental illness are available and relevant.

The earliest studies of community integration were based on samples of adults with serious mental illness who had been deinstitutionalized and had returned to live in community-based care facilities. Segal and Aviram[10] examined the influence of client, facility, and community factors on residents' integration and found community characteristics were the most important predictors; these characteristics included neighborhood response to clients, location of facility, and distance of facility from community resources. Another study found personalizing care practices, such as celebrating residents' birthdays, was predictive of residents' higher levels of community integration; this study also found that staff interaction with clients in informal, everyday routines had more influence on their community integration than the formal social skills training the facility offered.[11]

By the 1990s individuals with serious mental illness were far more likely to be living in apartments and outside of community-based long-term care settings that characterized residents' living situations in the 1980s. A study that documented the impact of three organizations' shift to a greater emphasis on empowerment, community integration, and social justice[8] showed that consumers became more involved in leisure activities, churches, and with friends and families. Similarly, Hardiman and Segal[12] found that consumers involved in self-help agencies (SHAs) that gained a say in decision making had higher self-esteem and were more likely to include fellow SHA participants in their networks. These findings from community integration studies of adults with serious mental health problems may be used to sensitize behavioral health service providers to a variety of individual, organizational, and community factors that can inform efforts with young adults and their families.

Like others, young adults with mental health needs belong to multiple communities of place, such as neighborhoods, school districts, and metropolitan areas, as well as multiple communities of identification, interest, and association. Naturally, these may overlap. A young person's "personal community" denotes her/his membership in a mix of communities in which s/he engages in social interactions and gains goods and services to achieve social and economic well-being.[13] However, pervasive lack of understanding of mental health and mental illness in American communities results in high levels of stigmatizing attitudes toward young people with mental illness. The effects of stigma are discrimination, segregation, social isolation, and limits on community participation.[6,13]

Prolonged use of restrictive residential and inpatient services is antithetical to community integration; even in the shift to community-based services, however, the combined effects of stigma, poorly coordinated, developmentally inappropriate services, and weak transition planning efforts have constrained young people with mental, emotional, and behavioral disorders and their families from achieving their preferred levels of community integration.[14–17] Furthermore, opportunities for this group of young people to participate optimally in community life are compromised by low employment rates, below average post-secondary educational achievement, above average involvement with juvenile justice, and ongoing difficulties managing thoughts, feelings, and behaviors.[17,18] Thus, a distressing proportion of young people with mental health disorders become "disconnected youth,"[19] who struggle on the margins of their communities, without work, without stable housing, without supportive relationships, and often in trouble with the law.

In recent years, researchers have begun to attend to the lived experience of adults with mental illness and the meaning of recovery from their perspective.[20–22] However, most of these qualitative studies do not include specific information about the ages of the participants. Studies that include age generally report a broad age range;[21,23] in only one instance was the mean age of participants (41 years) provided.[24]

This study is the first study explicitly designed to gain understanding of community integration from a diverse sample of transition-age individuals with mental, emotional, or behavioral disorders from their own perspectives. For this exploratory, descriptive qualitative study, the aim was development of understanding of community integration for this population of young adults. The study reported here was part of a larger study that also explored the perspectives of family members on the community integration of their children with mental health disorders. Portland State University's Human Subjects Research Review Committee approved the study.

Study Methods

At each research site (Portland, Oregon and Seattle, Washington), advisory groups were developed that included ethnically and racially diverse young adults with mental health disorders and family members of transition age individuals with mental health involvement. Advisory board members provided consultation at all stages of the project including development of recruiting tools, prefocus group questionnaires, and focus group questions.

Focus groups were selected as the method of data collection because they are ideal for examining similar subjective experiences and encourage mutual shaping and extending of participants' ideas.[25] Another strength is that individuals are less likely to feel vulnerable in a group than in a one-to-one interview, and more likely to feel a greater degree of control, relative to individual interviewees, over how much they feel under pressure to contribute to the discussion.[26] Focus groups offer the opportunity for participants to hear the perspectives of other participants and thereby extend the complexity of their personal reflection and analysis.[25] A key assumption of the focus group literature is that individuals with common concerns and experiences will be more willing to share viewpoints and disclose personal information.[27]

Participatory research teams were formed at the two sites; both included a young adult research assistant and a family member research assistant who were trained in focus group methodology, ethical aspects of research, and issues related to confidentiality and who served as focus group moderators. The principal investigators expected that young people would feel more comfortable participating in focus groups co-facilitated by a trained research assistant of similar age, and would be more open to discussing their experiences and perceptions with other young people who had also used mental health services. The project's principal investigators were European American, but the team included three persons of color. Most project staff were family members themselves and/or had personal experience with the mental health system.

To meet the research team's goal of including young adults with varying ethnicities, gender, and socioeconomic status, the research team used purposive sampling, sampling deliberately for heterogeneity on factors designated as important to the concepts studied.[28,29]

At both research sites young adults were recruited through contacts with schools, colleges, family support organizations, youth employment, and alternative educational programs, as well as agencies serving homeless and GLBTQ youth. Project staff distributed brochures, electronic message board announcements, and flyers at youth serving agencies inviting youth who had been involved with mental health services and were between the ages of 17 and 24 to contact project staff. In some cases, agency staff shared project materials with youth being served by their program; in others, meetings with parent support groups identified youth who were interested in participating. All of the youth referred to the focus groups were either identified by a mental health provider as someone who had received mental health services or by their parent who was active in a family support organization. The team's recruitment efforts resulted in a moderately diverse group of participants.

Twelve 90-minute focus groups for young adults were held in a variety of community settings in the Seattle and Portland metropolitan areas, at public libraries, human service agencies, offices of family support organizations, and university settings. Before the start of the focus group participants completed a prefocus group questionnaire and signed consent forms to participate in the focus group and to have their comments audio-taped. Young adult research assistants assumed the lead role in facilitating the groups, whereas a principal investigator or the project manager assumed a secondary role of taking notes and taping the session with two audiocassette recorders. After the focus group interview, participants received $30.

Whereas both research sites shared the same overall sampling goals, community differences in the availability of alternative programs, parent support networks, and relationships with educational and social service agencies resulted in samples with differing characteristics. Whereas staff at both sites aimed recruitment efforts at the same types and variety of community-based agencies, the sites varied in terms of securing cooperation from community-based agencies. Four of the Seattle area focus groups were comprised of youth recruited through presentations at family support group meetings and were held in meeting rooms in public libraries located close to their homes or the office of a family advocacy organization. The remaining Seattle group interviews were conducted either at an alternative educational and work program site or a county office that provided space for participants in a youth support and advocacy group. Two of the groups had members with multiple-system involvement, most frequently including criminal justice and mental health.

Recruitment efforts with community agencies in Portland were less successful, for the most part, in attracting diverse participants. The most effective recruitment occurred at the local public university where the research team was housed. The young adult research assistant placed an announcement about the study on the university's website bulletin board, inviting students who had used mental health services to contact the research team. As a result, with the exception of one focus group at an agency that served young people who had multiple-system involvement, Portland focus groups were held on campus, with participants who were primarily college students or the young adult children of participants in the family focus groups. Because of these variations in youth recruitment between sites, their demographic characteristics were quite different. The Seattle sample was more ethnically diverse (54% Caucasian vs. 83% in Portland groups); had lower educational levels (0% had any college education vs. 37.5% who had some college in Portland); and the Seattle sample was somewhat younger (18.9 vs. 20.5 years of age). This demographic information is provided to describe the diversity of the sample; however, it was not a purpose of the study to compare the experiences of participants at the two study sites.

Participants

The final sample of focus group participants included 36 young men and 23 young women (all participants' gender was known, and additional demographic information was returned by all but one participant). Their ages ranged from 15 to 28, with a mean age of 19.5 years and standard deviation of 2.45. The majority of participants were European American (66%), with 15% African Americans, 10% multiracial, 7% Pacific Islander and 2% Native American. Of the 58 young adults who responded, 5% were currently enrolled in high school, 41% had dropped out of high school, 39% had graduated from high school or gained a general education diploma (GED), 14 % had some college, and 2% had completed a four-year degree. The largest percentage of youth were living with their parents (42%), with 21% living with roommates, 16% alone, 10% with other extended family, 7% with a partner or spouse, and 9% in a homeless shelter. On the pre-questionnaire participants were asked to check their most recent diagnosis and all others that applied. Anxiety, depression, and bipolar disorder were the three most repeatedly identified diagnoses. Frequencies of participants' reported diagnoses are shown in Table 1 below. It is noteworthy that 22% of youth participants did not report a current diagnosis.

All of the Native American and Asian/Pacific Islander young adults checked one or more diagnoses, whereas 13% of European American, 43% of multiracial, and 56% of African American young adults did not check a diagnosis. Similarly, no Native American or Asian Pacific/Islander young people checked "unknown" for most recent diagnosis, whereas 8% of European American, 14% of multiracial, and 33% of African American young people did. These interesting differences between the proportion of African American and European American young adults' identification of a personal diagnosis may result, at least for some, from the prevalence of stigmatizing attitudes that people of different races express toward psychiatric illness. There is some evidence that African American parents tend to perceive professional contact as increasing the risk that family members will be inappropriately labeled, medicated, or

Table 1

Young adult self-report of most recent mental health diagnoses,[1] *N*=59

Diagnosis	Percentage of youth reporting diagnosis
Anxiety disorders[2]	45
Depression and dysthymia	40
Bipolar disorder	28
ADHD and other disruptive behavior disorders[3]	26
Learning disabilities	14
Substance abuse	14
Schizophrenia and schizo-affective disorder	5
Did not check any diagnosis	22
Checked 'Unknown'	12
Other[4]	22

[1] Percentages add to more than 100% because of multiple diagnoses.

[2] Includes obsessive compulsive disorder (OCD), posttraumatic stress disorder (PTSD)

[3] Includes conduct disorder and opposition defiant disorder

[4] Includes Asperger's, attachment, adjustment, and other disorders.

hospitalized.[30] Black parents have reported a prime reason for not allowing their child to receive a psychiatric assessment is the great perceived potential for punitive intervention in the family by social service agencies.[31]

Data collection instruments

Each focus group participant completed a self-administered questionnaire before the focus group that included questions related to demographics, living arrangements, participation in school and work, and their use, need for, and access to services. Given that the purpose of the study was to explore participants' experiences and perspectives, the team developed a set of open-ended questions asking young people to share their views of: (1) the meaning of community integration and a successful life in the community; (2) barriers to community integration; (3) supports to community integration; (4) their hopes for the future; and (5) advice they would give another young person struggling with similar challenges. In early focus groups, it became apparent that participants, regardless of educational level, had difficulty talking about community integration in the abstract. Therefore, for ensuing groups, the team added a probe that asked participants to identify those places and situations where they felt a sense of belonging.

Data analysis

Responses from the questionnaire were entered into SPSS for computation of descriptive statistics. Focus groups were audio-taped, transcribed, and entered into N6 qualitative software.[32] With the assistance of the software, the research team analyzed the data using the constant comparative method originally developed by Glaser and Strauss.[33]

A three-stage process of analysis was developed. First, each team member was assigned several transcripts to read independently, using the five major areas of questions to guide the preliminary analysis: the meaning of community integration and a successful life in the community, barriers and supports to community integration, hopes, goals, and dreams, and advice they would give to others in similar situations. Within these broad categories, team members identified themes in an inductive analysis process and a preliminary code list was developed through negotiation during a series of team meetings. Next, all team members independently assigned these preliminary codes to two transcripts and added additional codes where needed. In an intensive review process, team members compared coded transcripts, reconciled differences, and reached agreement on the coding system. Then pairs of team members independently coded an assigned transcript and reconciled codes. Finally, after acceptable agreement among coders had been established on these transcripts, the remaining transcripts were coded by research team members independently.

Provisional codes were generated from categories that arose within the data. These analytic categories flowed from responses to the focus group questions and related to the meaning of community integration (framed as "a successful life in the community"), barriers and supports, hopes and dreams, and advice, were retained because of their utility as a broad analytic framework. Within these categories, multiple subcategories emerged from the data. For example, within the category of supports for a successful life in the community, participants' comments were coded as being related to relationships with others (e.g., supportive relationships, feeling appreciated, feeling connected); providing opportunities for young people to experience a sense of achievement (e.g., access to positive experiences, developing strengths and talents, opportunities to meet or achieve goals, volunteer activities); addressing their mental illness (e.g., accurate information, understanding of mental health difficulties, effective services); or allowing a sense of personal control (empowerment/choice, independence/confidence).

After the analysis of data, available research participants were invited to member checking meetings where preliminary findings were reviewed. Participants commented on the extent to which the report of findings resonated with their own experiences and suggested clarifications. In addition to taping and transcribing interviews, developing an audit trail, and peer debriefing, member checking is a recommended strategy for increasing the credibility of qualitative research findings.[34,35] The team also shared preliminary findings with members of the youth advisory group and gained increased understanding participants' responses.

In the process of analysis, additional themes emerged in regard to participants' experiences with relationships and their perspectives on claiming adult roles. In the following report of findings, the researchers have organized the presentation of primary themes according to participants' descriptions of their experiences and perspectives related to forming connections with others, including decisions about whether to tell or not tell others about their mental health; their needs for practical, accessible supports and services; challenges and successes in the educational system; finding meaningful adult roles; searching for a place to call home; and finding personal fulfillment. Where relevant, quantitative data from pre-group questionnaires are included in thematic reports.

Findings

Forming connections with others

When asked about their sense of community integration, young people tended to focus on the importance of having relationships with people around shared interests and their desires to make a positive contribution to the community. For example, one young person commented,

"I think whenever I have things in common with other people; those are the times when I feel more part of that community."

These young people expressed their intent to make positive contributions and to be involved in community activities, as expressed in the following comment: "Success for me in three years is knowing that I can help others and be involved in my community as much as possible." For some young people, the meaning of community integration was closely related to their beliefs about civic responsibility and the importance of volunteer activities:

"Being successful in the community for me would be giving back to other people, like she was saying, like going outside of the community and doing other stuff."

The theme of getting involved in the community was also represented in their advice to other young people ("If you use services, try to give back to the community in some way"), as well as their encouragement to find an interest: "Get into gardening. Get into something that is beauty, that is beneficial for you, like a passion." Some participants acknowledged beneficial effects of community engagement on their mental health, as indicated in one young woman's comment: "Helping other people, it keeps me feeling like I am doing something progressive and it also helps me feel good about myself."

The lack of understanding of mental health difficulties: the dilemma to tell or not tell

When talking about their experiences in all types of community settings, participants spoke to the common theme of a pervasive lack of understanding of mental health difficulties:

"You are going back and forth, you are bipolar, you are suicidal...but nobody else understands you, because you can't explain what you are going through...So they push you away, so you have absolutely no support to integrate back into society, to be able to figure out who you are, what you are doing, how you can function with this disorder that you have."

Associated with reports of the lack of understanding were comments about the prevalence of stigmatizing attitudes, which led these young people to be guarded in their decisions about disclosure of their mental illness: "Now I don't tell people as often, because I think, one, the stigma. I'm afraid that I will be judged..." Some young adults reported being able to overcome their fear of stigma when they learned about other people with mental illness living successfully in the community. As one participant commented, "It was an awesome feeling that this is a thing that other people experience...After that [an experience of meeting an artist with serious mental illness] I kind of got to the point where I just tell everyone."

Being able to be open about their disorder was an underlying theme for young people when they talked about their hopes, desires, and goals for the future, as reflected in the following comment:

> "I would want to be a part of something... I would like to be comfortable enough with my disability to not feel like I have to hide anything from anybody. That would allow me to really be around other people."

Participants described the risks involved in disclosing their illness to peers who did not understand. For example, one young man said,

> "I lost a lot of friends once I did try to share it. It was devastating, because one of my friends...was scared that I may go off the deep end. He didn't want to get sucked into that."

These young people advised other young adults with mental health difficulties to seek support people who have had similar experiences:

> "It really helps to have people who have either similar symptoms or just understand it, that they have actually experienced it, not just that they accept it, but they actually know what it is like."

The importance of support from family and friends

Supportive relationships with friends and family were reported to be especially important to these young people:

> "...having parents who finally got what was going on—I think I was lucky in a lot of ways, because my parents do understand."
>
> "My foster mom was the best...She let me make my own decisions. She was there for me when I made the wrong ones and she was there for me when I made the right ones."

In addition to support from parents, participants acknowledged emotional support from relatives, including uncles, aunts, and grandparents. Furthermore, two young adults who were parents also reported the importance of their sense of connection to their children and they agreed that having a child have forced them to seek stability in their lives, as indicated in one comment: "Other than that, I would probably be doing what I was doing, out there still doing drugs." As noted above, focus group participants reported that knowing people who had similar experiences that they could relate to was helpful:

> "...realizing that I had friends who also had some similar things, or just had something wrong with them...like talking to people I am kind of equal with, and being able to talk a lot and really open up about it."

The need for practical, accessible supports and services: Avoiding "by the book and by the clock" professionals

These young people reported variations in their capacity to access mental health services. Of the 59 young adults who participated in the study, 36% reported private insurance as a source of payment for mental health services, 12% indicated personal or family funds, 20% mentioned public sources of funds (Medicaid, Medicare, SSI), 19% identified no coverage for mental health funds, and 7% wrote in "not sure". Responses to questions about their receipt, need, and access to mental health services are reported in Table 2 below.

For some young people, defining community integration incorporated the need for formal supports and services, as suggested in the following comment: "Having relationships and connections with a lot of people, and also having resources, like having a lot of resources and being able to access them." However, many barriers and challenges were reported around the lack of accessible, developmentally appropriate formal resources, as exemplified in the following comments:

> "They gave me like a list, and there was no one to call and nothing online..."
> "It was the stupidest thing I've ever done. It was a free community service and everything, but the things that we had to do! We were all older than 15 and they were making us paint the insides of boxes and make clay figures..."

Additionally, there were frequent complaints about uncaring, clueless, "by the book and by the clock" professionals, for example,

> "Psychiatrists, I saw a lot, and you know, they kind of messed with me for a while, because I was on the wrong meds and I was zoned for a year...I was given the wrong diagnosis and the wrong meds."

Another young person described an experience with an unhelpful service provider:

> "I would see her twice a week, but I got absolutely nothing out of that... we would sit down and go through the number, one through ten, of your symptoms and stuff like that. I just kind of felt

Table 2

Young adults' self- report of current receipt, need, and access to community-based mental health services, *N*=59

Service	Currently receiving (%)	Needed, but not received (%)	Offered, but could not access (%)
Medication	36	10	5
Individual counseling	34	9	7
Case management	22	5	5
Mentoring	14	10	7
Employment support	14	17	5
Support group	14	9	9
Drop-in center	9	5	7
Group therapy	9	8	16
Wraparound	6	7	14
None	12	3	5
Other	3	9	2

like, okay, just give me the medication and let me go because I am wasting every week just sitting here. There was no relationship or anything. It didn't feel like caring."

In contrast, young adults appreciated programs focused on transition-age youth that offered practical and emotional support and were staffed by caring, skilled, professionals:

"They gave me this list of ten coping skills...They were giving me a way out, or at least something to believe in."
"My high school counselor was my best support...She was always there, she was really accessible..."
"[Transition specialist] was the first person I would call when anything went wrong...now I am learning how to step back and look at it and realize that she is there if I need her, the program is there if I need it, but I don't need it as much as I did."

In regard to service providers, these young people offered advice to others about taking charge of their lives:

"If you feel like your therapist isn't really listening to you or if something is not right with a particular doctor or therapist, go ahead and see someone else."

Education and training: fitting square pegs in round holes

Of young adults 18 and under, 12.5% (*n*=3) were currently attending high school, 58.3% (*n*=14) had dropped out or been expelled, and 29.2% (*n*=7) had graduated or received their GED. Of the 34 young people aged 19 and older, 29% (*n*=10) had not graduated from high school or received a GED, 44% (*n*=15) had graduated from high school, 23% (*n*=8) had some college, and one participant was in graduate school. Thirty percent of the young people in the study described themselves as full-time students at school or college and 14% reported attending school or college part-time. For these young people, community integration related to their hopes of educational and employment-related accomplishments; one youth, for example, stated, "I think for me having opportunities to be able to meet my goals in the community as far as school and jobs and stuff like that." For other young people, however, unsupportive high school culture (viewed mainly in retrospect) and educational system shortcomings had serious negative impacts on their lives:

"I think it is like this awful social structure in high school that totally insulates everyone to think that all there is, is...the suburbs and there is nothing else."
"...high school, it was such a huge part of your life, and if that is ignoring your mental health problems, then it is harder to deal with."

On the other hand, school was also a venue where some young people reported gaining solid information about mental illness and mental health, finding encouragement and fostering hope.

"I took a psychology class in high school and that like totally opened up everything...I remember reading the OCD section of the book, and I was, Ohmigod, everything in here is exactly me."

Several participants reported the benefits of taking classes that helped them to understand their illness and one college student reported that by choosing psychology as his major, he had learned a lot that disproved what he had previously believed about himself:

"To be able to analyze it and turn it into a science in my head has helped out a lot with me not feeling that there is something wrong with me... makes it easier to deal with."

College was also a venue where some young people discovered others with similar conditions with whom they could form relationships; this discovery also helped them to feel normal:

> “It was so relieving for me to start finding people who also have mental illnesses and... the knowledge base that people who have bipolar, schizophrenia, depression, OCD, whatever, aren’t only in hospitals. They are in society [and] are contributing as well.”

When asked about their hopes and goals related to education, some of these young people expressed their desires to complete more advanced schooling, ranging from gaining a child care license to a Ph.D. Their advice to other young people focused on encouraging others to stay in school, to take studies seriously, and to build a support system to enhance their success. As one young woman expressed,

> “Don’t transfer. Try to find people who are really solid, like they are rooted. You don’t have to tell everybody your problems. You can just quietly learn from people.”

They also recommended that educational institutions recognize and work with students’ individual needs, giving: “A little more flexibility on who they are going to help out, even if it is a reasonable accommodation, saying, hey, this guy needs a couple of weeks, he will be back, and it is understandable.” These young people were thankful for access to training opportunities, such as those provided by a youth leadership organization and other trainings that gave a chance, as one young woman commented, “not just to get paid more, but to help us in the long run.”

Finding meaningful adult roles

Some young people described having a job as an important aspect of life in the community. For the group as a whole, there were mixed patterns of employment, education, and training. Twelve per cent reported working full-time and 21% said they were working part-time. Eleven per cent reported participating in a Training/Vocational Rehabilitation program and 4% in supported employment. Twenty-five per cent reported being unemployed and 7% described themselves as unable to work.

These young people described many of the same barriers that affect other young people trying to get their first jobs, such as the lack of transportation or appropriate education. Some young adults also faced challenges in gaining employment resulting from having a learning disability or a criminal record, or because of being homeless. In addition, some young people reported that it was difficult to get or keep a job because employers did not understand their mental health difficulties and they had experienced stigmatizing attitudes in the workplace. For example, one young woman reported, “I actually had to quit my last job because it was so bad, because my boss was so unaccommodating.” Another young woman commented, “I would say stigma, people saying okay, you are probably not capable of doing it then. You are having problems now, so we don’t want to deal with you.” Another young woman described the dilemma of whether to tell her employer about her mental health difficulties:

> “There are times when there is so much pressure you have to tell [your employer] so they understand what is going on. That’s when they don’t want to hear it or they don’t want to understand.”

In contrast, some young people reported positive outcomes of having a job or being involved in volunteer work, particularly when their employer understood their needs. One male participant commented, "My direct supervisor, who is a psychologist, knows I have PTSD, but we never bring it up. I just tell him I want to take a few hours off or a day off every once in a while and he never asks or pressures."

Other participants expressed positive attitudes toward work, specifically for the opportunities to form relationships with coworkers and to feel appreciated by others, as well as the satisfaction of a job well done. Some participants enjoyed their involvement in volunteer activities where they formed relationships, increased their skills, and gained a sense that they were contributing to the community.

A place to call home

In response to questions about their living situation, 41% of these young people reported living with their parent(s), 21% with roommates, 9% with extended family, and 7% with a partner. Sixteen per cent said they were living alone and 9% reported being homeless or staying at a shelter. Those who were living in their own apartment valued the freedom and sense of independence that having their own place allowed, and those who were living in other situations (mainly with family members or roommates) desired to live independently. One young man spoke to this desire for freedom when he stated his ideal living situation: "Apartment just to myself, no roommate. Don't got to worry about nobody else. I do what I want. That's what I want." One young person expressed appreciation for practical information and assistance related to housing:

"There is a place...and they have a section there that just deals with people finding low-income housing. They have been helping me out with looking, and giving me a list of low-income apartments that I can get into and stuff."

However, young people reported encountering significant barriers to affordable housing. For many, the cost of housing was prohibitive in urban and suburban areas of the Pacific Northwest and there were reports of long waiting lists for federally subsidized housing. For example, a young woman commented: "For me, it means a whole lot, a whole lot that we don't have. A place to live where you don't have to worry if your rent is going to get paid." Others described their own home as a goal for the future that would be an important part of their general stability and well-being:

"Three years from now I want to be more stable and not have as many crises as I do have. I just want to be more stable. I want to be able to have a job and a place of my own and be able to manage that well."

Some young people wanted to maintain contact with family, regardless of their living situation, and one young man expressed his wish to have his own home close to his parent and siblings.

Finding personal fulfillment

Focus group participants described using their talents and strengths in ways that gave them a sense of personal fulfillment. This was often tied to creative pursuits, such as art; as one participant related with pleasure, "I drew Mt. Rainier and there is a butterfly on Mt. Rainier... and I drew Downtown... That was really cool." A young person described his vision of a successful life in the community as, "[I would] probably be creating things, such as art, or whatever...I feel productive and just hoard things that I create. A lot of it is kind of 'shopping' in my own head." Other participants said that they enjoyed reading and sometimes experienced positive effects, as in the case of one young man who commented, "That's such a good book and it made me feel so much better about myself... you find out stuff about yourself that you don't even know."

In response to questions about barriers to community integration, participants described the effects of their disorders on their personal motivation and behavior. As reported in Table 1 above, these young people had been diagnosed with a variety of mental health conditions; these were described, often in moving terms, as affecting their functioning. For example, several participants described being vulnerable to stress and paralyzed at times by their anxiety. One young person reported that he had held back from activities because of “my own sense of failure, whether or not I can actually do it and what that meant about me and my future prospects if I failed.” Several participants described the effects of depression on their lives. As one young person said,

> “I suffer from depression, which causes me to just shut my life out, close the window, shut the blinds, tell people to go away, don’t answer the door, don’t answer the phone. Just sit there and sit.”

Opportunities for rejuvenation, spiritual guidance, and self-expression were described as important for helping these young people to maintain their sense of well-being. One young person commented: “I like to go to a quiet place and have my own time to think, just me, going to the beach and walk around.” One young man reported finding a sense of well-being in playing music: “For me, it’s my music equipment; you know what I’m sayin’? That’s where I find my peace at.” Some young people reported finding comfort and strength in their faith; for example, one participant said, “I am a Quaker, so I believe in making myself better, not having anyone help me.” Another participant recommended, “The Bible is a comfort; it will get you through life.”

Finally, when describing their hopes and goals, young people mentioned a wish for a sense of personal success, for example, “The biggest thing is I want a sense of accomplishment in three years.” Another participant emphasized taking charge of one’s own life: “You have to be able to put the best foot forward, and actually want to change your life.”

Discussion

This qualitative study used focus groups to gain understanding of the perspectives of young adults with mental health disorders as they attempt to live successfully in the community. For the 59 young people who participated in focus groups, their references to community integration incorporated objective elements related to activities, relationships, and meaningful roles across a number of domains. They also referred to subjective elements related to feeling connected with and appreciated by others, as well as having choices and a sense of self-determination, themes reflected in literature on adults with other types of disabilities.[2–4] Participants frequently mentioned having supportive relationships with others, including friends and family, mentors, teachers, employers, and service providers, as being vitally important to their ability to do the things they wanted to do. They expressed desires for opportunities to develop their strengths and talents and to achieve their goals in relation to school, employment, and friendships.

Like other people in their age cohort, these young people were dealing with the developmental tasks of adolescence and young adulthood, including clarifying personal beliefs and values, exploring life opportunities, and making choices related to education and training, jobs, and relationships.[36,37] Like other young adults, they desired independence in their living situation, self-determination in decision making about their goals and activities, and opportunities to form relationships with friends and supportive older adults. For many of these young people, their desire to connect with others and form relationships was linked with their interests and passions. However, for some young people, aspects of their illness constrained their capacities to pursue dreams and to connect with others. For example, their depression or anxiety resulted in little energy and led them to shut themselves away from others. The tendency to isolate was also linked with fears of others’ reactions if their mental health history was discovered.

The decision about whether to disclose their mental illness to friends and acquaintances was described as fraught with risk. Stigmatizing attitudes were reported as prevalent among teachers, families, and even service providers, and some young people reported examples of extremely negative reactions from people with whom they dared to share their diagnosis. Understandably, such reactions resulted in continuing fears about sharing this information and some young people described their own behaviors designed to keep people away from them, which may in turn have reinforced the fears of other people. Some young adults—perhaps in particular those who declined to report a mental health diagnosis—may have internalized stigma, whereas others simply did not want to be "labeled" in any manner.

In contrast, some participants shared very positive experiences when they discovered a bond with someone who also had personal or family experience of mental illness. These young people wanted access to enjoyable activities in safe settings and to experience a sense of achievement and fulfillment; for some this occurred through school, work, recreation, or volunteer activities. They described the importance of accurate information about mental health to increase their own and other people's understanding of their difficulties and to reduce stigma. For these participants, a sense of personal control was central to their vision of a successful life in the community. A recurring theme was their need for flexibility in educational settings and in employment to increase the possibility of successful outcomes. To support their success, they also recommended greater flexibility on the part of service systems and service providers.

Study Limitations

One limitation of this study was its sample size; a larger sample would have permitted analysis of within-group variation in terms of gender, different ethnicities, sexual orientation, age, educational level, and urban/rural geographic locations. Future research efforts would benefit from study samples that include participants from an even wider range of social and economic status. Other limitations included using an initial question focused on integration that did not resonate with young adults and asking all participants the same core questions instead of using early groups to identify additional questions that could be explored in more depth in later interviews.

Nevertheless, these findings address a gap in knowledge of young people's perceptions of community integration, in particular through looking across the multiple domains that appear to represent "community" to young adults with mental health disorders. Intriguing differences were noted between the experiences of participants in Seattle area focus groups and those in the Portland area. These differences were not examined in the analysis because they were seen as an artifact of the sampling strategy, but they point to the need for future systematic research to compare the experiences of young people with mental health difficulties receiving services in different service system configurations.

Implications for Behavioral Health

For planners and providers of behavioral health services, these findings illustrate that young people with mental health difficulties have many of the same goals and interests as other people of their age.[37] Whereas participants mostly reported receiving services that were related to treatment of their disorder, many participants wanted assistance provided flexibly to meet their needs and to prepare them for valued adult roles in the community. Young people served in public systems have problems across life domains and need support that addresses their educational, occupational, and social goals as well as their mental health needs.[38] To improve the quality of life of young people with mental health difficulties, behavioral health programs need to expand their focus beyond symptom relief to develop multilayered, individualized strategies to support young people to fulfill meaningful roles in the community. Continuous comprehensive supports to maximize all aspects of adult functioning, including educational attainment, employment, personal and professional relationships, and independent living are recommended for this population of young people through at least age 25.[39] During the last two decades, the children's mental health field has been transformed by the emergence of collaborative, comprehensive, community-based systems of care.[40] Based on the recognition that young people with mental health difficulties have needs across multiple life domains, wraparound services for transition-age individuals are designed to identify and strengthen formal and informal supports to meet needs for as long as needed.[41] There is a beginning body of research that includes studies using randomized clinical trials that provide evidence of the effectiveness of such services.[41]

A key aspect of community integration noted by these young people was the importance of feeling connected to friends, family members, and mentors. Successful role models with mental health disorders—close in age and experience to young people themselves—can normalize disclosure and provide hope; thus, behavioral health service providers are encouraged to promote and support connections with such peers. Role models who share the interests and passions of young people are likely to be particularly appealing and potentially more encouraging.

Young people's personal talents and strengths are important in their progress toward a successful life in the community. As noted in the resilience and recovery literature,[42,43] resilient young people have their personal talents nurtured and recognized by others in supportive contexts in the community. Young people report finding fulfillment and a sense of accomplishment from school, work, and giving back to the community through volunteer activities. Developing opportunities for volunteer activities could be a valuable part of recovery-oriented services for youth and young adults. Behavioral health services should be designed to recognize and support young people's competencies and their wish to take charge of their own lives.

Educational institutions are especially important in the lives of youth and young adults with mental health disorders. Studies suggest that school functions as the de facto mental health system for children and adolescents, with more than three-fourths of children receiving mental health services being seen in the education sector; for many youth, school mental health services were reported as their sole source of care.[44] Yet with an estimated 43–56% of students with emotional or behavioral disorders dropping out of school, their likelihood of receiving mental health services falls precipitously.[45] In this study, the majority of young people's comments about school reflected institutions where teachers and classmates exhibited a pervasive lack of understanding of mental health issues. A recent study underscores the difficulty these young people face within the educational system. Results of a national survey found that youth classified as having emotional disorders were provided services an average of more than 1 year later than youth with other disabilities, and even when identified at the appropriate age to receive early intervention services for their disability, they were less likely to receive those services than children with other disabilities.[46] Successful school-based programs have found that the school culture, climate, and leadership are important ingredients in program outcomes; behavioral health service providers can support and advocate for programs that recognize that all aspects of school environments are likely to influence child mental health outcomes.[47] Research supports the use of programs to promote the development of social-adaptive skills needed for successful transitions to adulthood.[48]

There is growing attention to the need for universities and colleges to improve their services for students with mental health difficulties.[49,50] Despite their mental illness, young people can be and are successful in higher education and their chances of success are increased if faculty and counselors understand their difficulties and have the skills to support them. Behavioral health services can increase academic success among college students with mental illness. Similarly, in regard to employment, behavioral health providers may support programming to assist young people with mental health difficulties to acquire the skills that are necessary to job success.[51]

Stigmatizing attitudes are present in all domains: broad educational efforts are needed for families, behavioral health service providers, teachers, college faculties, employers, and communities to gain accurate information about mental health. A recent study of adult mental health consumers' subjective experience of stigma identified four dimensions of stigma: interpersonal interaction, structural discrimination, public images of mental health, and access to social roles.[52] This study highlighted the importance of not only providing accurate information but recognizing the inequitable distribution of resources as a form of structural discrimination that could be reduced if there is political advocacy on the part of behavioral health professionals. The perspectives of young adults reported in the current study affirm the importance of behavioral health service systems addressing the broad range of young people's community integration needs as they transition from child- and family-serving systems to adult mental health systems. In this exploratory study, young people reported many positive experiences pursuing their dreams while living with mental illness, and these findings provide hope that other young people can live fulfilling lives and achieve optimal levels of community integration.

Acknowledgments

This research was supported by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services (Grant #H133B040038). The content does not necessarily represent the views or policies of the funding agencies. The authors wish to thank Jan Lacy and Lacey Vankirk for their valuable contributions to the project and study participants for sharing their experiences and perspectives.

References

1. Stroul BA, Friedman RM. *A System of Care for Children and Youth with Serious Emotional Disturbances*. July 1986 Revised Edition 1994. Washington, DC: Georgetown University Child Development Center.
2. Jacobson N, Greenley D. What is recovery? A conceptual model and explication. *Psychiatric Services*. 2001;52(4):482–485.
3. McColl MA, Davies D, Carlson P, et al. The community integration measure: development and preliminary validation. *Archives of Physical Medicine and Rehabilitation*. 2001;82:429–434.
4. Minnes P, Buell K, Nolte ML, et al. Defining community integration of person with brain injuries as acculturation: a Canadian perspective. *NeuroRehabilitation*. 2001;16:3–10.
5. Bond GR, Salyers MP, Rollins AL et al. How evidence-based practices contribute to community integration. *Community Mental Health Journal*. 2004;40(6):569–588.
6. Prince PN, Gerber GJ. Subjective well-being and community integration among clients of assertive community treatment. *Quality of Life Research*. 2005;14(1):161–169.
7. New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America*. Final Report; 2003. Rockville, MD: DHHS Pub. No. SMA-03-3832, 5.
8. Salzer MS. Introduction. In: Salzer MS, ed. *Psychiatric Rehabilitation Skills in Practice: A CPRP Preparation and Skills Workbook*. Columbia, MD: United States Psychiatric Rehabilitation Association; 2006:2–4.
9. Aubry TM, Myner J. Community integration and quality of life: a comparison of persons with psychiatric disabilities in housing programs and community residents who are neighbors. *Canadian Journal of Community Mental Health*. 1996;15:5–20.
10. Segal SP, Aviram U. *The Mentally Ill in Community-Based Shelter Care: A Study of Community Care and Social Integration*. New York: John Wiley; 1978.
11. Kruzich JM. Community integration of the mentally ill in residential facilities. *American Journal of Community Psychology*. 1985;13:553–564.
12. Hardiman ER, Segal SP. Community membership and social networks in mental health self-help agencies. *Psychiatric Rehabilitation Journal*. 2003;27(1):25–33.
13. Fellin P. *The Community and the Social Worker* (3rd. ed.). Itasca, IL: F.E. Peacock; 2001.
14. Delman J, Jones A. *Voices of Youth in Transition: The Experience of Aging Out of the Adolescent Mental Health System in Massachusetts*. Dorchester, MA: Consumer Quality Initiatives, Inc; 2002.
15. Collins ME. Transition to adulthood for vulnerable youths: a review of research and implications for policy. *Social Service Review*. 2001;75:271–291.
16. Federation of Families for Children's Mental Health. *Blamed and Ashamed: The Treatment Experiences of Youth with Co-occurring Substance Abuse and Mental Health Disorders and their Families*. Alexandria, VA: Federation of Families for Children's Mental Health; 2001.

17. Vander Stoep A, Davis M, Collins D. Transition: A time of developmental and institutional clashes. In: Clark HB, Davis M, Eds. *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties*. Baltimore, MD: Paul H Brookes; 2000:3–28.
18. Blackorby J, Wagner M. Longitudinal postschool outcomes of youth with disabilities. Findings from the National Longitudinal Transition Study. *Exceptional Children*. 1996:399–413.
19. Levin-Epstein J, Greenberg M. Eds. *Leave No Youth Behind: Opportunities for Congress to Reach Disconnected Youth*. Washington, DC: Center for Law and Social Policy; 2003.
20. Baxter EA, Diehl S. Emotional stages: consumers and family members recovering from the trauma of mental illness. *Psychiatric Rehabilitation Journal*. 1998;21(4), 349–355.
21. Johnson B, Montgomery P. Chronic mentally ill individuals reentering the community after hospitalization. Phase II: The urban experience. *Journal of Psychiatric Mental Health Nursing*. 1999;6(6):445–451.
22. Ochocka J, Nelson G, Janzen R. Moving forward: negotiating self and external circumstances in recovery. *Psychiatric Rehabilitation Journal*. 2005;28(4):315–322.
23. O'Day B, Killeen MB, Sutton J et al. Primary care experiences of people with psychiatric disabilities: barriers to care and potential solutions. *Psychiatric Rehabilitation Journal*. 2005;28(4):339–345.
24. Young SL, Ensing, DS. Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*. 1999;22(3):219–232.
25. Morgan D. *Focus Groups as Qualitative Research*. Newbury Park, CA: Sage Publications; 1988.
26. Farquhar C. Are focus groups suitable for 'sensitive' topics? In: Barbour RS, Kitzinger J, eds. *Developing Focus Group Research: Politics, Theory, and Practice*. London: Sage Publications; 1999:47–63.
27. Jarrett R. Focus group interviewing with low-income minority populations: A research experience. In: Morgan DL, ed. *Successful Focus Groups: Advancing the State of the Art*. Newbury Park; 1993:184–201.
28. Blankertz L. The value and practicality of deliberate sampling for heterogeneity: a critical multiplist perspective. *American Journal of Evaluation*. 1998;19(3):307–324.
29. Luborsky MR, Rubenstein, RL. Sampling in qualitative research. *Research on Aging*. 1995;17(1):89–113.
30. McMiller WP, Weisz JR. Help-seeking preceding mental health clinic intake among African-American, Latino, and Caucasian youths. *Journal of the American Academy of Child and Adolescent Psychiatry*. 1996;35(8):1086–1094.
31. Breland-Noble AM. Mental healthcare disparities affect treatment of Black adolescents. *Psychiatric Annals*. 2004;34(7):534.
32. N6 qualitative analysis software. Melbourne, Australia: QSR International Pty. Ltd.; 2002.
33. Glaser B, Strauss A. *The Discovery of Grounded Theory*. Chicago: Aldine; 1967.
34. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Thousand Oaks, CA: Sage Publications; 1985.
35. Rodwell MK. *Social Work Constructivist Research*. New York: Garland Publishing; 1998.
36. Erikson EH. *Identity: Youth and Crisis*. New York: Norton; 1968.
37. Arnett JJ. Emerging adulthood: a theory of development from the late teens to the early twenties. *American Psychologist*. 2000;55:469–480.
38. Duchnowski AJ, Kutash K, Friedman, R. Community based Interventions in a System of Care and Outcomes Framework. In: Hoagwood, K, Burns, B, eds. *Community Treatment for Youth: Evidence-Based Interventions for Severe Emotional and Behavioral Disorders*. New York: Oxford University Press; 2002:16–37.
39. Davis M. *Issue Brief. Supporting the Transition to Adulthood*. Massachusetts: Center for Mental Health Services Research, University of Massachusetts Medical School; 2004;1(4):1–2.
40. U.S. Department of Health and Human Services. *The Comprehensive Community Mental Health Services for Children and their Families Program, Annual Report to Congress, 2002–2003*. Washington, DC. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration; 2003. http://systemofcare.samhsa.gov/newinformation/docs/CongReport20022003FINALPUBLICATION.pdf Retrieved 11/11/2006.
41. Burchard, JD, Bruns, EJ, Burchard, S. The Wraparound Approach. In: Hoagwood K, Burns B, eds. *Community Treatment for Youth: Evidence-based Interventions for Severe Emotional and Behavioral Disorders*. New York: Oxford University Press; 2002:69–90.
42. Luthar S. *Resilience and Vulnerability: Adaptation in the Context of Childhood Adversities*. New York: Cambridge University Press; 2003.
43. Werner EE, Smith RS. *Vulnerable but Invincible: A Longitudinal Study of Resilient Children and Youth*. New York: McGraw-Hill; 1982.
44. Burns BJ, Costello EJ, Angold A et al. Children's mental health service use across service sectors. *Health Affairs*. 1995;14(3):147.
45. Landrum TJ, Tankersley M, Kauffman, J.M. What is special about special education for students with emotional or behavioral disorders? *Journal of Special Education*. 2003;37(3):148.
46. Wagner M, Kutash K, Duchnowski A et al. The children and youth we serve: a national picture of the characteristics of students with emotional disturbances receiving special education. *Journal of Emotional and Behavioral Disorders*. 2005;13(2):79–96.
47. Farmer EMZ, Farmer TW. The role of schools in outcomes for youth: implications for children's mental health services research. *Journal of Child and Family Studies*. 1999;8(4):377–396.
48. Armstrong KH, Dedrick RF, Greenbaum PE. Factors associated with community adjustment of young adults with serious emotional disturbance: a longitudinal analysis. *Journal of Emotional and Behavioral Disorders*. 2003;11(2):66–76.
49. Mowbray CT, Collins M, Bybee D. Supported education for individuals with psychiatric disabilities: long-term outcomes from a longitudinal study. *Social Work Research*. 1999;23(2):89–100.
50. Berman S, Strauss S, Verhage V. Treating mental illness in students: A new strategy. *Chronicle of Higher Education*. 2000;46(41):B9.
51. Carter EW, Wehby JH. Job performance of transition-age youth with emotional and behavioral disorders. *Exceptional Children*. 2003:69(4):449–465.
52. Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*. 2003;56(2):299–312.