



Portland, Oregon



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

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# Improving Transitions to Adulthood for Youth with Mental Health Needs: Youth and Parents' Experiences and Recommendations for Improving Transition Supports

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# Project purpose and participatory research methods

- To gain understanding of community integration from the perspectives of transition age youth with mental health needs and their families.
- Separate 90-minute focus groups for youth with mental health difficulties and their family members.
- Youth and family research assistants facilitated focus 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 reaching acceptable agreement on coding a portion of the transcripts, they were coded by research team members independently to identify common and unique experiences and perspectives.
- In this presentation we share findings from a sub-group of pairs of 16 youth and their family members focused.



# Participants

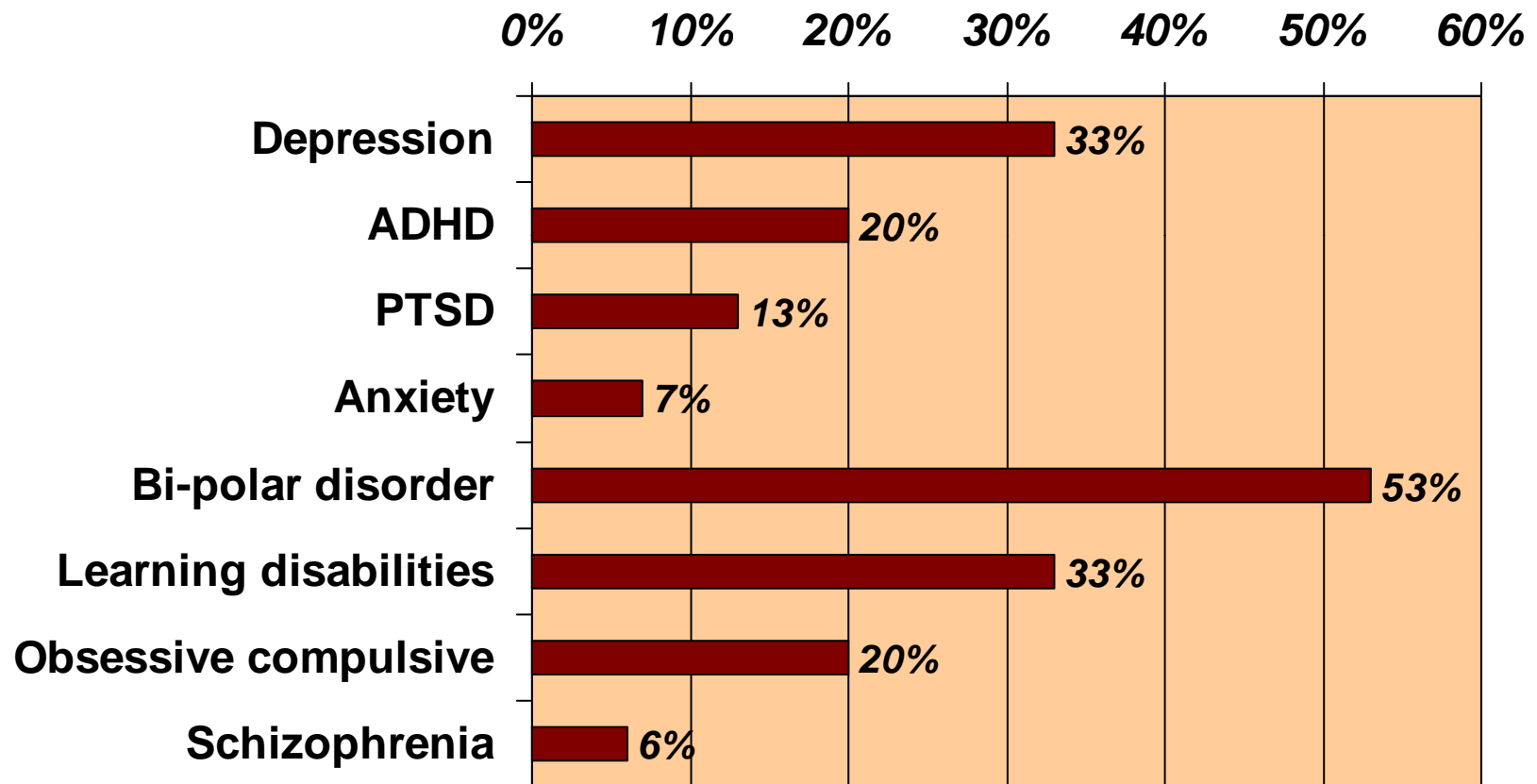
## Youth (n = 16) Gender: 88% male

- Age: Mean = 19.4; range = 17-23
- Living situation: 73% with parents; 12% with extended family; 6% alone or with room-mates
- Race/ethnicity: 88% European American; 6% Native American; 6% Asian/Pacific Islander

## Family members (n = 17) Gender: 87% female

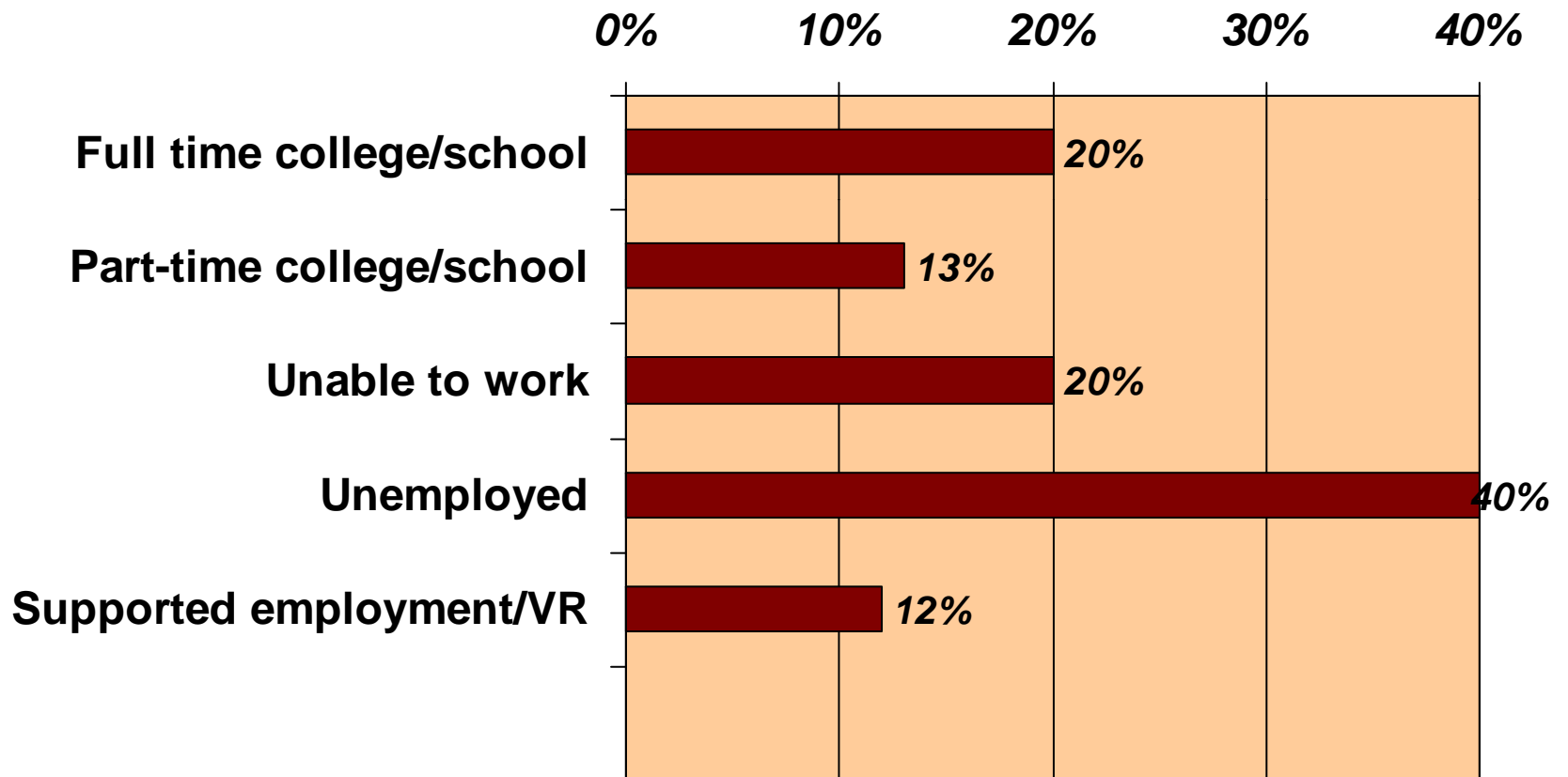
- Race/ethnicity: 88% European American; 6% Native American; 6% Hispanic

# Youth mental health diagnoses\*



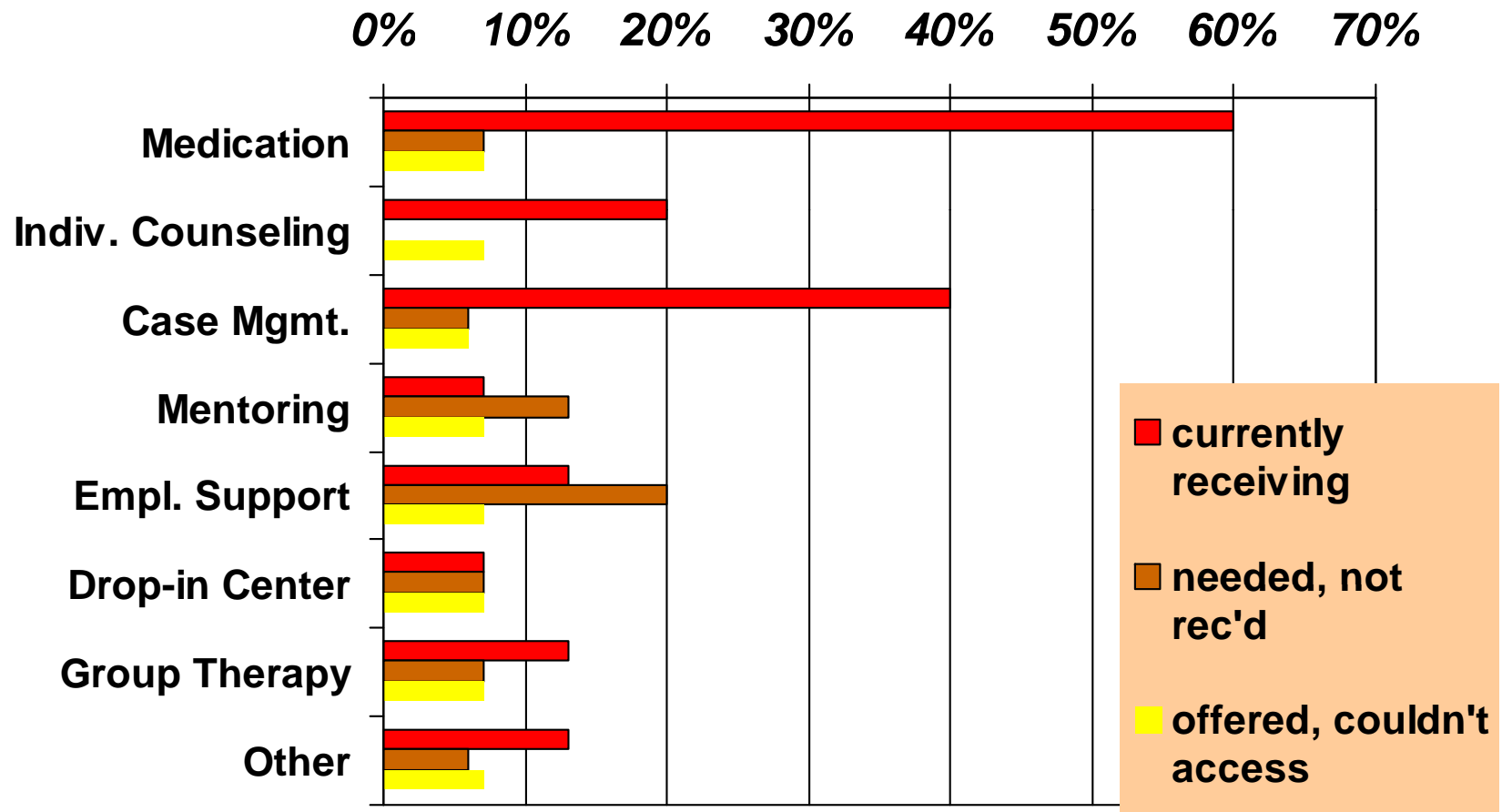
\*Percentages add to more than 100% because of multiple diagnoses.

# Youth involvement in employment and school\*



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

# Youth access to mental health services





# Stages of the Family Life Cycle

(Erikson, 1959: Carter & McGoldrick, 2005)

## Stage: Adolescence

### Youth Transitions

- Identity development
- Increased peer affiliations
- Incorporation of role models
- Intimate relationships emerge
- Clarification of values & ideals
- Exploration of career options.

### Family Transitions

- Parent/child relationships shift to permit adolescents' moves in and out
- Refocus on couple relationship & career issues
- Shift to care for elders.

## Stage: Young Adulthood

### Youth Transitions

- Increased independence from family, including financial, residence.
- Pursuit of educational/career goals.
- Emerging worldview.
- Choices in friendships & intimate relationships.

### Family Transitions

- Renegotiation of couple relationship.
- Development of adult-adult relationships between grown children and parents.
- Realignment of relationships with older generation.



# Youth views of service providers' support

## ■ Skill development

- “He had good advice of how to calm myself down, give me some things called cognitive thinking skills that I started using...tools to use to calm myself down and get my mind straight.”
- “I had counseling. It made me look at what I did during the week and what I could change if I did something bad, to make it better.”

## ■ Responsiveness

- “Whenever I needed to talk, he would be there. He would come by. It was like 4:00 in the morning and he would come over and talk to me.”

## ■ Providing hope

- “She helped me a lot through a lot of this stuff, and she is still helping me...she just gives me that little glimmer of hope and that's cool. She can relate to the alcoholism. She understands.”



# Youth views of challenges in services

## ■ Lack of communication

- “There is poor communication, not much competence in the hospital, so they do things like up my meds because I was sleeping a lot and they thought I was depressed. Normally just didn’t think to ask me why I am sleeping a lot or anything.”

## ■ Negative attitudes of service providers

- “It held me back, because kind of the mindset of a hospital is really pessimistic, and they give out a lot of pessimistic prognosis. They try to refute any sort of objectives that I had personally, like to go to college. They tell me things like, ‘You are going to be on meds the rest of your life. Here is your prognosis. You are going to be in and out of hospitals, in and off the streets.’”



# Family views of service providers' support for youth

## ■ Benefits of mentoring

- “My son had a mentor for six to eight months, I believe, maybe a little longer. He was kind of like boy-interrupted when he came back. He had missed those transition years between elementary school and high school. That was my biggest fear, how do we bridge that gap? He worked with him on things about how to manage yourself around people, what you should and shouldn't say, how you should and shouldn't act.”

## ■ Importance of family participation

- “He was also open to hearing his dad and my thoughts on what we thought would be especially helpful for [name]. We fed him information...What also worked for [name] was having a psychiatrist that asked for input and accepted our input, our observations.”



# Family views of service providers' support for them

## ■ Shared responsibility

- “[Having a wraparound team and a parent partner] made it possible for me not to have all the answers... what she said is you no longer need to be his doctor, his therapist, his nurse, his playmate, his interpreter, his counselor, whatever professionals there were. You don’t need to do that. All you have to do is be his mom.”

## ■ Practical support

- “[in-home respite care] allowed me to keep my professional life separate from my personal life, I guess is what I am saying... he was getting what he needed and I got a chance to kind of regroup before I had to go home to him.”



# Family views of challenges in services

## ■ Staff unprepared to work with youth

- “My kid runs everybody off. We have gone through Big Brothers, so it gets really frustrating. I have even had counselors just throw their hands up going this kid is way over my head. I have had school counselors bail out. So it gets frustrating.”

## ■ Lack of appropriate opportunities

- “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 and that kind of a thing so he figured that is all they want to offer me, why bother?”



# Youth perspectives on family support

## ■ **Appreciation for family support for transitioning**

- “My mom has helped me a lot. My mom has been a really big supporter of me trying to achieve my goals... Once I turn 18, the supports that I have, some of them are going to disappear because they are only for under the age of 18...I am going to have to be able to deal with my issues on my own and find other supports. My mom has been helping me out with figuring that stuff out.”
- “My parents have been a pretty big support, too. I’m 19, so I can’t get support like I did when I was under 18, so my parents had to still kind of stay in there and help me through all the legal troubles, and helped guide me through programs, support groups. They really helped me out and kind of gave me motivation to go out and get jobs and help me fill out the applications.”



# Family perspectives on support for their transition-age youth

## ■ Finding a balance between offering support and increasing dependency

- “Somebody with schizophrenia tends to rely on their family a lot. [We are] all the time trying to find ways to push him out, encourage that, always letting him know that he has a choice. It is really okay to go and be with your buddies instead of come here.”
- I told [my son], if you need me in there, you need to voice that. I can’t say it for you and I can’t ask to go in. So if it is something that you need me sitting there, just for your security or whatever, you say, “I am not doing this without my mom present or my father.”



# Peer-peer support for youth

## ■ Age-appropriate groups

- “There were a couple of groups that I have been to that were really cool, actually. Everybody in there was like 20. It is like the trials and errors of going through high school... things that we can relate to, going through what we have been through and trying to make it in life with all these obstacles” (youth participant)

## ■ Leadership development

- “[Name of program]... is a supportive group of people that do the same thing for him that we do for each other, and that is make them feel . . . they are good people with a difficult childhood” (family participant).



# Peer-peer support for families

## ■ Benefits of sharing information and resources

- “We have a great family organization structure here that is helpful for resources, information, training and support. We also do peer supports, and it helps us as parents have that extra support, too.”

## ■ Support and normalization

- “One of the things that I think has been so helpful for us as parents to heal and not feel shame and guilt about our kids has been our support in our community. It is our... group... which is where a core group of parents got together for many, many years, going through the adolescent years with our kids. That has been the saving grace for us, to know that we are not bad parents. We are parents doing a difficult job with difficult kids.”



# Youth perspectives on educational supports

## ■ Supportive teachers

- “Teachers, mostly. They don’t even need to know about it. They just have got to be the right kind of people. The good ones were usually my English teachers, my drama teacher.”
- “My English teacher liked me from the start, even though I butted heads with her a lot. She put more effort into me than most of my other teachers. She went one-on-one with me whenever I had that dumb look of “Huh!” She took an interest in me.”



# Youth perspectives on educational challenges

## ■ Unfair treatment by teachers

“When I asked the teacher if he could use the laptop he said, “No, you are going to use the paper like everyone else.’ I was like, ‘Why not? I have the stuff (IEP) that says I can do this.’ He said, ‘It is too much work for me’”.

## ■ Lack of involvement in IEP

“Usually they bring me in the room, but I am usually quiet and... I still think they just try to just sign something off. My IEP, for like five years I had the same IEP. All they do is cross it off and wrote the same thing, like for three or four years.”



# Youth perspectives on educational challenges

## ■ Not implementing IEP's

- “My IEP says that I need somebody reading the test but what they say and what they do is two different things.. I don't know if they tell my other teachers or if my other teachers just don't listen to them.”
- “The IEPs usually tend to work if the people have read them. The problem is the teachers who don't care. I've actually had teachers who looked at it and said, 'No, I am not going to do it.' 'You have to do this for me.' It is like, 'No I don't.'”



# Youth perspectives on educational challenges

## ■ Stigmatizing by other youth

- “A youth repeated comments he had heard from other students, ‘So what, you are special? Go to a special school.’”
- “Because of all the mental hospitals and time I spent in juvie I had people saying Oh, you are that schizophrenic kid... I am like, ‘What are you talking about?. That’s not what I am.’ Yeah, I had a lot of problems. People wouldn’t hang out with me.”



# Family perspectives on educational supports

- A special teacher or social worker
- “A teacher was critical in making him feel confident about going to college, just by saying a few words. Saying to us, in public, in front of him, ‘This kid needs to go to college.’ That stayed in [my son]’s mind.”
- “He had a social worker that kept really good tabs on him and that connected, understood [his] needs.”



# Family perspectives on educational supports

- **Helpful transition program for youth with disabilities**

“They taught him how to interview... Then they build a resume. [His] first job, he was a junior janitor... [He] actually got hired at a pet store, the second job. There is no program like that here.”

- “In this program, they got to pick where they wanted to go. It was empowering to them. Do you want to go trim animals, go to a pet salon, or do you want to go to a gym?... We went anywhere they picked to go. Anywhere an employer would see us.”



# Family perspectives on educational challenges

## ■ Need for vocational training

- “We need vocational program for our kids, where they could stay in school, get into a program where it was hands on, trade-oriented, helping these kids get skills to go out and get employment.”

## ■ School staff’s lack of understanding

- “When you have a principal that says she is amazed he has any friends at all and that she thought we would have to put him in a mental institution. This kid is getting bombarded with this constantly, and he won’t go back to school this year if it is the same district.”



# Family perspectives on educational challenges

## ■ Lack of responsiveness

- “They don’t seem to have any services for him that are working. I have been trying to get hold of them for three weeks now to get an IEP done before school starts and it doesn’t look like I am going to get one before school starts. No one will even call me back.”
- “I had people come in and help me with the IEPs. Nothing was ever done. Nothing was ever changed... They said in front of us that this is the type of child they would not allow back in the school.”



# Youth perspectives on employment challenges

## ■ Criminal record

- “It makes it kind of look bad on me. It also makes a bigger gap, since the last time I worked, which now it is like six months... they do background checks and it could show up.”

## ■ Learning disabilities

- “It is hard to find a job if you can’t read. If you can’t read you can’t really do most of the work.”
- “I had one job where I wasn’t catching on to learning what they wanted me to learn. They just didn’t want to work with me.”



# Youth perspectives on community integration challenges

## ■ Risky neighborhoods

- “Like when I get this job, I don’t have a car. I am going to have to walk through my neighborhood where there’s gangs, shootings to go to my work.”
- “Where I live it is really hard to meet people because all we really have is gang bangers and drug dealers, really, and little kids. If you are not one of those three, then it is like you don’t fit in.”
- “My community is all screwed up... it is really bad. Like gangs, violence, stuff like that.”



# Youth perspectives of community integration challenges

## ■ Vulnerability to negative relationships

- “The only friend is like 22 or 23, I don’t hang out with him anymore because one day I went down to his house. We had a mirror and he had crank on it so I just quit hanging out with him. That is like the only friend I really had I talked to.”
- “I think [she] was probably in AA or something like that... she was like 25. My parents trusted her because she went to AA and stuff, but she wasn’t following the program. We would go to like crazy punk shows and do crazy drugs. I never had any positive experiences with that.”



# Family perspectives on community integration challenges for youth

## ■ Youth vulnerability

- “He would get his allowance and his ‘friends’ would be there every day, but only when it was [his] allowance. He would call and beg them to come over to play video games at other times but no one would show up.”

## ■ Stigma

- “People who don’t have disabilities are almost afraid of people with disabilities. They don’t know how to act around them.”
- “If you live in a small community you are kind of the poster child, he doesn’t want to get involved in the community because he is marked, he is branded.”



# Family perspectives on community integration challenges for youth

## ■ Recreation

- “We spend so much time in speech therapy, occupational therapy and those kinds of things, but we didn’t for recreation. I look back and feel so bad. All the other kids were all playing ball and soccer and stuff and we were out going to therapy.”

## ■ Church

- “When our son was diagnosed we were pretty much dropped like hot potatoes. Our pastors didn’t come and visit. They knew nothing about how to offer us any help.”
- “He won’t go to church now because the youth pastors told him that his disability is a sin.”



# Recommendations for improving supports and services

## ■ Family perspectives

- “[We need a place where] families know where to go to get a complaint heard, or a concern heard and it addressed without these people getting off the hook for the damage that they cause to families.”
- “I wish that everybody that was working in our child serving system were nonjudgmental, helpful people that really wanted to help our kids.”
- “a mentor that either has a disability or has been around with people with disabilities... and teach him, help him, show him.”

## ■ Youth perspectives

- Recommendations for crisis response services.



# Recommendations for improving educational supports and services

- **Family perspectives: Reach out to school staff**
- “I emailed teachers and fortunately he had a couple of teachers who were really great. I just wanted to let them know if something had occurred and email worked pretty well.”
- **Youth perspectives: Hands-on learning, practical skills**
- “Hands on learning would make school a lot easier for me.”
- “While I was getting my GED, they taught you how to look for transportation to get to work and back home, how to look for a job.”



# Family recommendations for improving employment supports

- Youth need social skills and some pre-job types of skills.
- Programs that can find jobs for kids with disabilities during the school year.
- Programs for youth who don't have profound disabilities but aren't ready to go to college or start work
- Need for an employment bank of people willing to take on a youth that needed some mentorship, that needed a job.



# Recommendations for improving community supports

- Community education regarding mental illness and recovery.
- Critical role of churches and recreational centers for positive activities, recreation and connections with community.
- Programs that provide transition age youth with options for engaging in advocacy, peer support and a way of making positive connections with like-minded youth with similar needs and interests.



# Implications of our study

- The transition from adolescence to young adulthood is challenging for youth with mental health difficulties.
- Youth and families benefit from relationships with responsive, helpful, service providers and support from peers, mentors, and support groups.
- Families want to play important roles to support their youth and young adult children despite legal constraints.
- Service providers can ally with families to support transition-age youth and young adults to achieve optimal levels of wellbeing.
- Families need support, education, legal advice, and to stay involved in their children's lives.
- Every youth needs community beyond their family.



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