

Voices of Youth and Families on Living a Successful Life in the Community

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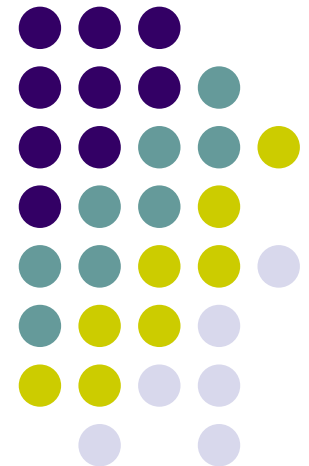
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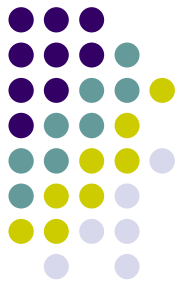
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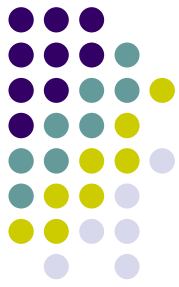




Purpose of study

To gain 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 serious mental disorders, and families on:

- The social, psychological, cultural, and economic barriers to community integration, including the effects of stigma.
- Supports for community integration.
- Relationships between resilience/recovery, empowerment, and community integration.
- The roles of families in supporting transitions to adulthood.

Defining community integration



Definitions address:

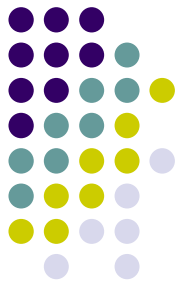
- The *right* of youth and adults with mental disorders to live in the community and to have opportunities to live, study, work, and have recreation with other people.
- The sense of belonging in the psychological or social sense.
- The sense of empowerment or choice and control in making one's own decisions.

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

Research methods



- Recruitment of youth, young adults, and family members to participate in focus groups through contacts with schools, colleges, family support organizations, mental health agencies.
- Separate 90-minute focus groups for youth, young adults, and family members (7 groups to date; goal is 20 groups total).
- Youth and family members take lead roles, while PI and Project Manager take secondary roles in moderating groups.
- Participants also completed a pre-focus group questionnaire and received \$30.
- Focus group discussion audio-taped, transcribed, and preliminary analysis reported here.

Focus group questions



Parallel questions focused on:

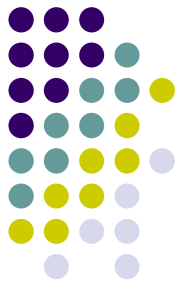
- The meaning of a successful life in the community.
- Community connections and activities.
- Three year goals.
- Barriers and supports to community integration.
- Best and worst experiences with professionals.
- Advice to others in similar situations.

Sample description: Youth



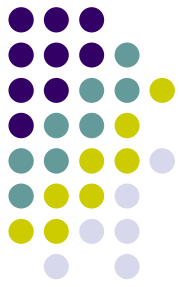
- Gender: 10 young men, 8 young women.
- Age: Range 16-28
- Ethnicity: 1 Asian-American, 1 African, 3 multi-racial, 4 white, 5 black/African-American (2 declined to answer)
- Living situation:
 - With parent(s): 5
 - With roommates: 6
 - Alone: 1
 - Other: 3 with spouse or fiancée, 1 homeless
 - In his/her own apartment or home: 8
- Mental health diagnoses: 5 youth declined to answer; others marked varied diagnoses, including: Anxiety Disorder: 2; Attention-Deficit Hyperactivity Disorder: 1; Bipolar Disorder: 3; and Depression: 6.

Sample description: Family members



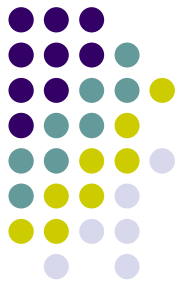
- Family members: 7 female/Caucasian. Age: Range 35-59; mean 46
- Their youth: 5 male, 2 female. Age: Range 17-22; mean 20
- Living situation of their youth:
 - With parent(s): 2
 - With roommates: 2
 - Alone: 2
 - In college dorm or student housing: 1
 - In his/her own apartment or home: 3
 - Other: 1 (group home)
- Mental health diagnoses of their youth: Varied, including: Anxiety Disorder: 2; Attachment Disorder: 1; Attention-Deficit Hyperactivity Disorder: 4; Bipolar Disorder: 1; Depression: 3; Emotional Disorder (SED or EBD): 1; Fetal Alcohol Syndrome or Effect (FAS or FAE): 1; Obsessive-Compulsive Disorder: 1; Oppositional-Defiant Disorder: 1; Post Traumatic Stress Disorder: 3; Alcohol and Drug Dependence/Abuse: 1; Schizo-Affective Disorder: 1

Youth perspectives: Meaning of a successful life in the community



- 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 (young woman).
- 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 and having them really be a base of support that can't really fall through (young woman).
- 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. A car that you don't owe, that you don't have to make payments to. Somebody that you could call on if something happened to you (young woman).
- For me, to tell you the truth, it means my family. If I had all my family all together in one place, that would be a successful life for me (young woman).

Youth perspectives: Community connections and activities



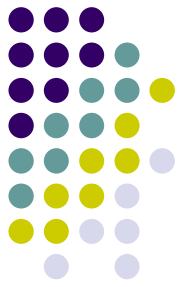
- Well, I have friends from my work that I hang out with outside of work. I think that makes for a good workplace when you get along. (young man)
- Health N' Action [a Seattle youth social service program] is one of my family, actually. Health N' Action is a good part of my life. (young woman)
- Church is what is important, even though I don't go, I don't attend.... The Bible is a comfort. It will get you through life. (young man)
- Yeah, I attend 12 steps myself, because I partied a lot and got in a lot of trouble. My spirituality has become a lot stronger, and helping others, man. That is what helps me get out of myself. (young man)
- I like recreational venues, basketball courts, indoor basketball courts, like somewhere where you don't got to pay. (young man)

Youth perspectives: Three-year goals



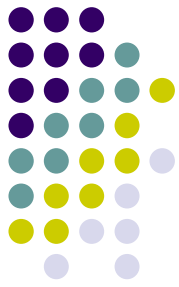
- I envision my life being pretty much a workaholic. I dream of living in my office, because I don't like socializing. It is not what makes me happy. It makes me stressed out and nervous, so I would rather just do a whole lot of work, because I am good at that. (young woman)
- The biggest thing is I want a sense of accomplishment in three years. (young man)
- Three years from now, I want to be a dental assistant. After I do that, I want to really go on to the school and become a dentist . (young woman)
- Mine is actually to go to school and get a good job and be able to get on my feet. I want something new. You know what I'm saying? I'm trying to leave the old behind and get something new for myself. (young man)

Youth perspectives: Barriers to community integration



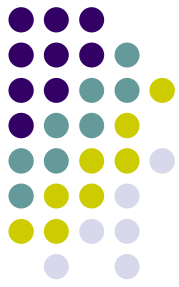
- Stigma:
 - “Now I don’t tell people as often, because I think, one, the stigma. I’m afraid that I will be judged...” (young woman)
 - “I lost a lot of friends once I did try to share it. It was devastating, because one of my friends...was scared that I may go off the deep end. He didn’t want to get sucked into that.” (young man)
- 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.” (young man)
 - “...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.” (young woman)

Youth perspectives: Barriers to community integration



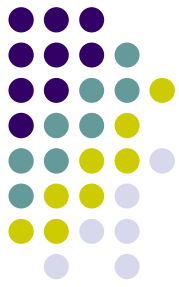
- Lack of accessible, developmentally appropriate resources:
 - “They gave me like a list, and there was no one to call and nothing online...” (young woman)
 - “It was the stupidest thing I’ve ever done. It was a free community service and everything, but the things that we had to do! We were all older than 15 and they were making us paint the insides of boxes and make clay figures...” (young woman)
- 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.” (young woman)

Youth perspectives: Supports for community integration



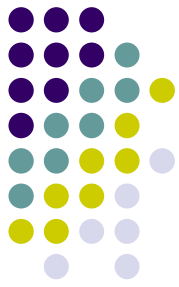
- Openness of others –even strangers- to interacting:
 - “It’s just like there’s people in Portland that will come up and talk to you just because you look like someone they knew...” (young woman)
 - “Just having approachable people in my life is helping.” (young man)
- Friends and family, including grandparents, were mentioned frequently.
- 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.” (young woman)

Youth perspectives: Supports for community integration



- Caring, thoughtful professionals and mentors:
 - “My high school counselor was my best support...She was always there, she was really accessible...” (young woman)
 - “[Seattle social worker] had helped me throughout a lot of stuff.” (young woman)
 - “I compare [a coach/mentor] to Mr. Miyagi, in the sense that he pushes you, but he cares about you.” (young man)
- 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.” (young woman)
 - “They gave me this list of ten coping skills...They were giving me a way out, or at least something to believe in.” (young woman)

Youth perspectives: Best experience working with professionals



- Supportive exchanges with high school teachers and college professors were cited by several youth.
- Professionals who listened, were thoughtful in their approach, had a sense of humor and, above all, were caring:
 - “He said, ‘Okay, I think here is what is going on.’ I was like, yes, actually you are right, that is what is going on...what makes a good psychiatrist isn’t someone who goes out on a limb, but someone who is willing to just think for themselves...instead of just going through the motions of writing another prescription.” (young man)
 - [Reflecting on a childhood experience with a play therapist] “She was really good. She made me feel like really, really comfortable and I was just going and playing...If there was a comparable thing you could do for people who are older, to make them feel like you are going in and kind of hanging out and talking and not feeling like it is treatment.” (young woman)

Youth perspectives: Worst experience working with professionals



- Youth spoke of feeling that some professionals were just concerned about picking up a paycheck.
- “Sterile” professionals, relating to youth in a too-formal, overly clinical manner, were disliked:
 - “He would be like, ‘Hello, sir, thank you, sir.’ I am like, ‘Don’t call me sir!’ There is no reason for that.” (young man)
 - “...we would sit down and go through the number, 1 through 10, of your symptoms and stuff like that. I just kind of felt like, okay, just give me the medication and let me go, because I am wasting an hour every week sitting here.” (young woman)
- Youth involved in community activism and public speaking described feelings of “being exploited” for some organizations’ publicity purposes.

Youth perspectives: Advice to other young people



- Importance of having support people who have had similar experiences and can relate on a personal level.
- “Make sure you’re comfortable... whether it’s a mentor or a counselor or a peer or whatever.”
- Keep hopeful:
 - need more success stories
 - more information and knowledge are necessary
 - stay positive
 - work hard
 - go to school.
- “Keep your head up. Do what your heart tells you”

Family perspectives: Meaning of a successful life in the community



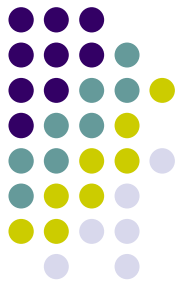
- Developing a sense of independence including: finding and keeping a job, feeling a part of the neighborhood, taking classes and time management.
- Participating in healthy relationships, developing social and communication skills.
- “She was finally able to advocate for herself when she went to one of her college professors and stated her problems. He said, “ Oh, no wonder! Now it all makes sense!”
- A sense of self-esteem and confidence that is reflected in profitable work, creative outlets, and real friendships.
- Creating happiness and a degree of success amidst sleep habit challenges, organizational difficulties, and social barriers.

Family perspectives: Community connections and activities



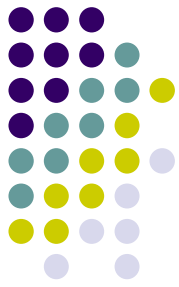
- Support groups, parent education resources and wrap around services valuing both family dynamics and involvement.
- Acquiring jobs, responsibility for transportation, developing skills and talents through college, community resources, and independent pursuit.
- Local artists and organizations providing support for individual strengths and facilitating recognition for youth's abilities.
- “She is well known for playing the [musical instrument]. She has played at a few weddings!”
- “My son loves to cook! He has been forbidden to cook though at the group home where he is living. It is a real source of frustration for him and myself!”

Family perspectives: Three-year goals



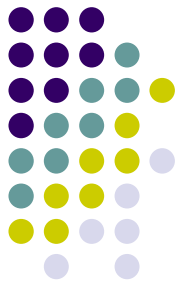
- Hope to have their children functioning well, managing their challenges, and having some contentment.
- Their talents identified and nurtured.
- To continue on a positive path.
- To still be taking classes and living on his own. We have to have hope.
- A job that matches their abilities and ambitions.
- To continue to progress, going to school, and working.

Family perspectives: Barriers to community integration



- Parents' lack of information.
- Having to label oneself as disabled, to access services, e.g. Student Office of Disability Services.
- Problems with transitions from residential treatment to high school, e.g. the “short yellow bus,” and huge, over-stimulating school environments.
- Teachers' lack of knowledge about mental disorders.
- Parents feeling blamed by teachers and service providers.
- Rules about confidentiality at residential treatment center, which prevented kids having contact with each other after they left (would have been supportive).

Family perspectives: Supports for community integration



- College course work and jobs offering interest, support, and socialization.
- “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.”
- Participating in individual counseling and therapy as well as family therapy as needed.
- Proactive parents assuming the role of advocate.
- “There are a lot of therapists out there, but I think as a parent you really have to do a lot of searching yourself, because it is not like anybody else is going to do that for you.”

Family perspectives: Best experience working with professionals



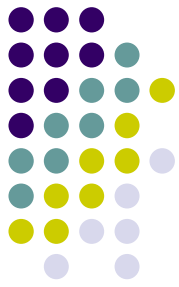
- Best experience was when she was first identified – the psychiatrist explained the issues clearly, was encouraging and sympathetic.
- Best experience was my son’s therapist asking me how I felt about myself.
- Teachers at X High School that were responsive.
- Excellent experience when he was leaving residential treatment when there was a meeting with everyone sharing ideas and resources... helped to make connections, identify follow-up resources.
- Enjoyed X, a social worker who came into our home – she would validate me and help me stay sane.

Family perspectives: Worst experience working with professionals



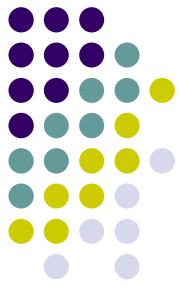
- “All the worst experiences were in public schools. 80% of my experiences with IEP meetings were horrific... Well, at that one school it was that principal who just thought everybody was just faking. And then her side kick, the psychologist, who says “Well, your expectations are too high. A “C” average is just fine. You don’t need to go to college.”
- CSD (old Child Welfare agency) staff tried to deceive us to get custody when we asked for help with funding for her residential treatment.

Family perspectives: Advice to other family members



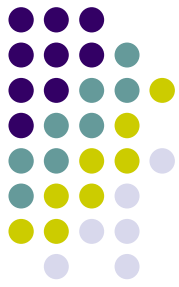
- “Get help for yourself.”
- Parents need to educate ourselves about the early signs of anxieties, fears, and paranoia.
- Groups like NAMI are helpful – to get ideas , feel safe, and develop a big social network.
- “Sleep. Get enough rest.”
- “Your child has to learn to be their own person. It’s really, really hard when you see them in dangerous areas... you have to trust in your child’s own strength.”
- Call a friend and ask for help with cleaning house.
- Notice the effects on siblings.

Questions for the audience



- How do our findings reflect your experiences with community integration for transition-age youth?
- How do you think about connections and activities in the community?
- What else would you like to tell us?

Contact information



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