



Portland, Oregon



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

www.rtc.pdx.edu

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

Presented at:

Building on Family Strengths
Conference

May 30-June 1, 2007

Portland, OR

Research Team Members

Presenters:

- Pauline Jivanjee, Research and Training Center on Family Support and Children's Mental Health, Portland State University
- Jean Kruzich, University of Washington

- Jan Lacy, Portland State University
- Tamara Johnson, Curtis Dickerson, Health 'N Action/Statewide Action for Family Empowerment of Washington (SAFE-WA)

Collaborators:

- Lyn Gordon, Clark County, WA, Department of Community Services
- Cathy Callahan-Clem, Cynthia Brothers, University of Washington
- Lacey Vankirk, Portland State University



Purpose of presentation

To share findings of a qualitative study of youth and family perspectives on community integration of youth and young adults with mental health difficulties. This presentation will focus on:

- A comparison of the experiences and perspectives of African American and European American young adults with mental health difficulties.
- 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 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

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

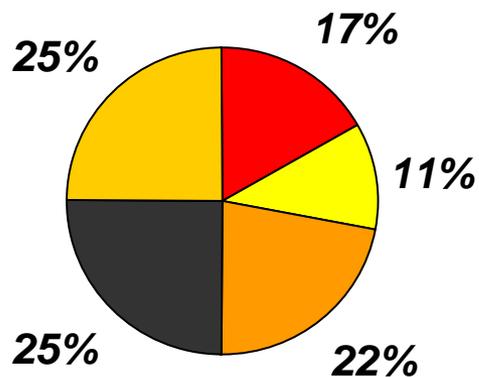
We asked young adults and family members about:

- 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.

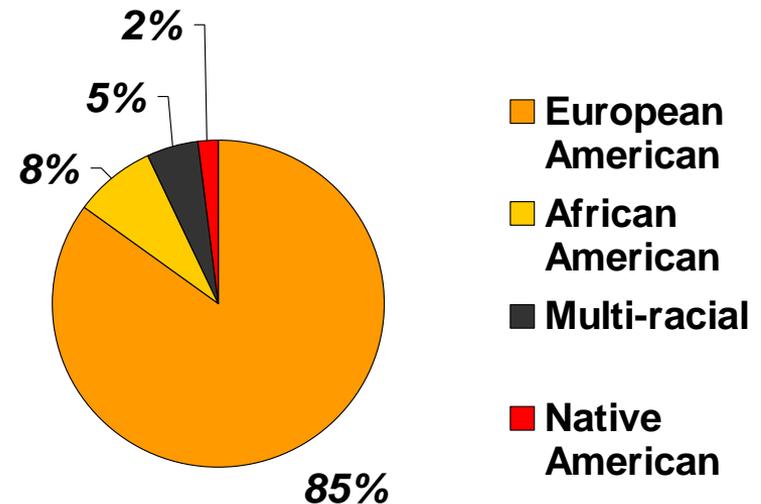
Family characteristics (N = 42)

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

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



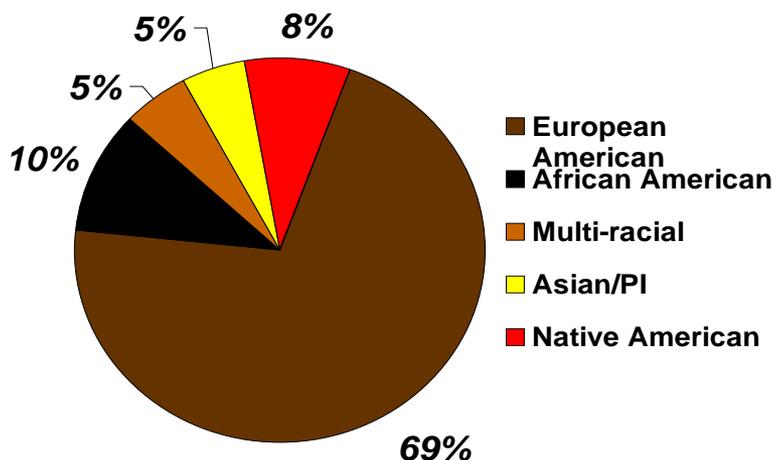
- Age: Range 36-65; mean 47.7 (SD 7.6)
- Race/Ethnicity:



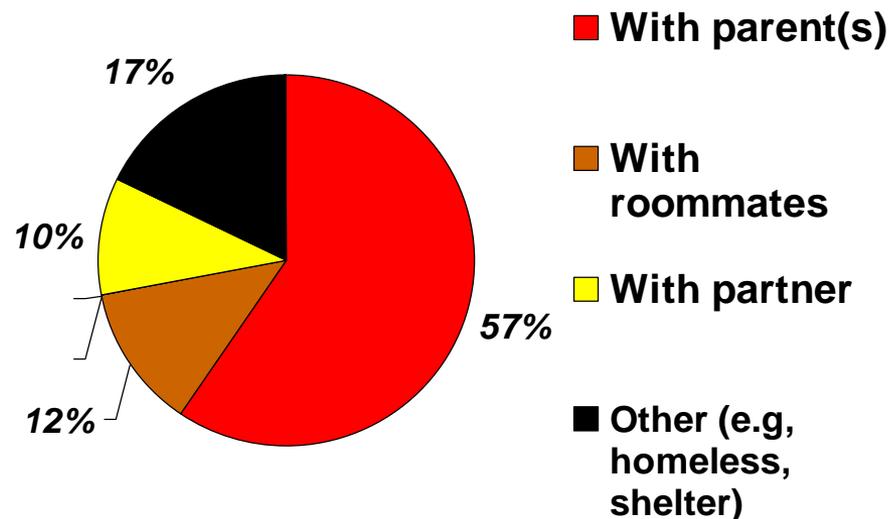
Youth Characteristics (N = 42)

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

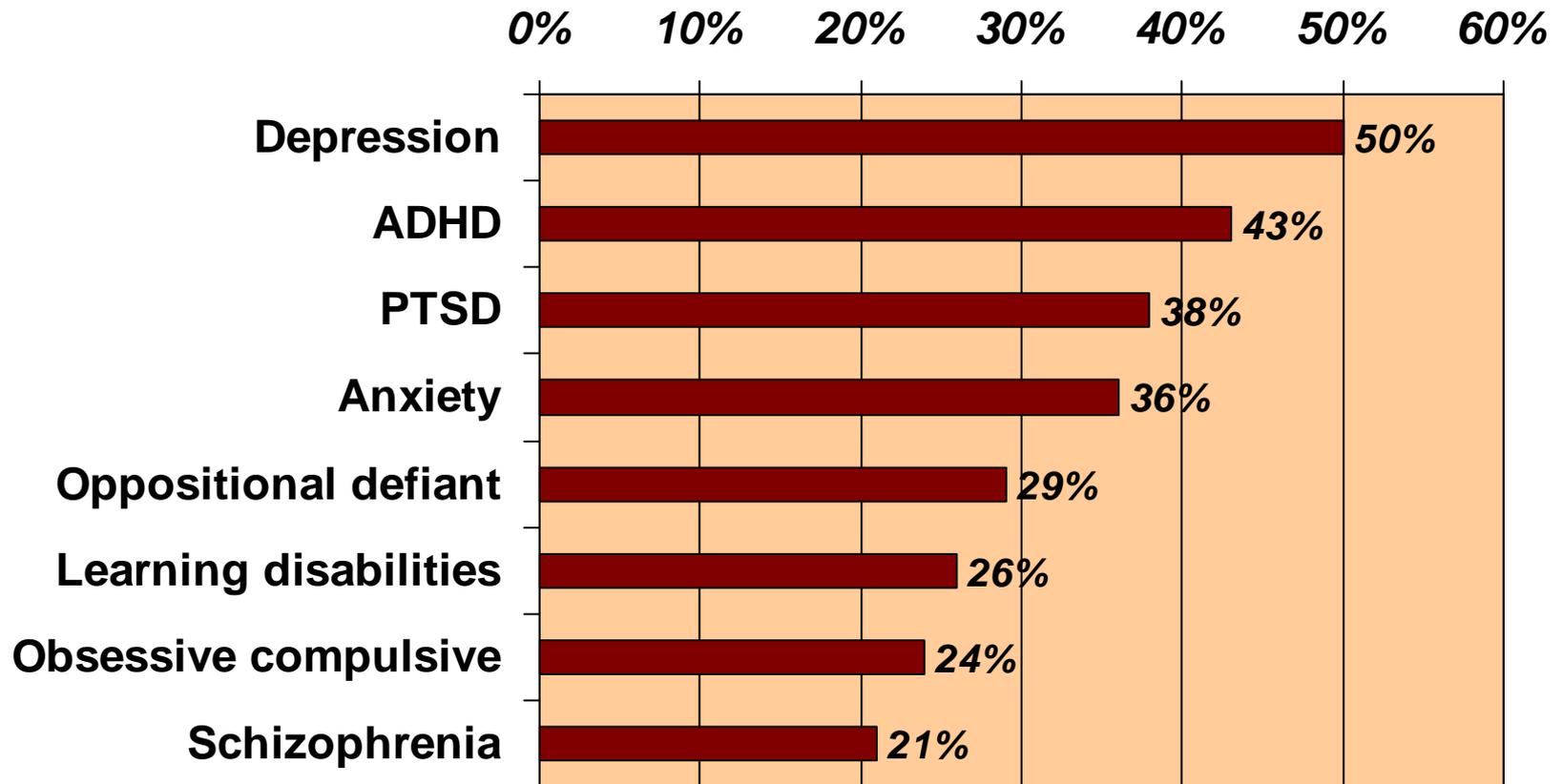
- Race/Ethnicity:



- Living Situation

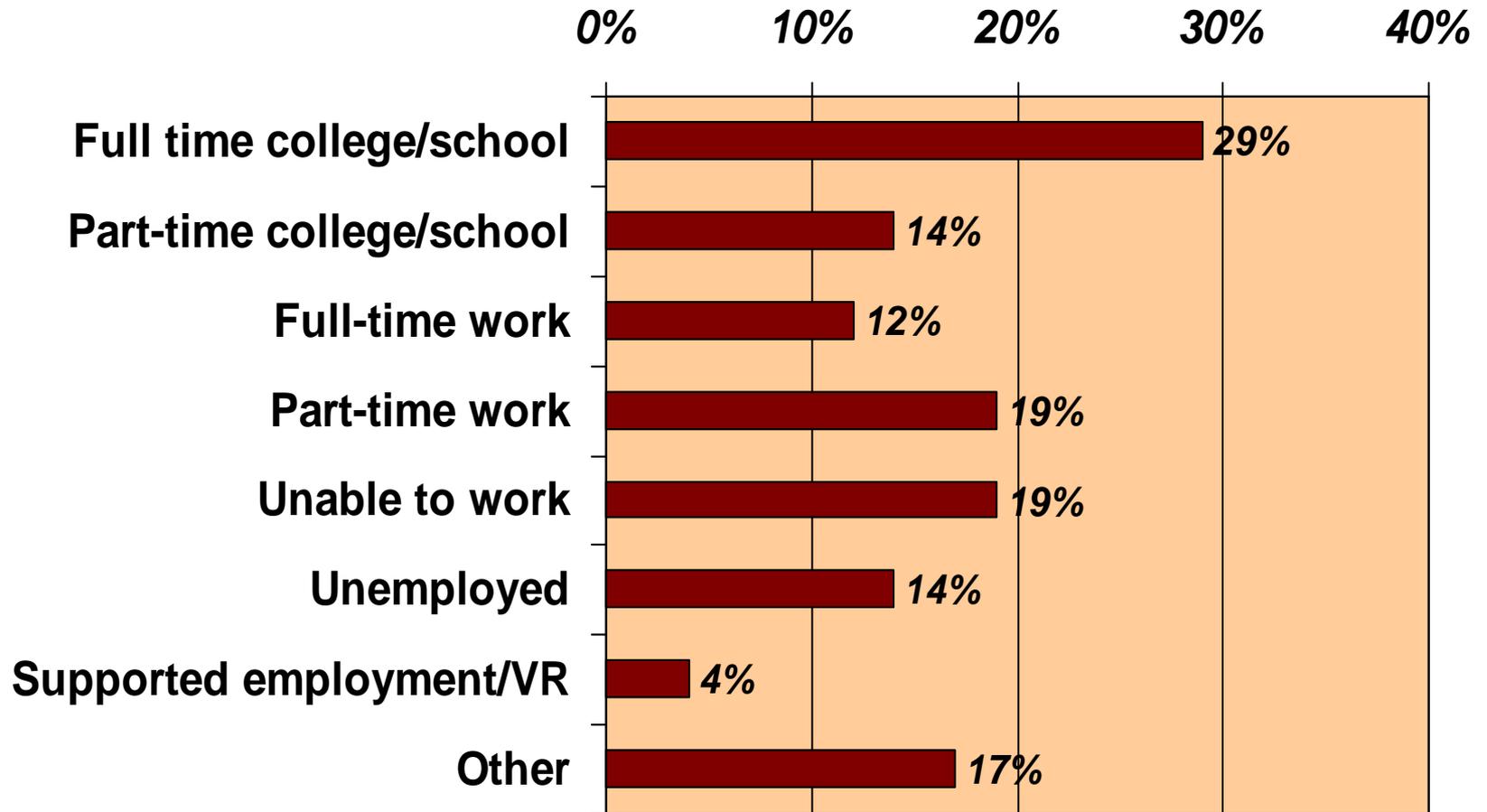


Family reports of youth mental health diagnoses*



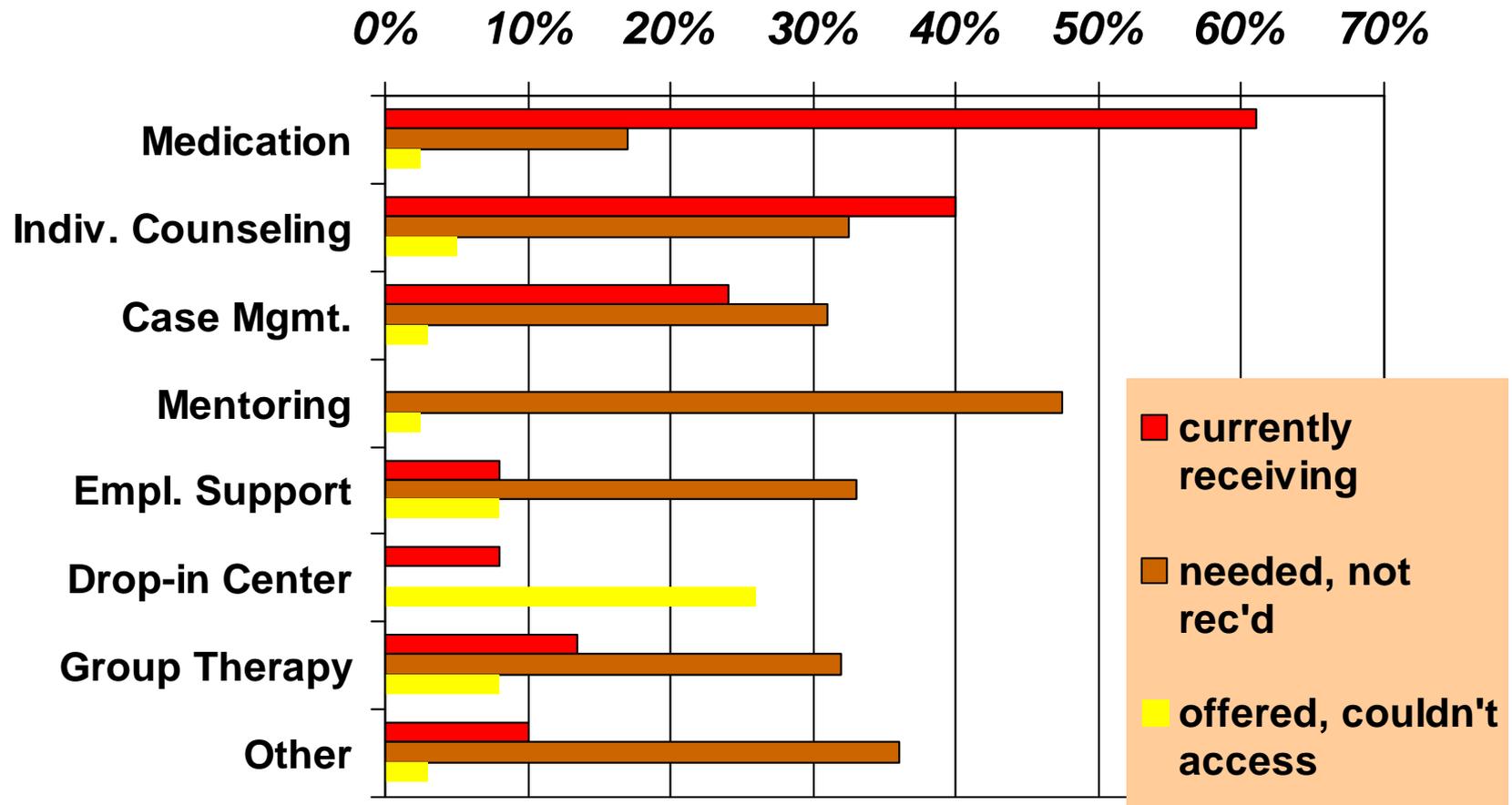
*Percentages add to more than 100% because of multiple diagnoses.

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.”
 - “... 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.”
- 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 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

- **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: 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 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].”

Parenting dilemmas in the transition stage

■ 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.’”

■ Being in a supportive role

- “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.”

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.”

■ Parents’ 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.”

Barriers to family support during transition years

■ 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 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.”

Stages of the Family Life Cycle

(Erikson, 1959: Carter & McGoldrick, 2005)

Stage: Families with Adolescents 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.

Launching Children & Moving On 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.



Limitations of our study

- Geographically limited, “convenience” 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

- Families want to play important roles to support their young adult children's community integration.
- Legal rules around confidentiality and self-determination and the consumer movement 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 families to support transition-age youth and young adults to achieve optimal levels of community integration.
- Families need self-care, education, legal advice, and support to stay involved in their children's lives.
- Public education about mental health and the roles of families supporting their children is needed for service providers, employers and communities.



Acknowledgements

Sincere thanks to all who helped with this project:

- 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.



Portland, Oregon



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

Funds to support this activity come from The Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse Mental Health Services Administration, U.S. Department of Health and Human Services; and from

The National Institute on Disability and Rehabilitation Research, U.S. Department of Education.



Center for Mental Health Services,
Substance Abuse and Mental Health
Services Administration, U.S. Department
of Health and Human Services



National Institute on Disability
and Rehabilitation Research,
U.S. Department of Education



Contact information

Pauline Jivanjee
Portland State University
RRTC on Family Support and Children's Mental Health
Tel. 503-725-5015
e-mail: jivanjee@pdx.edu

Jean Kruzich
University of Washington
School of Social Work
Tel. 206-543-7965
e-mail: kruzichj@u.washington.edu