



Portland, Oregon



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

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# Community Integration of Young Adults with Mental Health Difficulties: Family Perspectives and a Comparison of African American and European American Youth Perspectives

Presented at:

Building on Family Strengths  
Conference

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# Research team members

## *Presenters:*

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## *Collaborators:*

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# Purpose of presentation

To share findings of a qualitative study of young adult and family perspectives on community integration of youth and young adults with mental health difficulties.

This presentation will focus on:

- A comparison of the perspectives of African American and European American young adults with mental health difficulties on barriers and supports affecting their community integration.
- Family perspectives on the meaning of community integration and barriers to and supports for their children's community integration.
- Family perspectives on their shifting roles and relationships through the transition years; and
- Advice for other family members about supporting their children through the transition years.

# Research methods

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

# Research methods & analysis

- Twelve 90-minute focus groups for young adults with mental health difficulties and eight focus groups for family members of youth and young adults.
- Young adult and 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 discussions were 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

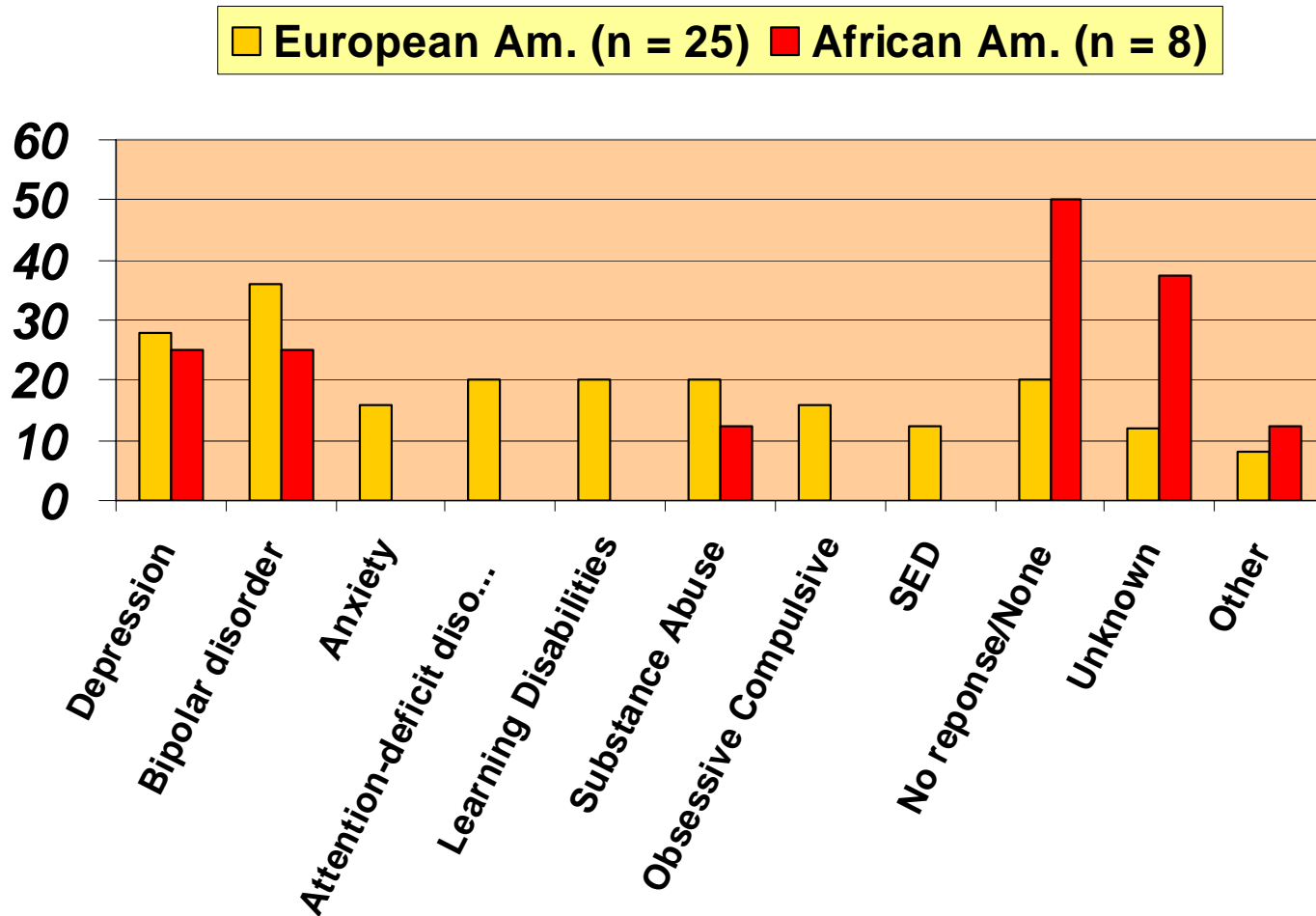
We asked young adults and family members about:

- The meaning of community integration and a successful life in the community for transition-age youth with mental health difficulties.
- Hopes, goals, and dreams for transition-age youth with mental health difficulties.
- Barriers to and supports for community integration.
- Advice to other young adults/family members in similar situations.

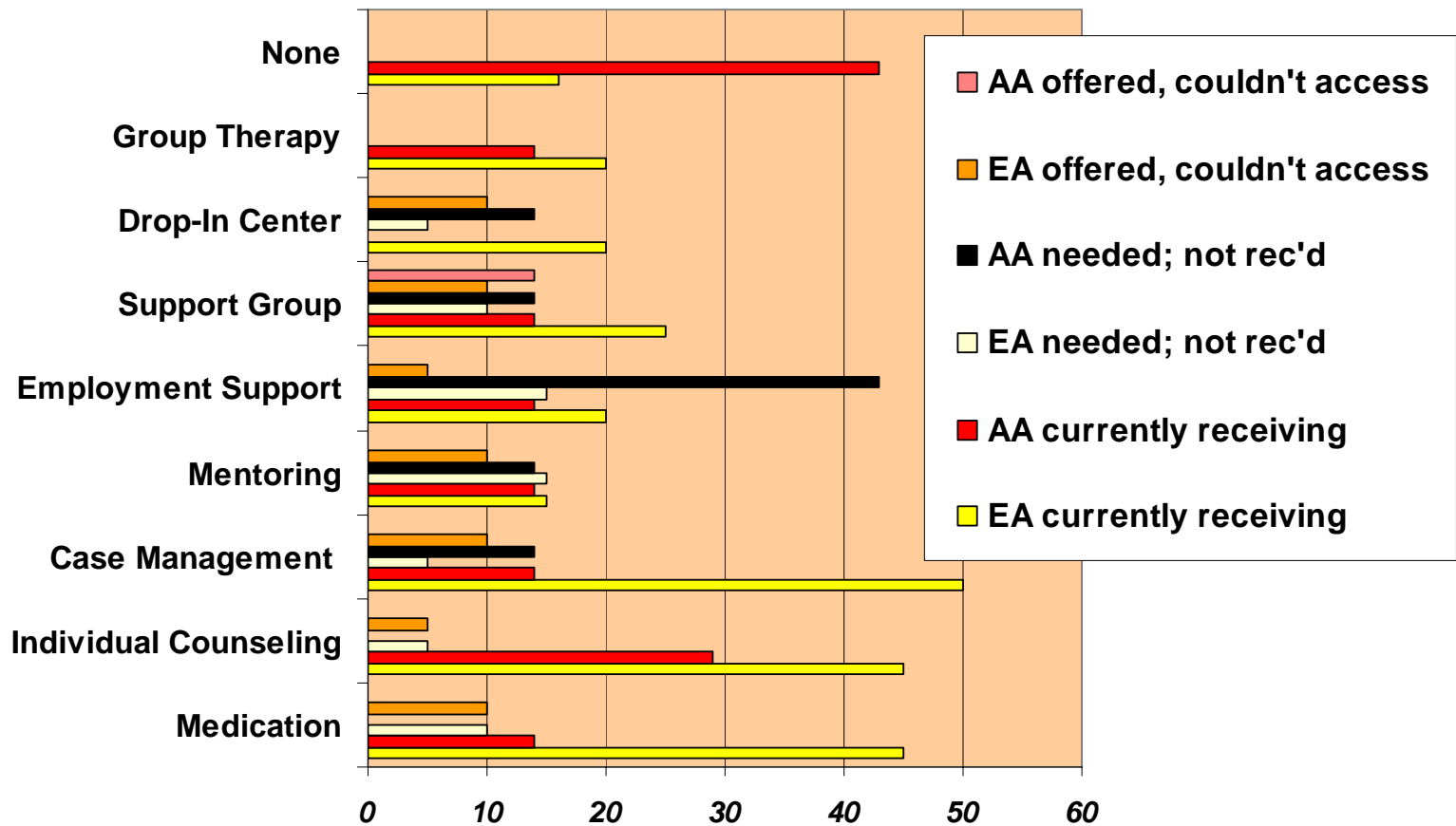
# Focus Group Participants

	<b>European-American (n = 25)</b>	<b>African-American (n = 8)</b>
<b>Age</b>	Mean 18.2; range 16-23	Mean 19.4; range 15-23
<b>Gender</b>	72% male	62% male
<b>Level of School</b>	20% in school/GED prgm.; 40% <H.S.; 40% H.S. or GED	0% in school/GED prgm.; 63% <H.S.; 37% H.S. or GED
<b>Living with parents</b>	54%	38%
<b>Living with roommates</b>	13%	0%
<b>Living alone</b>	13%	25%
<b>Living with extended family</b>	17%	25%
<b>Other living situation (e.g., homeless)</b>	13%	13%

# Youth-reported mental health diagnoses (percentage by group)



# Youth reports of access to mental health services (percentages)



# Shared barriers to community integration: Personal

## *Personal responsibility*

- “I’m crazy, so nobody holds me back but myself.”
- “I was my biggest obstacle. I was my own weapon of mass destruction.”

## *Not graduating from high school*

- One youth noted, “the most trouble I ever got in school was detention. One thing, and they kicked me out.”

## *Drugs and alcohol*

- “If you can't pass a UA, you can't get the job.”
- “Drugs and alcohol; that's what holding me back right now. I know that I need to work on it.”

## *Lack of economic resources*

- “When you go to fill out an application and you don't have a permanent address or a phone number that you can be reached at, If you live in a place like me (youth shelter), you can only make phone calls after 8:00. It is hard to get hold of any employers at that time.”
- Just to go fishing you need “to buy a thing of worms, you have to have money. You have to have gas.”

# Shared personal barriers: Criminal justice involvement

## *Criminal record*

- “A lot of time you can't get an apartment because of your criminal background. You can't get a job because of your criminal background.”
- “A criminal record is a big one. It stopped me from working, getting financial resources, and succeeding in school.”

## *Probation*

- “My barrier is probation and all this treatment stuff that I have to do. It costs money and it takes time. I have to pay probation \$50 a month. I have to go there once a week.”
- “Once you are in the system they own you, you have a probation officer, you have to do what they say, and I want to get out of that, and get into school.”

# Personal barriers unique to AA

## *Getting pregnant/becoming a parent*

- “Having kids at an early age, drugs, dropping out of school. Just trying to be a grown too early, just grow up too fast.”
- “Mine was I had a baby, but I was going to school and I only had two weeks left until I graduated, but I had to drop out.”
- “... it wasn't about school. I got shot and then got a baby on the way and I already have a baby. I am a parent at a young age. I've got to face reality.”

# Personal barriers unique to EA

## *Lack of motivation/depression*

- "Emotional problems are the worst. When my depression is bad, I have no motivation whatsoever you only want to lay there until you die."

## *Isolation/avoidance and anxiety/depression*

- "I just mostly block myself out from everybody and just barricade myself in my room."
- "I think a lot of people who have bipolar and things like that are worried about what other people are going to say, what other people are going to do, are afraid to even expose themselves to anybody because of that."

# Personal supports unique to AA

## *Spiritual and religious beliefs*

- “I just really need to read the Bible and get insight and some kind of encouragement to be able to see the world for what it is. The Bible is a comfort. It will get you through life.”
- "God is the thing that keeps me going," A young woman noted.
- "I just go with my spirituality. I believe that is what my higher power wants me to do, is to help out people, work with people.”

# Personal supports unique to EA

## *Computers, video games and reading*

- "I'm usually home, TV, computer games, something."  
"The only out that I have is books, just reading. I just sit and read. "

## *Outdoor activities*

- "I like to go to the park or the mountains. I like going swimming at the lake and jumping off cliffs."
- "I feel connected at the beach. Whether I am alone or with a friend, it doesn't really matter. I can kind of reflect back on my life at the beach".

# Shared barriers: Family & friends

## *Family substance abuse*

- “Everybody in my family smokes weed, like my aunts and uncles, brothers and sisters, everybody.”
- “I have never known my father. My mom is a meth addict, coke, crack you name it. I've never celebrated my birthday. I have never had a Christmas. I had to take care of myself and cook my own food when my neighbor stopped doing it at seven years old. I had to take care of myself then.”

# Shared barriers: Family & friends

## *Child maltreatment*

- “I have a lot of stress and anxiety from childhood stuff that I still put up with every day.”
- “I was too hell-bent on getting revenge for my childhood... because my dad used to whoop my ass and my mom wasn't there, so I was going to show them.”

## *Negative peer groups*

- “Hanging out with old friends led to my relapse. I had figured when I got out of drug treatment I could get together with my old friends and not use. It only took 5 minutes being around them and I was using again”.

# Shared supports: Family & friends

## *Family*

- “...The safe place for me to go to would be like dinner or whatever; I would go straight to my auntie's house or my mother's house with my daughter.”

## *Friends*

- “ It is just somebody you feel comfortable talking to, who knows what you have been through and probably been through it with you.”

# Supports unique to AA: Family & friends

## *Street family*

- We have barbeque sessions and stuff. That is basically family and friends. I ain't talking about immediate family. I'm talking about people on the streets that you call family."
- Its' important to have relationships with many people, "street family, because "you learn a lot of stuff."

## *Fictive kin*

- There are older people in my neighborhood, who help me out, non-relatives who I look to for advice, learn things from."

# Shared community barriers

## *Police*

- “The police make it harder. They harass you for no reason. Or they harass me for no reason, you know. They pull you over, tell you to drop on the ground. I didn't do nothing. It is stressful.”
- A young man mentioned the police would not come to their house when his mother called to ask for help when one of her children was hurting a younger sibling and they would not help.
- "I've been picked up by police twice in the last 4 months. When they found out the warrant wasn't for me they apologized, said they made a mistake but that I'd need to pay for a taxi to take me home. I refused and finally they gave me the money to pay for a cab."

# Shared community barriers

## *Too old*

- “It’s like when you get to a certain age, Boys and Girls Club they don’t want us there 16, 17 you are kind of out of there.”
- “We go to the Y sometimes, because they have the late night on Fridays. Sometimes they let everybody lift weights and play basketball. But I’m getting kind of old.”

# Community supports unique to AA

## *Community recreational venues*

- "...indoor basketball courts like somewhere where you don't got to pay."
- "...the YMCA and the Boys and Girls Club keeps kids out of trouble and when they get older they will be more successful in the community, I think."

## *Faith community*

- "My whole family goes - my sister, my mom. They always got something positive to say. When you are going down there, you have people that care about you, going to pray for you, too. It is somewhere you can go..."
- "Church helped me turn things around in what I am doing."

# Community supports unique to AA

## *Places to hang out*

- “I hang out in ghetto areas, places where people tend to hang out, and you know if you go there, there is going to be people you know. It is just a comfortable feeling. It is not like you actually have to know them, but you just feel like a connection.”

## *Advocacy and support organization*

- “That's why you don't see a lot of these youth that be hanging around on the corner, they would be here today. Most of our groups are people who used to hang around at the bus stop, and they're here today, and they had cleaned up their act.”
- “They accept everyone in the program, no age limit or criteria.”

# Community supports unique to EA

## *Volunteering*

- “I volunteer a lot. We have different workdays, at Starbucks. The next one is going to be really cool, graffiti. You get to work with a bunch of people that have the same passion that you do.”
- “There is this little church down the road, and there is barely anybody that goes to it anymore. So they try to make money to keep it going. I help them pass out flyers. The Fourth of July I helped them sell fireworks and stuff. I do a lot of stuff for the church down there.”

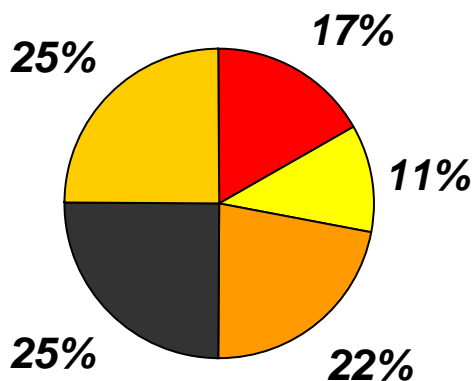
# Summary and implications

- A pervasive barrier shared across both groups of young adults was criminal justice involvement which impacted their ability to get a job, go to school, or rent an apartment.
- The importance of belonging to a religious congregation or religion/spiritual beliefs in the lives of African American youth represents a link to the larger community, social networks and culturally relevant role models that could support community integration efforts.
- African American young adults with mental health difficulties have a huge need for community places and spaces where they are welcomed and can meet their social, recreational, educational and employment needs and give back to the community.

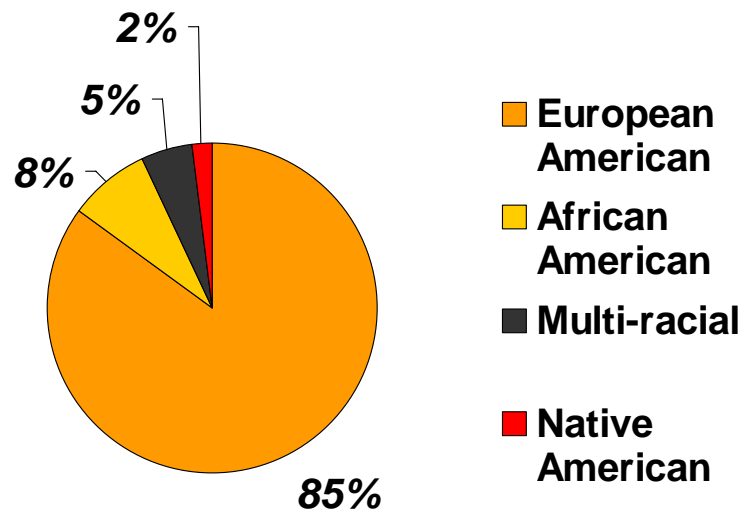
# Family participants (N = 42)

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

■ <15K    ■ 15-30K    ■ 30-45K  
■ 45-60K    ■ >60K



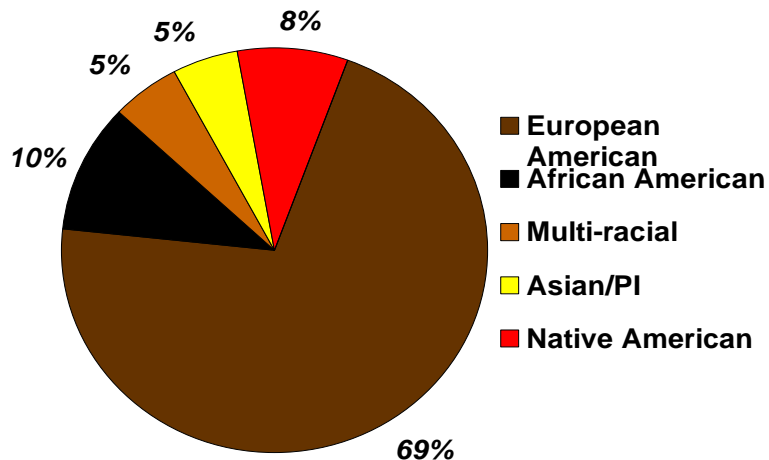
- Age: Range 36-65; mean 47.7 (SD 7.6)
- Race/Ethnicity:



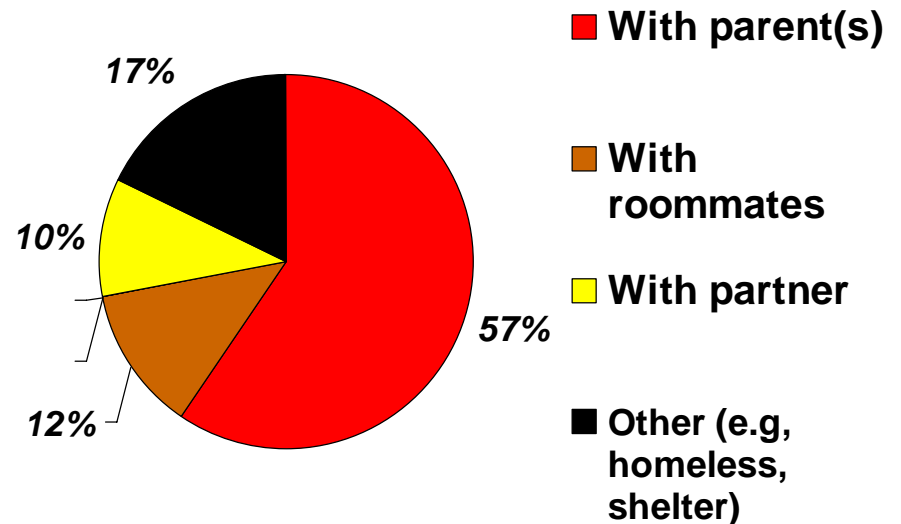
# Family reports of youth characteristics (N = 42)

- Gender: 72% male, 28% female
- Age range 15-28; mean 19.6

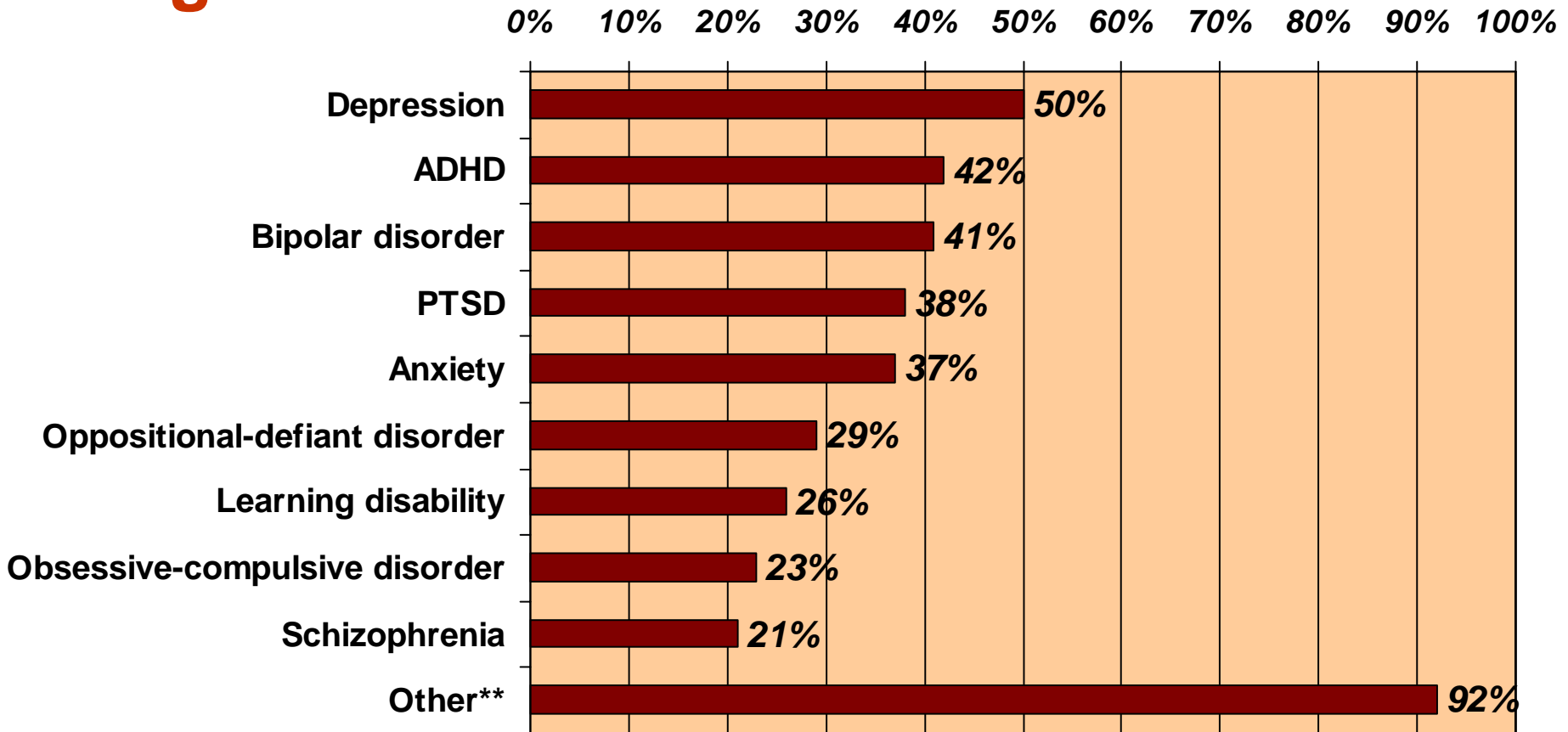
## ■ Race/Ethnicity:



## ○ Living Situation



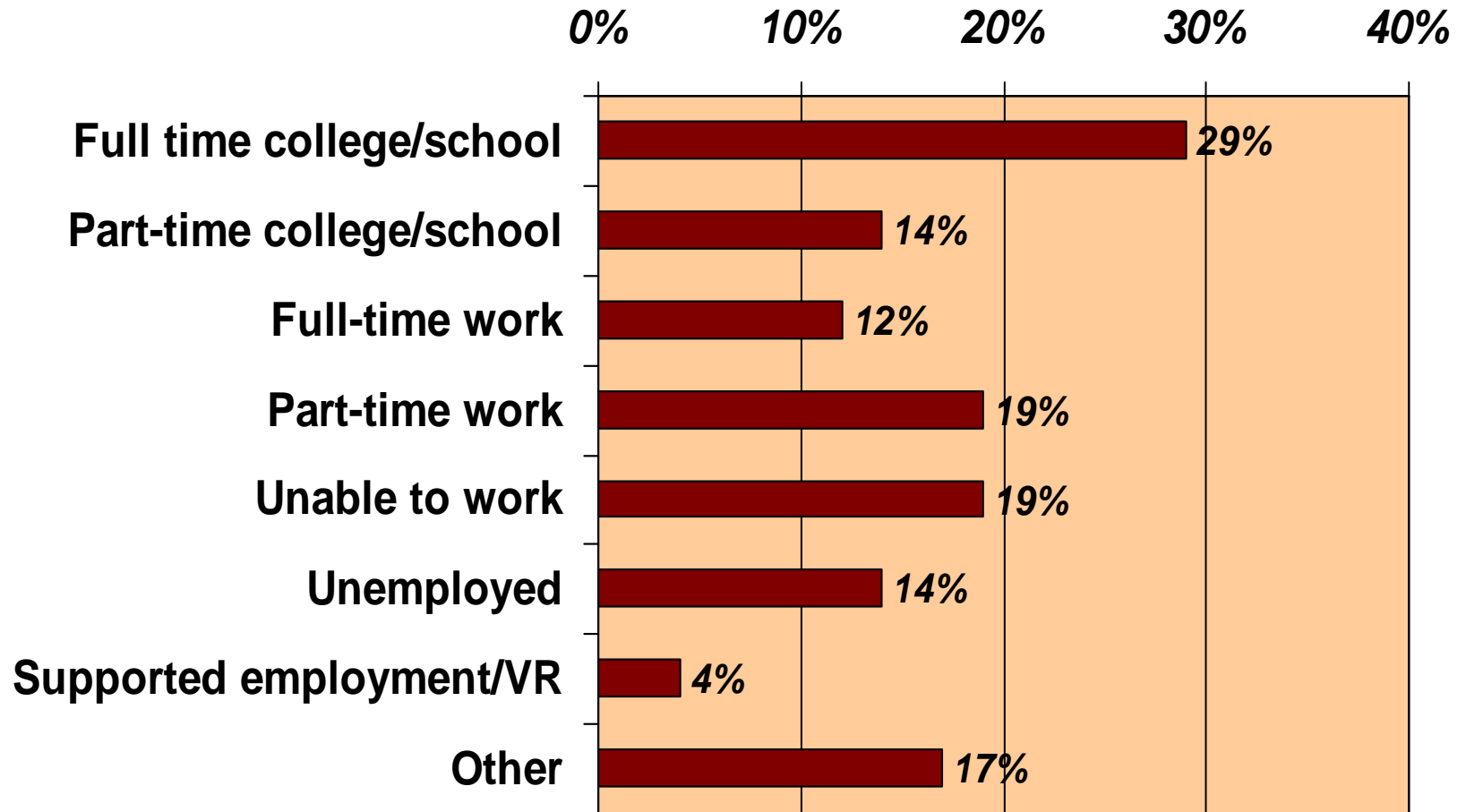
# Family reports of youth mental health diagnoses\*



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

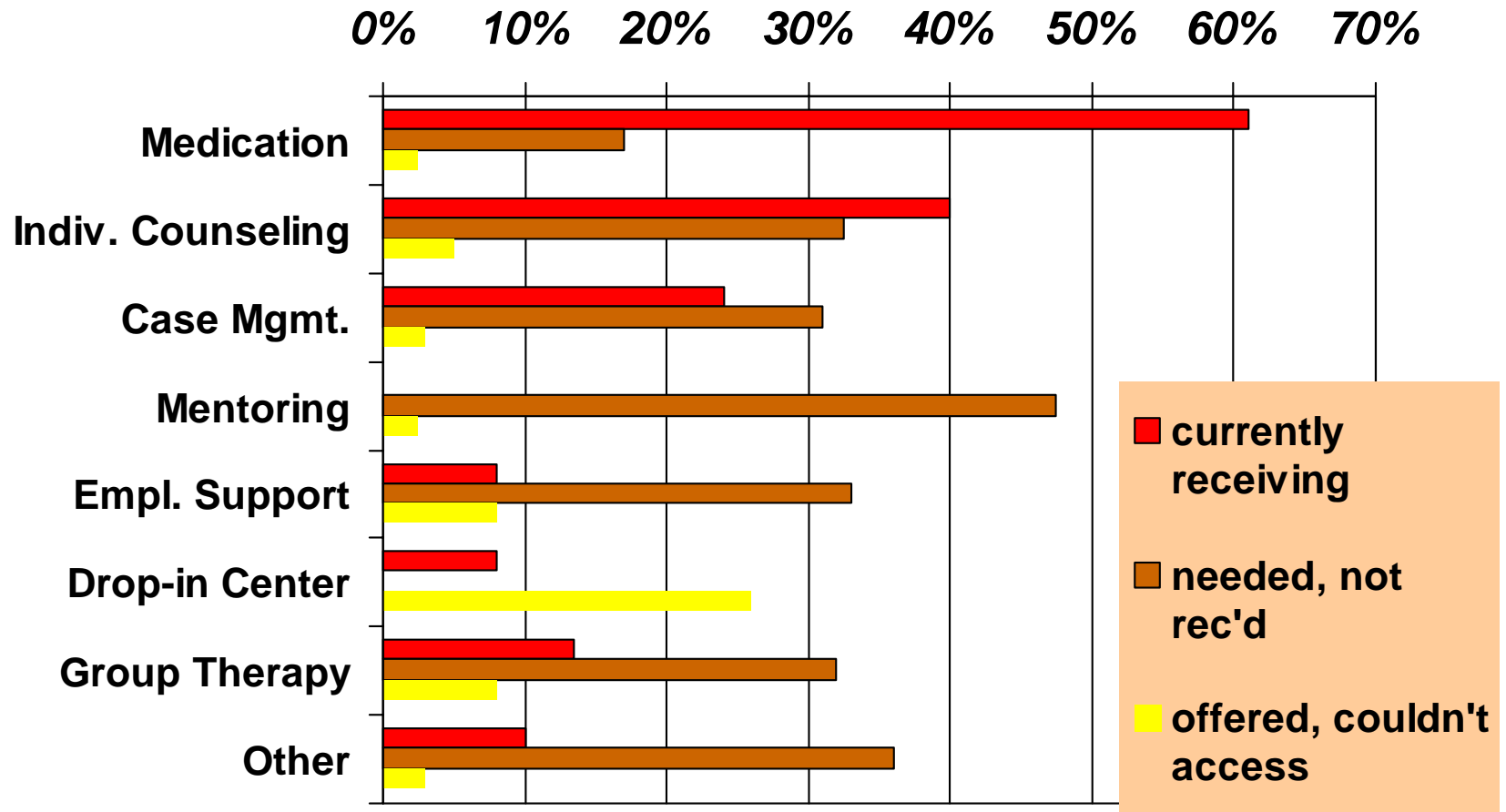
\*\*Includes Asperger's, Schizoaffective, and other disorders.

# Family reports of youth involvement in employment and school\*



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

# Family reports of youth access to mental health services



# Family perspectives: 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.’”
- “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 perspectives: Meaning of community integration

## *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 perspectives: 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.”

## *Personal barriers*

- “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.”
- “She tends to isolate herself...”

# Family perspectives: Barriers to community integration

## *Lack of resources for supportive activities and 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 supports for community integration

## *Families are a major support*

- “You may have to stay out there, being the cheerleader and providing information and... be the secretary sometimes for the things that are difficult for him to do... But all the time rejoicing in his growing confidence and independence, and knowing that is the end goal.”

## *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*

- “[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: 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 [issues].”
- “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.”

## *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.”
- “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 perspectives: Evolving roles and relationships

## *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?”

## *Concerns that others will not support their children*

- The natural thing for a child is to move away and be independent. It is a little different for kids like mine in that they tend to need the support of their families longer.”
- “As long as I was around, I would kick her out of bed, but if you’re at college, nobody [will do that].”

# Barriers to family support during transition years

## *Parenting dilemmas: Wanting to help but not take over*

- “Part of it is them growing up and saying, “I have my own mind and I know what I want to do.” As a parent you learn how to support them and encourage, and yet not trigger that separation thing, ‘Forget it, I don’t want you telling me what to do, so I’m not going to listen to you at all.’”

## *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.”

# Effects of transition challenges on families

## *Family stress may be high*

- “As a parent, I am just about to the point where I have given up. I have done all I can and that hurts, but that is all I can do. We now have to move on to finding other people who will fill in and motivate.”
- “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.”

## *Caegivers’ needs may be unmet*

- “He is, ‘When do we get a break? When do we get to have our years?’ We are tired of raising kids. We raised four and now we are raising five.”

# Family members' advice to other transition-stage families

## *Start transition planning early*

- “Let’s start sooner. Let’s not wait until they are this old and they are trying to transition... the mentoring and the support and the validation of people that genuinely care is going to be, in my opinion, the biggest integration-transition resource that we could have.”

## *Take care of yourselves*

- “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.”

## *Seek out other parents*

- “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.”

# Family members' advice to other transition-stage families

## *Seek education and support groups to be able to help your 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.”
- “NAMI is great. NAMI helps educate you. NAMI has people working here, volunteering here, that know the system, that know what it is like to have a son or daughter....”

## *Stay involved*

- “Find every way you can to be engaged. I e-mailed his [college] teachers and fortunately, he had a couple of teachers who were really great... You have got to communicate to represent your kid, because your kid often won't be forward with their needs.”

# Family members' advice to other transition-stage families

## *If necessary, take legal steps to maintain involvement*

- “Otherwise, once they turn 16, they can accept psychiatric care or not. They can talk about killing themselves and no-one has to tell you. There is no system that will work with you if you don't have some kind of guardianship, which is a huge barrier if you are trying to help a kid who is not their chronological age.”

## *Continue to educate yourself and be an advocate*

- “Know as much as you can about the system and be strong enough to advocate for something better and not to accept less.”

## *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.”



# Limitations of our study

- Geographically limited, “non-random” sample.
- Focus groups provided a single “snapshot in time,” and did not allow for follow-up to observe progress.
- We don’t know how well our sample represents all young adults with mental health difficulties and their families.
- Future studies would benefit from greater ethnic diversity and longitudinal study.

# Implications of our study

- Families want to play valued roles to support their young adult children's community integration.
- Families need self-care, education, legal advice, and support to stay involved in their children's lives.
- Legal rules around confidentiality and self-determination currently shut out many concerned parents from the treatment process and create barriers for families trying to support their children.
- Service providers can ally with youth, young adults, and families to support optimal levels of community integration.
- For young people, criminal justice involvement may impact their community integration by limiting their ability to get a job, go to school, or rent an apartment.
- For African American young adults, connections with faith communities appear to support their community integration efforts.
- Young adults with mental health difficulties need access to community places where they can enjoy social and recreational activities, meet their educational and employment needs and give back to the community.
- Public education about mental health, the needs of young people with mental health difficulties, and the roles of families supporting their children is needed for service providers, employers and communities.



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- Focus group participants
- Family member and youth research assistants
- Local and national advisors
- Our mentors at the Research and Training Center on Family Support and Children's Mental Health.



# Audience discussion

- How do our findings resonate with your experiences as families, youth, or service providers?
- We've given examples of participants advice to other family members. Do you have advice for others here?
- What ideas do you have about where we should share these research findings?



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