



Portland, Oregon



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

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Youth with Mental Health Needs Transitioning to Adulthood: Family Perspectives on Community Integration

Presented at:

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Conference on Increasing
Community
Integration of Individuals with
Psychiatric Disabilities

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Collaborators:

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Purpose of presentation

To share findings of a study of community integration of youth and young adults with mental health disorders, from the perspectives of family members of such youth. This presentation will focus on:

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



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 family members to develop focus group questions and plan recruitment.
- Recruitment, hiring, and training of family member research assistants.
- Recruitment of family members to participate in focus groups through contacts with family support organizations, mental health agencies, and personal contacts.



Research methods & analysis

- Eight 90-minute focus groups for family members of youth and young adults with mental health disorders.
- Family research assistants took lead roles in moderating groups.
- Participants also completed a pre-focus group questionnaire and received \$30; quantitative data were entered into SPSS for analysis.
- 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 to identify common and unique experiences and perspectives.



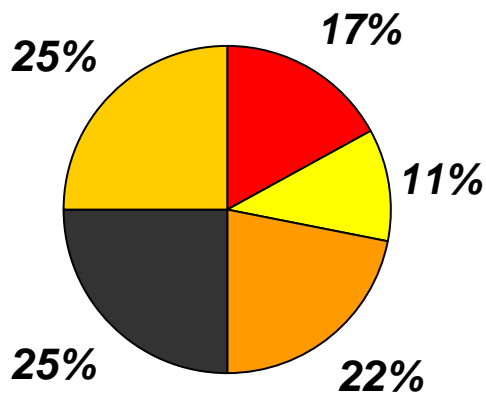
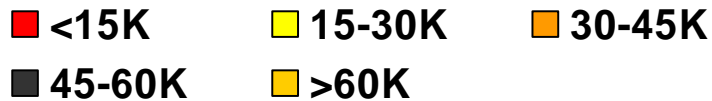
Focus group questions

We asked family members about:

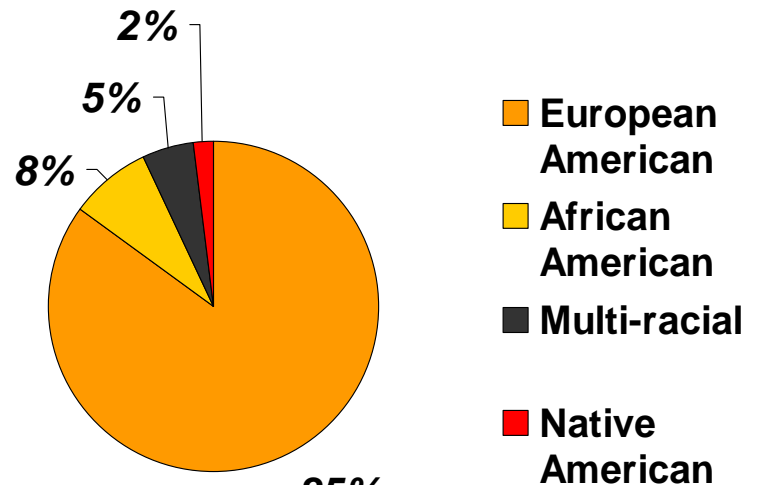
- The meaning of community integration and a successful life in the community.
- Hopes, goals, and dreams.
- Barriers to and supports for community integration.
- Advice to other parents or family members about supporting their children's community integration.

Family characteristics (N = 42)

- Gender: 95% female, 5 % male
- Family income:

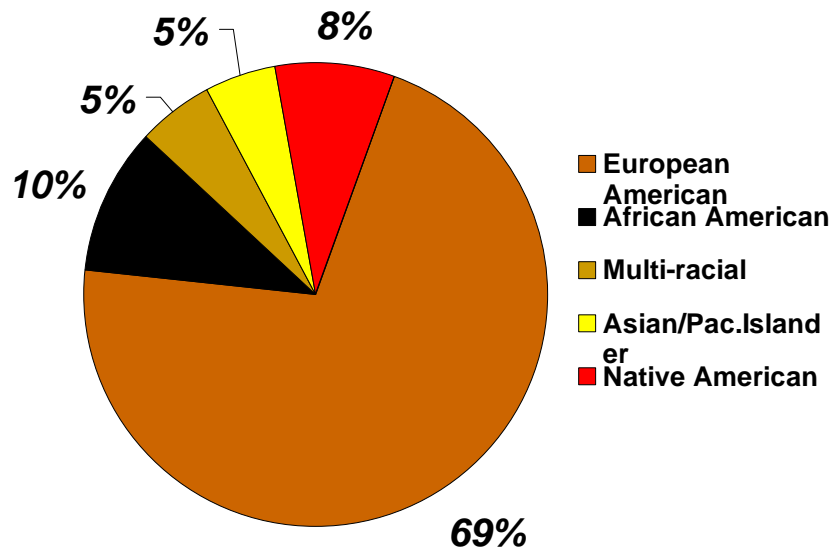


- Age: Range 36-65; mean 47.7 (SD 7.6)
- Race/Ethnicity:

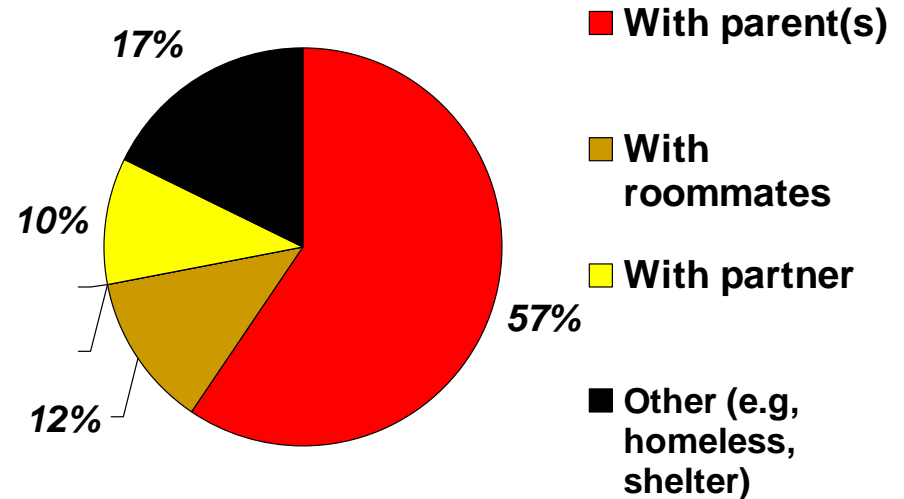


Youth Characteristics (N = 42)

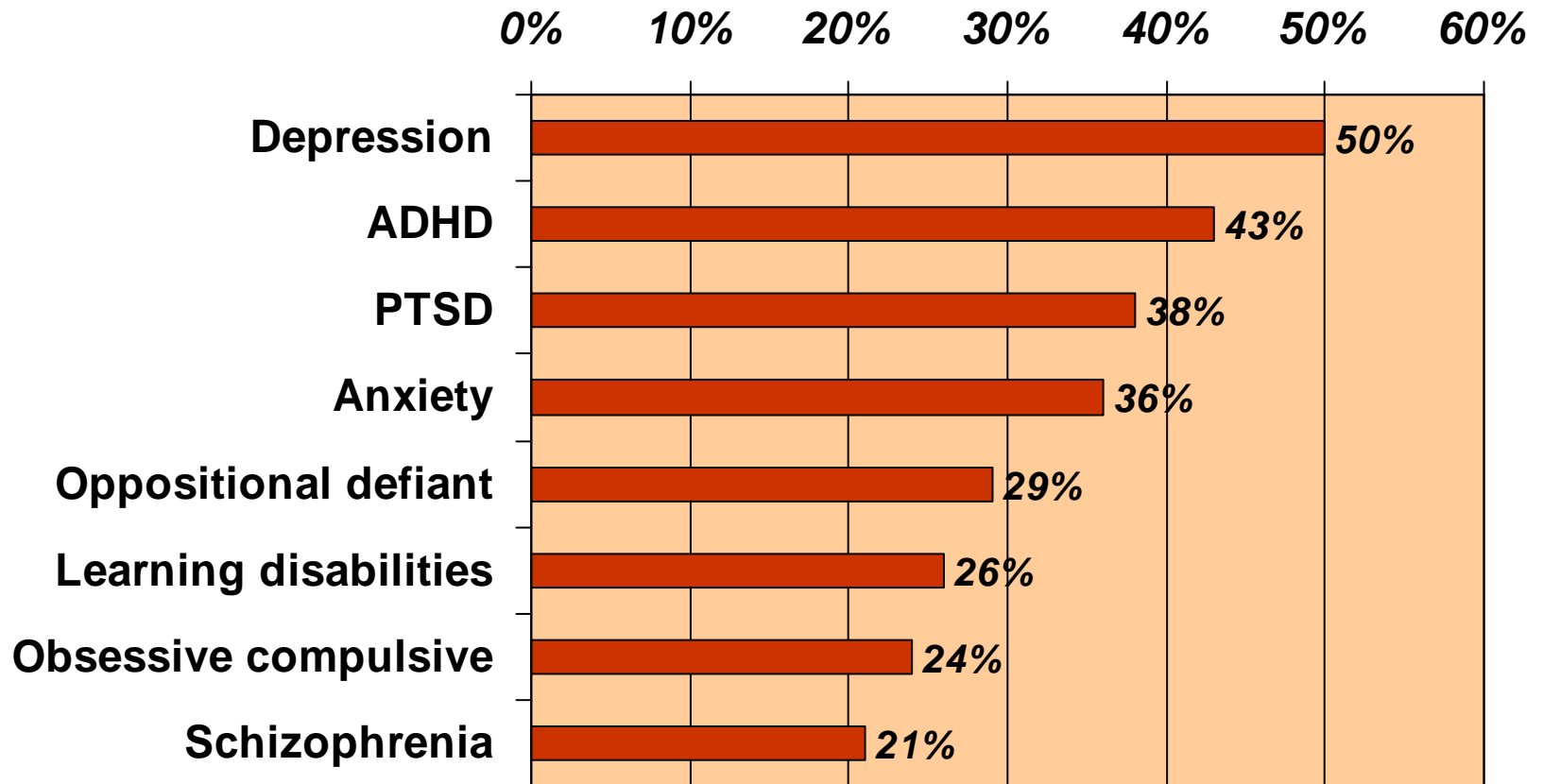
- Gender: 72% male, 28% female
- Race/Ethnicity



- Living Situation

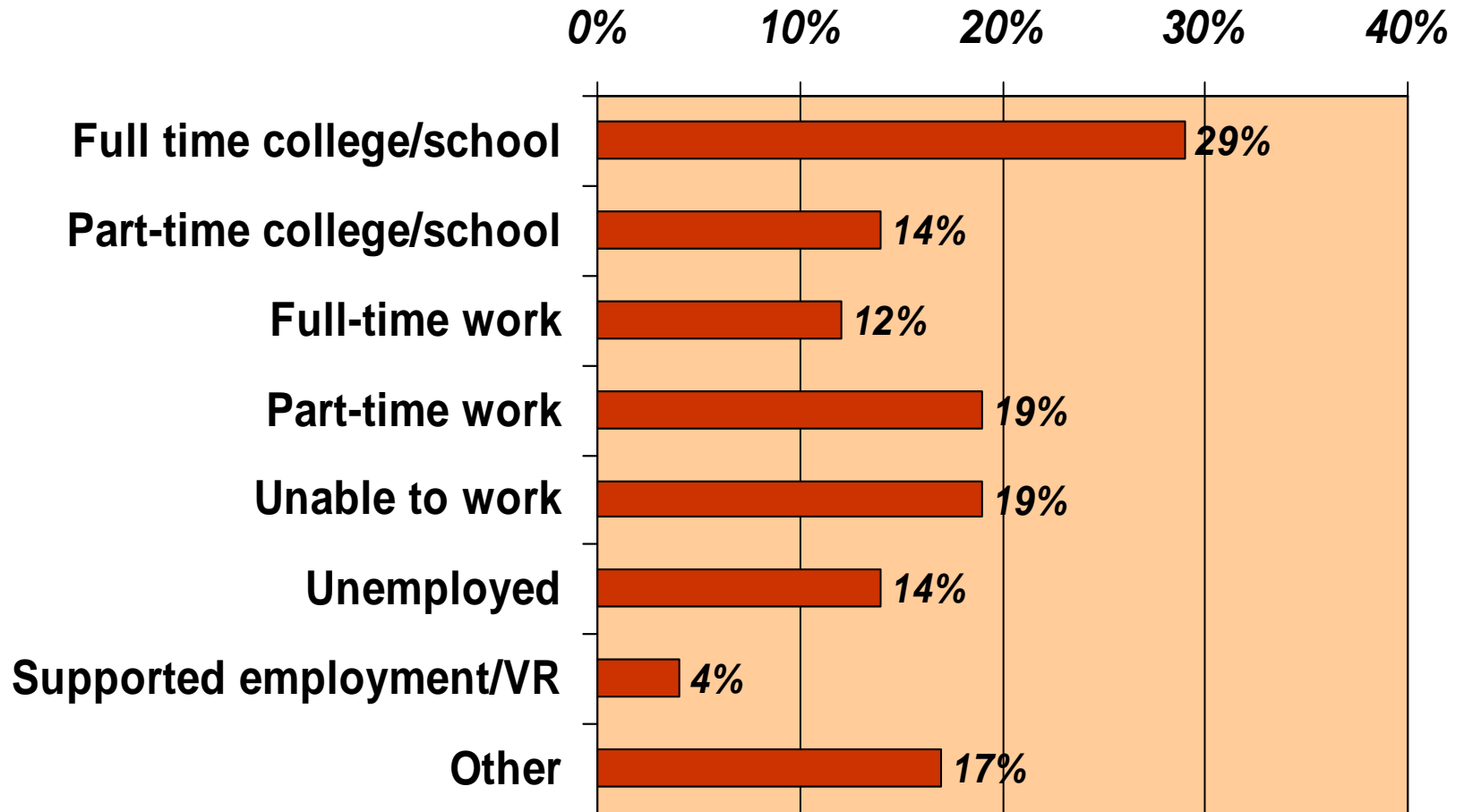


Family reports of youth mental health diagnoses*



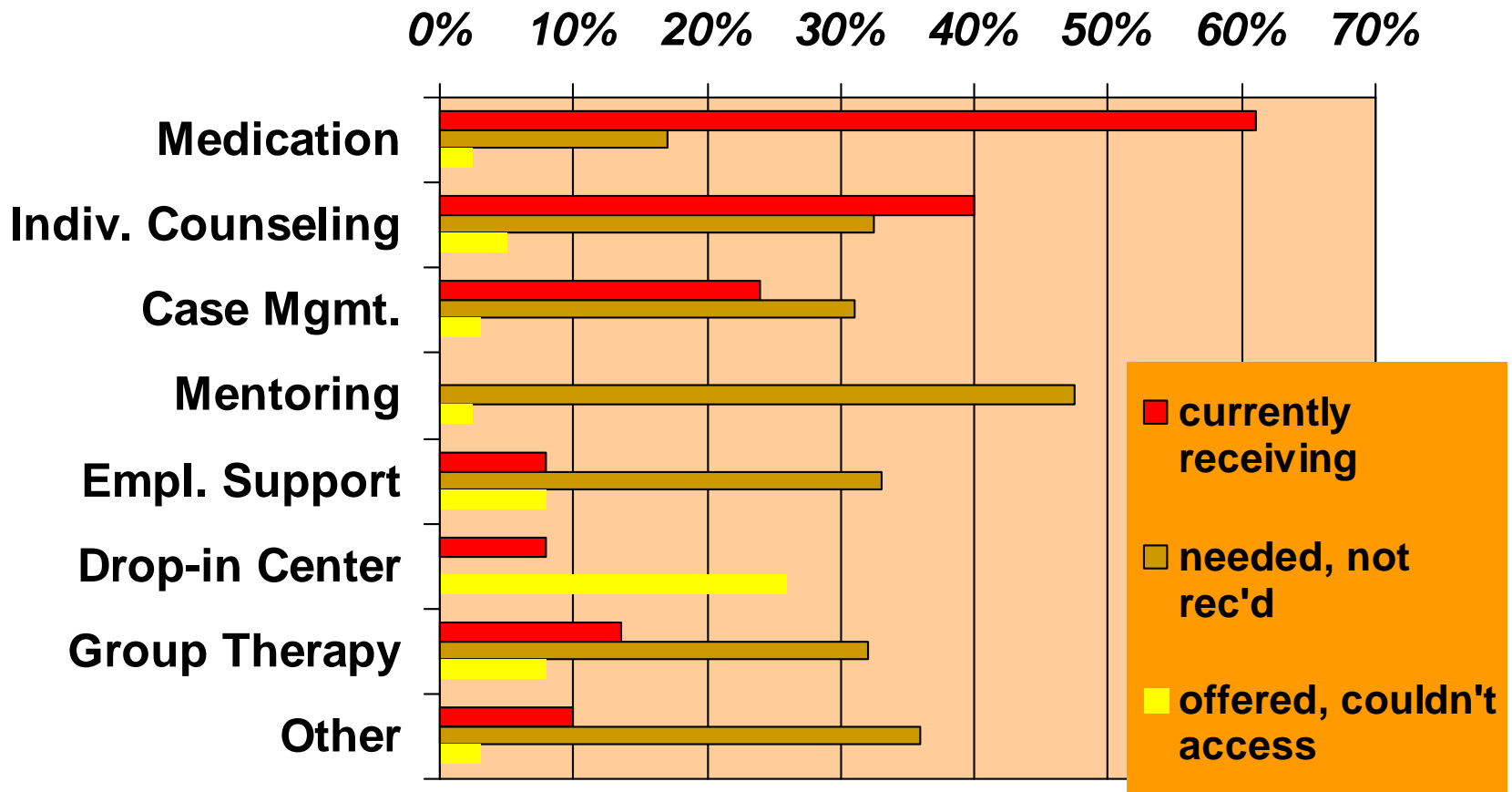
*Percentages¹⁰ add to more than 100% because of multiple diagnoses.

Family reports of youth involvement in employment and school*

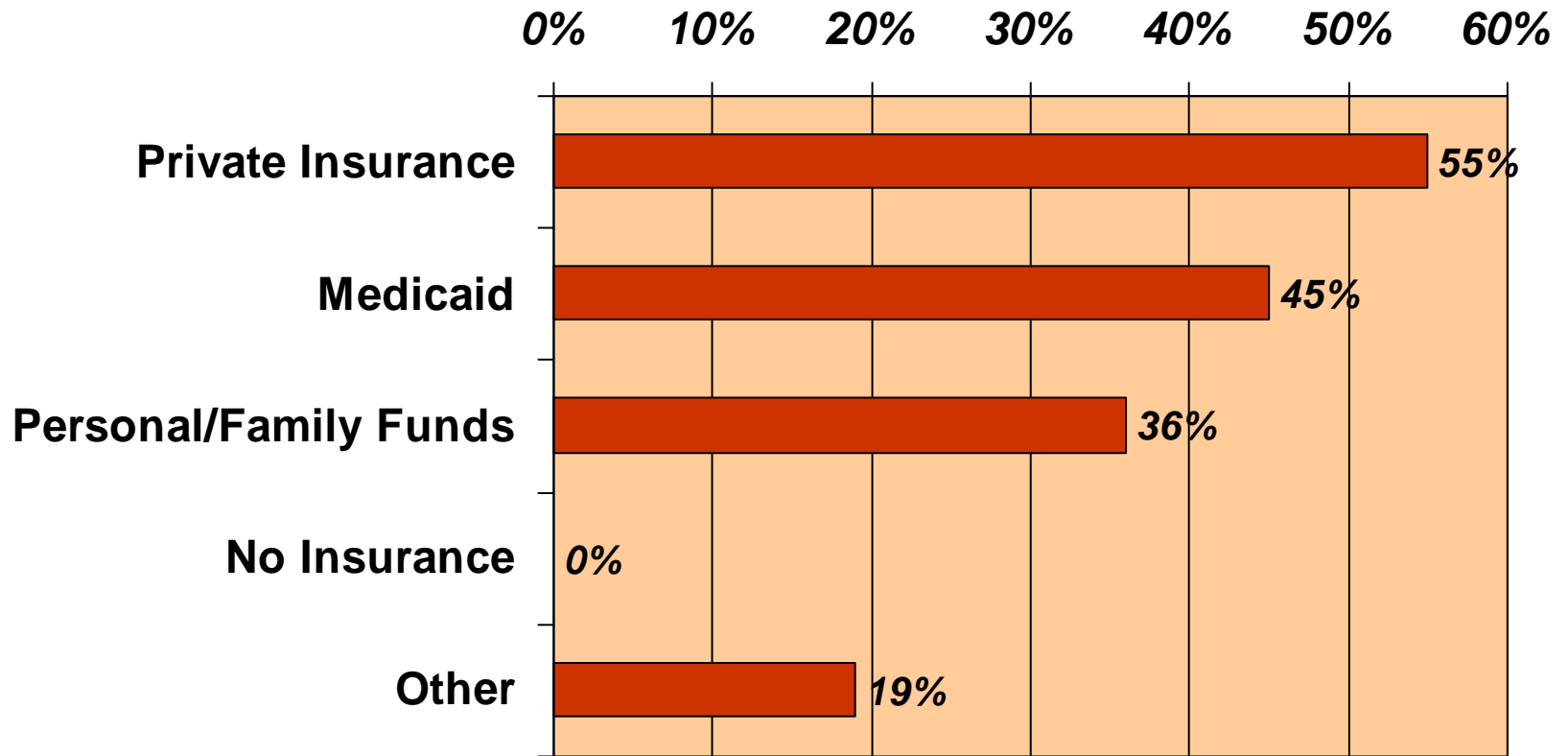


¹¹
*Percentages add to more than 100% because of multiple possible responses.

Family reports of youth access to mental health services

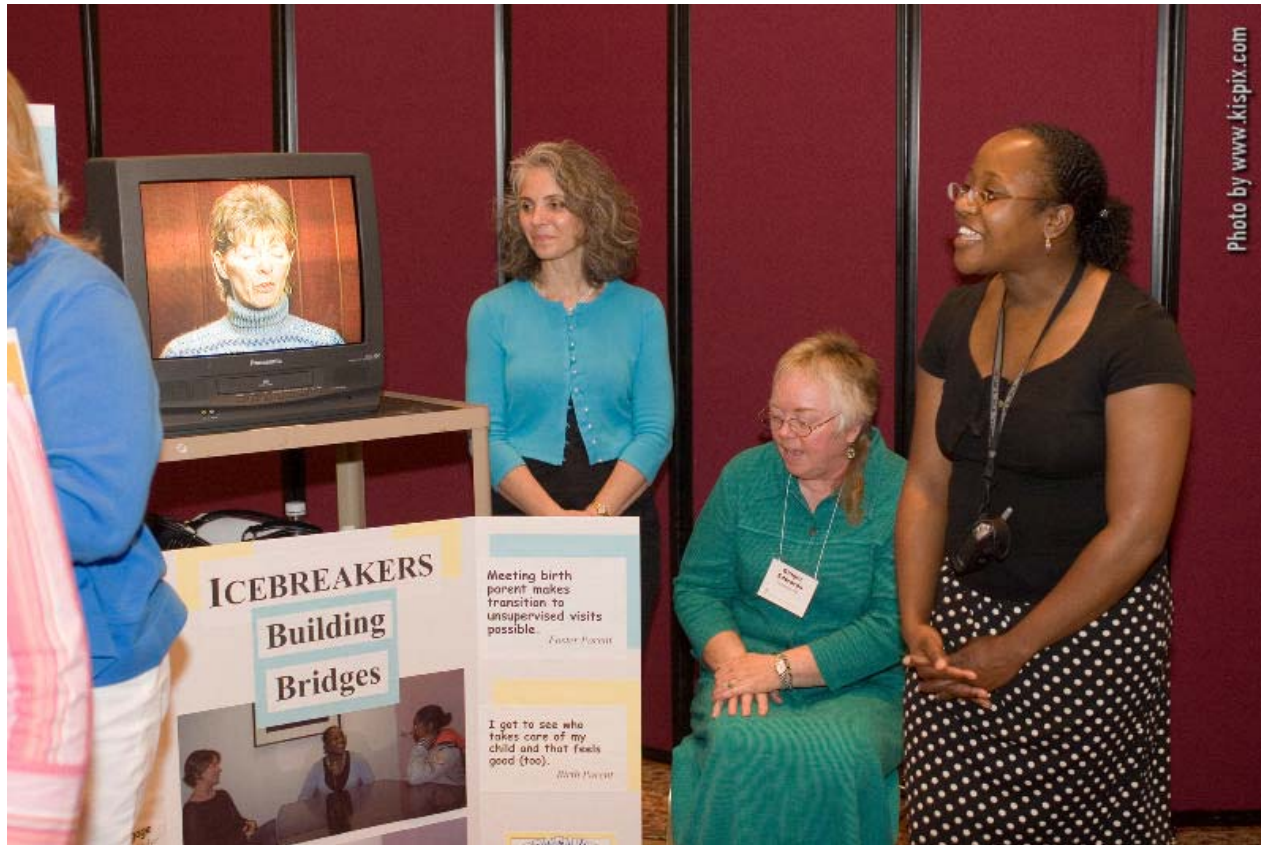


Family reports of youth access to mental health services: Source of payment for care*



¹³
*Percentages add to more than 100% because of multiple possible responses.

Findings from family member focus groups





Meaning of community integration

- Participating in interesting activities and developing strengths
 - “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
 - “He likes his teachers and he’s feeling like he’s a part-grown up person connected to real life things... for the first time ever, ever, he feels like, ‘Hey, Mom, I can make a living and I’ve got friends.’”



Meaning of community integration (continued)

- **Satisfying employment**
 - “For her to have a career and life that matches her abilities and ambitions.”
- **Opportunities to gain a sense of achievement**
 - “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**
 - “Now she does see herself, ‘I’m 18. I’m an adult.’ She is starting to see herself as wanting to live in the world outside of our home... She is working toward being able to live on her own.”



Family members' 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.”
- Relationships.
 - “One really good friend that he could go to have a burger with once or twice a week, you know, somebody who actually called and that wasn't dangerous to him... and they have a connection and they cared about each other.”



Family members' hopes, dreams, and goals (continued)

○ Independence.

- “I have more of a six-year plan. My hope is that by the time he is 25, that he can be at least halfway independent. He will always need a lot more support... I would hope that he could live, even if I sell my house and buy a duplex, and he lives next door, that he could have some sense of independence and that he could reach a point where he could work part-time, and have some semblance of an adult life.”



Family perspectives on barriers to community integration

- Lack of understanding of mental health difficulties
 - “He refuses to go to church because unfortunately... the youth pastors told him that his disability is a sin.”
 - “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.”
- 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.”



Family perspectives on barriers to community integration

- Lack of resources for supportive services
 - “There is no money for these young adults to become productive citizens.
 - “I think what would have really helped him in college and community...is a more active outreach from the mental health community.”
- Inadequate/ineffective services
 - “We went to DVR and they kind of made him feel really bad, so he has been really discouraged after that point. They said, ‘Well usually, we just deal with kids who work at McDonalds and make French fries.’ He loves computers ... so he figured, ‘That is all they have to offer me, why bother?’”



Family perspectives on barriers to community integration

- 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.”
- Dilemmas related to family support
 - “It is hard to help because, as your child ages, it is important that they have independence. It is really hard to know when to stop parenting. You want to be there to help them through every step of the way, because you know they need pushing and prodding, but you also know that you are not going to be there for ever. That becomes a barrier in itself-- how much can I do without getting in the way, without making things more difficult?”



Family perspectives on barriers to community integration

○ Legal constraints on family support

- “That dividing line, you are 18, you are an adult is so artificial. It puts parents in such a scary position because you no longer have – when they are a child, you can still have input and, as difficult as it is, you can advocate.”
- “We know the laws about confidentiality...as soon as the kid turns 18 nobody can talk to the family.”

○ Perceived effects of the consumer movement

- “I think family, a lot of times, gets shut out of that process because there is this whole adult consumer population... I am not trying to negate the importance of having their voice there, but I think families need to continue to be a voice.”



Family perspectives on supports for community integration

- **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.”
- **Peer relationships**
 - “He does have a friend. He does have his band. He is a skateboarder. He doesn’t have a big social group that he is with, but he does have certain friends that he hangs out with that have common interests.”
- **Mentoring 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.



Family perspectives on 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.”
- **Opportunities to develop 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.”
- **Opportunities to learn job skills**
 - “She taught them how to interview... Then they built a resume. [His] first job, he was a junior janitor. It was at the elementary school across the street from our house.”



Family roles in supporting their children's community integration

- Families need support to be able to help their young adult children.
 - “The best way to support them is for the parent to get the support and I get that through NAMI. I don't think you can start with the kids unless the parents have the ammunition to face the situation.”
- Families need to take care of themselves.
 - “You have to take care of yourself or you are not going to be able to take care of [your son or daughter]. That is one thing I can do, because it says I care enough about you to take care of me.”



Family members' advice to other families re: supporting CI

- 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 members' advice to other families re: supporting CI

- 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 families of youth and young adults with mental health disorders.
- Future studies would benefit from greater ethnic diversity.



Implications of our study

- Services and supports 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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Research and Training Center
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