Portland, Oregon

Research and Training Center on Family Support and Children's Mental Health

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Community Integration of Transition-Age Youth: Voices of Youth and Young Adults

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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 on:

- The meaning of community integration,
- Barriers to community integration, and
- Supports for community integration.

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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.

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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 and young adults to participate in focus groups through contacts with schools, colleges, family support organizations, and mental health agencies.

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Research methods

- 12 90-minute focus groups for youth and young adults.
- Youth 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 *N6* qualitative analysis software.
- After establishing acceptable agreement among coders on a portion of the transcripts, all were coded by research team members independently.

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Focus group questions and analysis

- The meaning of community integration and a successful life in the community.
- Hopes, goals, and dreams.
- Barriers and supports to community integration.
- Advice to other young people in similar situations.
- In analysis process, comments were sorted into categories under these general thematic areas and sorted according to seven domains of community integration: community, service system, employment, school/college, living situation, natural supports, and personal factors.
- Report of findings today will focus on comments about school, college, and employment.

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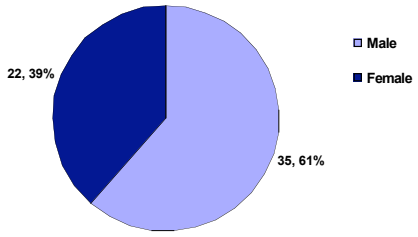
Youth characteristics: Gender



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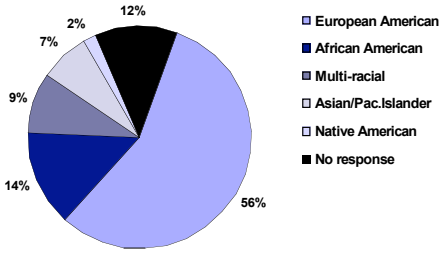
Youth characteristics: Race/Ethnicity



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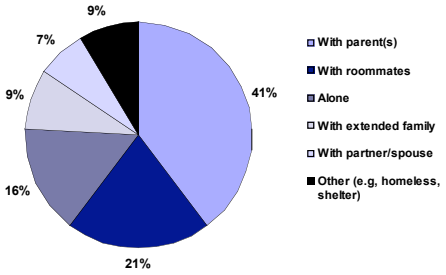
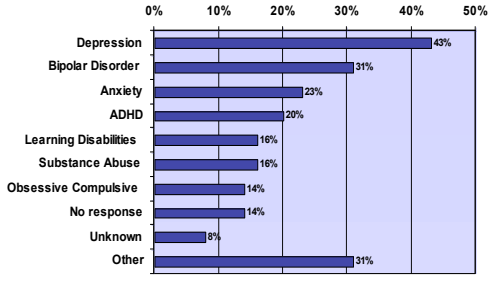
Youth characteristics: Current Living Situation



10

Youth-reported mental health diagnoses*



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

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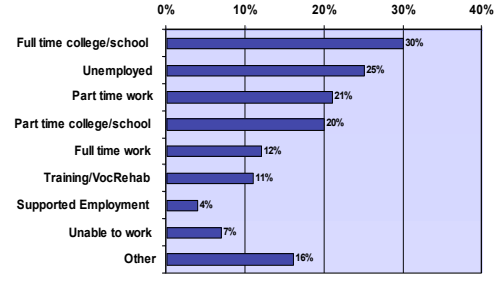
Youth involvement in employment and school*



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

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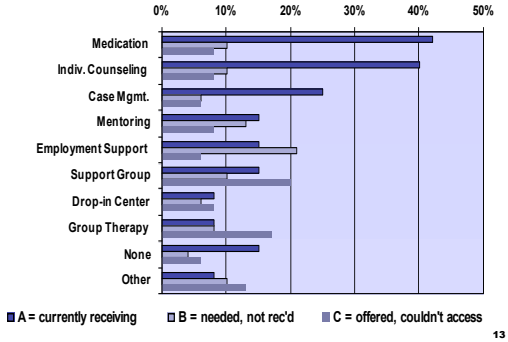
Youth access to mental health services



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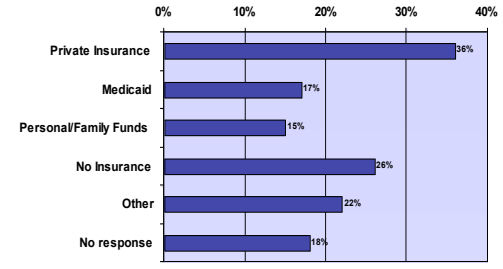
Youth access to mental health services: Source of payment for care*



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

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Findings from youth focus groups

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Meaning of community integration

- Opportunities to meet goals and access to resources.
  - "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.
  - "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."

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Hopes, dreams, and goals

- Stability
  - "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."
  - "For me I think I just basically want to finish the transition. I liked what he said about creating my own community and not feeling like I need to beat myself up…I want to be able to just have my own stability and stuff, depend on myself."
- Opportunities
  - "(My goal) is actually to go to school and get a good job and be able to get on my feet. I want something new. I'm trying to leave the old behind and get something new for myself."
- Feeling a sense of success.
  - "The biggest thing is I want a sense of accomplishment in three years."

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Hopes, dreams, and goals

- Support and Recovery
  - "I would love friends who were awesome or that I can be looking up to and have a really good relationship with. But I hopefully won't have other supports like psychiatrists or something like that. I won't have those. ."
- 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."

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Barriers to community integration: School/college

- 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's all there is."
  - "…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."
- Invisible nature of disorders creates additional anxiety and stress from expectations of others.
  - " When people don't know you have a disorder they expect things of you. You can't fulfill their expectations."
  - "At some point, like when I asked the teacher if I could use my laptop, this girl looked at me and asked, 'why do you have to use a laptop ?…oh, I think you can write just fine.' That was the last thing I wanted to hear out of someone who didn't even know who I was."

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Barriers to community integration: School/college

- Perceived as 'weird' by school mates and educators and pegged with labels and names.
  - "People don't believe you. They think you are doing it for attention."
  - "My name was Crazy David. That is what people wanted to call me, so that is what people did call me."
- Stigma.
  - "High schoolers are like, "You messed up, something in your head ain't working right." Even when you're saying them, they still hurt, because you know that you're one of the people that are messed up."
  - "I lost a lot of friends [at school] 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."
- Inability to talk about difficulties.
  - " I don't talk about it. Girls do not think much of special education."

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Barriers to community integration: School/college

- Inadequate/ Inappropriate services
  - "University counseling staff being unprepared to deal with major mental health challenges that were not acute, adjustment related."
  - "Even in high school they had a suicide counselor come in. I feel like they weren't really listening to what the real problems were. They were just trying to protect me from myself."
- Lack of Institutional Support for Individual Differences
  - "There isn't anything for people who are not visual learners and have to learn by doing or listening... The only different kids who get any sort of help are the ones who are retarded."

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Barriers to community integration: Employment

- Lack of resources
  - "It took me a lot to get this job, though, because I didn't have transportation to get nowhere and I was way far out."
  - "Not having anything behind you, like a high school diploma it is like really hard. I was kicked out at 15 also, but basically I have been on my own since I was a kid."
- Low expectations and lack of appropriate education and training
  - "…trying to make it look like I wouldn't be able to do that, to go to college or anything. They tell me things like you are going to be on meds the rest of your life…They will train you for working at McDonalds which is kind of what they are insinuating that that is the only work you will be able to obtain. They don't have very much emphasis on academics…so I fell behind a lot in my grades, which made it even harder to go to college."

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Barriers to community integration: Employment

- Stigma
  - "People saying, okay, you are probably not capable of doing it then. You are having problems now, so we just don't want to deal with you."
- Lack of Flexibility
  - "Work environments where they are like, oh, you are having a bad day. You shouldn't be here. Well, I have to work."
  - "I had one job where I wasn't catching on to learning what they wanted me to learn. I take longer to learn things and they just didn't want to bother with that."

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Barriers to community integration: Service system

- 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."
- Lack of accurate information to guide treatment
  - "Misdiagnoses. I've been diagnosed with everything in the book, and I've been on a lot of medications that didn't work because the person who was supposed to be helping me didn't listen."
  - "…. everyone had control of my life except me, because it was like the doctors, my parents, they were running the show. They thought they knew what was best for me. I think a lot of times, kids, they may know what is best for them."

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Supports for community integration: School/college

- Access to supportive school staff.
  - "My high school counselor was my best support…She was always there, she was really accessible…"
  - "I had a few teachers that I connected with really well, and I would hide out during lunch in teachers rooms ...That was the best part of high school."
  - "Just having someone that did believe in me."
  - "I dropped out of high school and she supported me to get my GED and stuff.. She helped me get ready to go to [name of college]."

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Supports for community integration: School/college

- 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."

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Supports for community integration: Employment

- Flexibility in the workplace
  - "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."
  - "I am a research assistant so it is mostly data entry and some other things, so I can do those whenever. That helps."
- Opportunities to develop skills
  - "Well, right now, my job, they put us through all these trainings, so that would be good for getting a child development license, CPE license. Not just get paid more, but to help in the long run."
  - "Leadership training through Health N' Action…we go to legislative meetings, like when there is a bill and it has something to do with youth, we are a group that have a little input."

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Supports for community integration: Employment

- 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%
- 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."

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Supports for community integration: Service system

- Programs focused on transition-age youth offering needed information and 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."
- Contact with others with mental health difficulties.
  - "The best support I've gotten is from people who have the same problem as me, because you can relate to it. My therapist was only a couple of years – she is 26… She had gone through the same things and she basically showed me some new treatments."

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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."
  - "Don't worry about what everyone has to say about what is best for you. Get one good person in your corner to help build you up to where you need to be."

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Limitations of our study

- Geographically limited, "convenience" sample.
- We don't know how well our sample represents all youth.
- Would benefit from greater ethnic diversity.

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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.

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Acknowledgements

- Participants
- Research assistants
- Advisors
- National advisors

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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?
- How do you suggest that we communicate our findings and to whom?

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Portland, Oregon

Research and Training Center on Family Support and Children's Mental Health

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