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Voices of Youth and Families on Transitions and Community Integration

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Voices of Youth and Families on Transitions and Community Integration

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Voices of Youth and Families on Transitions and Community Integration

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Purpose of study

To gain understanding of the perspectives of transition-age youth and young adults with serious mental, emotional, and behavioral disorders and families on the meaning of community integration for transition-age youth.



Objectives

To gain the perspectives of transition-age youth and young adults with mental health difficulties, and families, on:

- The meaning of community integration.
- The social, psychological, cultural, and economic barriers to community integration, including the effects of stigma.
- Supports for community integration.
- Hopes and dreams for the future.
- The roles of families in supporting transitions to adulthood.



Defining community integration

Commonly-held definitions that we used to guide our study address:

- The *right* of youth and adults with mental disorders to live in the community and to have opportunities to live, study, work, and play with other people.
- The sense of belonging in the psychological or social sense.
- The sense of empowerment or choice and control in making one's own decisions.



Research methods

- Literature review.
- Formation of Portland and Seattle research teams.
- Consultation with advisory groups of youth/young adults aged 17-24 and family members to develop focus group questions and plan recruitment.
- Recruitment, hiring, and training of youth research assistants and family member research assistants.
- Recruitment of youth, young adults, and family members to participate in focus groups through contacts with schools, colleges, family support organizations, and mental health agencies.



Research methods

- 20 separate 90-minute focus groups for youth, young adults, and family members.
- Youth and family member research assistants took lead roles in moderating groups.
- Participants also completed a pre-focus group questionnaire and received \$30.
- Focus group discussion audio-taped, transcribed, and entered into *NV6* qualitative analysis software.
- After establishing acceptable agreement among coders on a portion of the transcripts, all were coded by research team members independently.
- Preliminary analysis reported here.



Focus group questions

Parallel questions focused on:

- The meaning of community integration and a successful life in the community.
- Barriers and supports to community integration.
- Hopes, goals, and dreams.
- Advice to others in similar situations.

Findings from youth focus groups





Youth demographics

- Gender: 35 young men, 22 young women.
- Age: Range 15-28, median age 19.6
- Race/Ethnicity:
 - European American: 56%
 - African American: 14%
 - Multi-racial: 9%
 - Asian/Pacific Islander: 7%
 - Native American: 2%
 - No response: 12%
- Living situation:
 - With parent(s): 41%
 - With roommates: 21%
 - Alone: 16%
 - With extended family: 9%
 - With partner/mate: 7%
 - Other: Homeless/shelter: 9%



Youth-reported mental health diagnoses*

○ Depression	43%
○ Bipolar disorder	31%
○ Anxiety	23%
○ Attention-deficit disorder	20%
○ Learning Disabilities	16%
○ Substance Abuse	16%
○ Obsessive Compulsive	14%
○ No response	14%
○ Unknown	8%
○ Other* *	31%

* Percentages add to more than 100% because of multiple diagnoses

** Includes: Asperger's, Oppositional-defiant, Post-traumatic stress, Schizo-affective, and other disorders



Youth Involvement in Employment and School

○ Full time college or school	30%
○ Unemployed	25%
○ Part time work	21%
○ Part time college or school	14%
○ Full time work	12%
○ Training/Voc Rehab	11%
○ Supported employment	4%
○ Unable to work	7%
○ Other	16%

* Percentages add to more than 100% because of multiple possible responses.

Youth Access to Mental Health Services

	A	B	C
○ Medication	42%	10%	8%
○ Individual counseling	40%	10%	8%
○ Case Management	25%	6%	6%
○ Mentoring	15%	13%	8%
○ Employment support	15%	21%	6%
○ Support Group	15%	10%	20%
○ Drop-in Center	8%	6%	8%
○ Group Therapy	8%	8%	17%
○ None	15%	4%	6%
○ Other	8%	10%	13%

A = currently receiving; B = needed, but not received;
C = offered, but couldn't access



Youth Access to Mental Health Services

Mental health care paid for by:

- Private insurance 36%
- Medicaid 17%
- Personal/family funds 15%
- No insurance 26%
- Other 22%
- No response 18%



Youth perspectives on jobs and mentors

- Youth who know one or more adults with mental health difficulties with interesting careers: 60%
- Youth who say it would be “quite” or “very” helpful to learn about adults with mental health difficulties in interesting jobs: 55%
- Youth who say experience with a mental health difficulty is an important characteristic of a mentor: 46%



Youth perspectives: Meaning of community integration

- Opportunities to meet goals.
 - “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.”
- Relationships and access to resources.
 - “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.”
 - “I think whenever I have things in common with other people, those are the times when I feel more part of that community.”
 - “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.”



Youth perspectives: Barriers to community integration

- Stigma.

- “Now I don’t tell people as often, because I think, one, the stigma. I’m afraid that I will be judged...”
- “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.”

- High school culture and educational system shortcomings.

- “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.”



Youth perspectives: Barriers to community integration

- Lack of accessible, developmentally appropriate resources.
 - “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...”
- Uncaring, clueless, “by the book and by the clock” professionals.
 - “Psychiatrists, I saw a lot, and you know, they kind of messed with me for awhile, because I was on the wrong meds and I was zoned for a year...I was given the wrong diagnosis and the wrong meds.”



Youth perspectives: Barriers to community integration

- Effects of the disorder itself on personal motivation and behavior.
 - “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.”
- 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 your are, what you are doing, how you can function with this disorder that you have.”



Youth perspectives: Supports for community integration

- Supportive relationships with friends and family, including siblings, grandparents and foster parents.
 - "...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."
 - "...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."



Youth perspectives: Supports for community integration

- Caring, skilled, professionals and mentors.
 - “My high school counselor was my best support...She was always there, she was really accessible...”
 - “[Seattle social worker] had helped me throughout a lot of stuff.”
 - “I compare [a coach/mentor] to Mr. Miyagi, in the sense that he pushes you, but he cares about you.”
- Opportunities to give back, to be productive.
 - “For me, working with animals or children is helpful, just to kind of see my impact in the world.”
 - “...taking care of my plants every week...Doing just balanced, regular things, where you are watching the health of others.”



Youth perspectives: Supports for community integration

- Programs focused on transition-age youth offering practical and emotional support.
 - “...the independent living skills program has helped me just tremendously money-wise.”
 - “...if you have problems at home, they help you. They listen to you and stuff like that, not job related...they care just that much.”
 - “[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.”



Youth perspectives: Supports for community integration

- Opportunities for rejuvenation, spiritual guidance and self-expression.
 - “I like to go to a quiet place and have my own time to think, just me, going to the beach and walk around.”
 - “The Bible is a comfort, it will get you through life.”
 - “For me, it’s my music equipment, you know what I’m sayin’? That’s where I find my peace at.”
 - “[It would] probably be creating things, such as art, or whatever...I feel productive and just horde things that I create. A lot of it is kind of ‘shopping’ in my own head.”



Youth perspectives: Supports for community integration

- Solid information about mental illness and mental health, giving 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.”
 - “They gave me this list of ten coping skills...They were giving me a way out, or at least something to believe in.”
- Awareness of others living successfully with mental health difficulties.
 - “It was an awesome feeling that this is a thing that other people experience...After that I kind of got to the point where I just tell everyone.”



Youth perspectives: Hopes, dreams, and goals

- **Feeling a sense of success.**
 - “The biggest thing is I want a sense of accomplishment in three years.”
- **Feeling connected.**
 - “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.”
- **Giving back.**
 - “Success for me in three years is knowing that I can help others and be involved in my community as much as possible.”
 - “Being productive, like in the community, and helping kids out.”



Youth perspectives: Advice to other young people

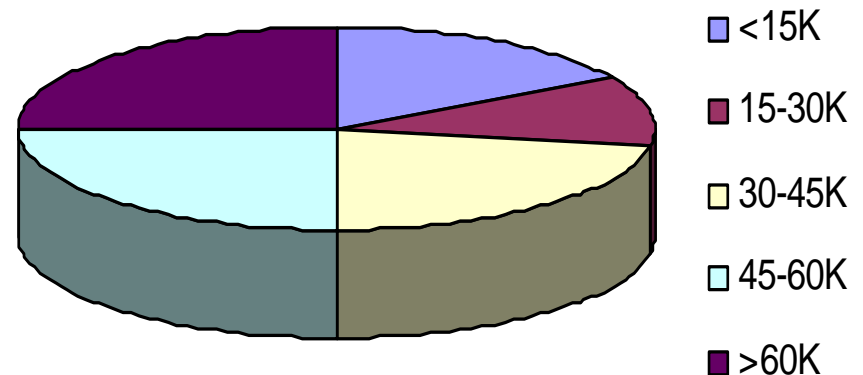
- Seek support people who have had similar experiences
 - “It really helps to have people who have either similar symptoms or just understand it, that they have actually experienced it, not just that they accept it, but they actually know what it is like.”
- Take charge of your life
 - “If you feel like 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.”
 - “You have to be able to put the best foot forward, and actually want to change your life.”

Findings from Family Member Focus Groups



Family member demographics

- Family members: 40 female, 2 male
- Family member age: Range 36-65; mean 47.7 (SD 7.6)
- Family member race/ethnicity:
 - European American: 85%
 - African American: 8%
 - Multi-racial: 5%
 - Native American: 2%
- Family member income:





Family access to mental health services

	A	B	C
○ Family support	43%	16%	5%
○ Individual counseling	21%	11%	8%
○ Family counseling	8%	21%	8%
○ Respite care	2%	19%	0%
○ Other	13%	5%	0%

A = currently receiving; B = needed, but not received;
C = offered, but couldn't access



Family-reported demographics

- Youth gender: 29 male, 11 female
- Youth age: Range 16-24; mean 19 (SD 2.28)
- Youth race/ethnicity:
 - European American: 69%
 - African American: 10%
 - Native American: 8%
 - Multi-racial: 5%
 - Asian American: 5%
- Youth living situations:
 - With parent(s): 57%
 - With roommates: 12%
 - With partner/mate: 10%
 - Other: 17%
 - Dorm/student housing: 30%
 - Family home: 28%
 - Own apt. or home: 28%
 - Other: 5%



Family-reported youth mental health diagnoses*

○ Depression	50%
○ Attention-deficit disorder	43%
○ Bipolar disorder	41%
○ Post-traumatic stress disorder	38%
○ Anxiety	36%
○ Oppositional-defiant disorder	29%
○ Learning disabilities	26%
○ Obsessive compulsive	24%
○ Schizophrenia	21%
○ Substance Abuse	14%
○ Other**	2-14%

* Percentages add to more than 100% because of multiple diagnoses

** Includes: Asperger's, Schizo-affective, and other disorders.



Family Reports of Youth Involvement in Employment and School

- Full time college or school 29%
- Part time work 19%
- Unable to work 19%
- Part time college or school 14%
- Unemployed 14%
- Full time work 12%
- Supported employment 2%
- Training/Voc Rehab 2%
- Other 17%



Family perspectives: Meaning of community integration

- Participating in interesting activities and developing strengths
 - “Artistically she is very talented. This year she is in an art class finally, and a drama class. She loves animals, so what I see the need for her is connection with people who can help her find her gifts and find a way to express those.”
- Connecting with other people
 - “They need someone out in the community that they can relate to that will help them transition. The last people they want to talk to is us. They want to break away.”



Family perspectives: Meaning of community integration

- **Satisfying employment**
 - “For her to have a career and life that matches her abilities and ambitions.”
- **Opportunities to develop skills**
 - “For her, it is ‘What have I accomplished? What have I done?’ So the sense of being able to say I accomplished something.”
- **Progressively developing independent living skills**
 - “I wouldn’t mind giving him a home to live in, but I want him to be able to keep a job and to run his own household and to be successful.”



Family perspectives: Barriers to community integration

- **Stigmatization**
 - “My family looks at mental illness, like anybody who doesn’t understand it, with a stigma.”
 - “... the [schools’] incredible lack of respect for both family members and for the kids. Treating them like they don’t have a brain in their head.”
- **Lack of understanding of mental health difficulties**
 - “...that huge disconnect between the biological basis of this disorder and behavioral component.”
 - “So many of the teachers... they don’t know what to do with these kids... They went to school to learn how to be teachers. They didn’t learn how to be mental health facilitators for these children.”



Family perspectives: Barriers to community integration

- **Inadequate/ineffective services**
 - “I think what would have really helped him in college and community...is a more active outreach from the mental health community.”
 - “The disability office [staff] are well-meaning people, but they are understaffed. Or, we know the laws about confidentiality...as soon as the kid turns 18 nobody can talk to the family.”
- **Lack of independent living skills**
 - “I worry about my son going out. He wants to move. He wants to get a job. He wants to get married. He wants to get this apartment and he can't even pay a bill.”



Family perspectives: Supports for community integration

- Supportive relationships
 - “That man [a school counselor] made a personal commitment to that kid... I don’t think my son would have made it through school without that man there.
- Understanding of mental health difficulties
 - “What has made it very fortunate for us with the tutor is that she has a brother who is schizophrenic, so she is familiar with the lack of interest.”
 - “The place she is [at] is a whole lot more accepting. And they look at what she can do as opposed to what her problems are.”



Family perspectives: Supports for community integration

- **Effective services.**

- “The resources that they brought and the wraparound team were really successful in sustaining her, getting her to a place where the fear was able to subside.”

- **Developing strengths and talents.**

- “A teacher at the community college took a great interest in my son. He recognized his abilities and let him use the resources and equipment above and beyond just what they were doing in these... classes.”



Family perspectives: Hopes, dreams, and goals

- Accomplishments in education and jobs.
 - “It would be great if she could complete the courses at college. It would be wonderful, she would love nothing more than to have a job where she is feeling important and like she is contributing. Those two things.”
- Relationships.
 - “ She needs to grow in social skills. She needs to meet girl friends, girl friends! And she is starting to.”
- Independence.
 - “He needs to know what is out there. He has no clue what is out there really. It is not cool to go with your mom to places. That separation needs to happen, because he has been so dependent on me for so long.”



Family perspectives: Advice to other family members

- Seek out other parents and use support groups.
 - “Find other people who are going through what you are going through so they can help you, because most people don’t have a clue.”
- Advocate for strength based services.
 - “What drives me is not accepting less than what I think he needs, even if he is high functioning.”
- Learn the system and trust your judgment concerning the rights and needs of youth.
 - “You have to know your kid and believe what you know about your kid, because everybody else is going to tell you something different.”



Family perspectives: Advice to other family members

- Advocate for education on mental health throughout the community.
 - “We need public education service announcements all the time on television. We need education. We need Oprah. Whoever it is, we need education in our society.”
- Remember self-care: seek counseling and other support for yourself.
 - “It’s hard, very hard-- it’s exhausting. I need to take care of myself and receive my own counseling to be there for him.”



Limitations of our study

- Geographically limited, “convenience” sample
- We don’t know how well our sample represents all youth and families
- Would benefit from greater ethnic diversity



Implications of our study

- Need to focus on recovery, success and strengths— youth’s competencies and desire to give back to the community should be recognized.
- Schools and colleges are seen as especially important in the lives of youth with mental health difficulties, yet a pervasive lack of understanding of mental health issues persists, and needs to be addressed.
- Stigma cuts across all domains-- broad educational efforts are needed for families, professionals, employers and communities.
- Successful role models –close in age and experience to youth themselves-- can normalize disclosure and provide hope.



Questions for the audience

- How do our findings reflect your experiences with community integration for transition-age youth?
- What kinds of solutions to the challenges of community integration are you aware of?
- What else would you like to tell us about this topic?
- Who needs this information?
- How do you suggest that we communicate our findings?



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