

Strengthening Family Support for Young People with Mental Health Needs in the Transition to Adulthood: *A Tip Sheet for Service Providers*

By: Pauline Jivanjee, Eileen Brennan, and Claudia Sellmaier in consultation with the Pathways Transition Training Collaborative, mental health consumers, families, and service providers

September
2012

T*o strengthen family support in the transition to adulthood, service providers need to be able to:*

- Articulate the value to young people of having family members involved in services
- Involve families of all diversities in supporting their young adult children to achieve their goals
- Navigate the legal and policy contexts that affect families' involvement in the transition years
- Call upon Family Support Organizations and Parent Advocates to support families in the transition years.

Consider the experiences reported by many families during the transition years:

- A shared sense of losing control with the natural pulling apart of adult family members and youth as youth become more independent.
- Initially parents may feel confident, although worried, but feel less adequate when service providers undermine their expertise and judgment by questioning and marginalizing them.
- The treatment system often forces young adults and families to disconnect.
- Families care for youth in a context of inadequate resources, and little support in the community.
- Systems do not necessarily support collaboration with families.

Service providers need to be familiar with federal, state, and local legal and policy issues:

- Individual and family developmental changes happen gradually but institutional transitions occur abruptly according to bureaucratic and legal rules.
- There are different definitions of serious emotional disturbance in special education versus mental health in the adult system.
- Youth with mental health disabilities have entitlements in the education system but when they have reached the age of adulthood there is only eligibility for adult services, no entitlement.
- **Consent:** Refers to the age-related shift of legal responsibility from parent to young person which varies by state.
- **Confidentiality:** According to HIPAA – Health Insurance Portability & Accountability Act of

1996 (PL 104-191), providers cannot discuss health information with a parent unless the youth specifically grants permission – need to explore possible benefits and concerns with young people.

- **Competency:** When a young adult is clearly not competent to make independent health care decisions, a parent may petition the court to become the guardian, generally before age 18.
- **Guardianship:** A guardian is appointed to arrange care of a person who is incapacitated:
 - Requires an attorney, filing for a petition, having a court visitor interview the young adult to be sure it is in that person’s best interest.
 - The protected person must be willing to sign the consent, or be served to appear in court to show cause. There is no universally accepted definition of competence and terms and conditions vary state-to-state.
- **Conservator:** A conservator is appointed by court to make decisions about property and assets.

Relationships with families

- Some young people may be grateful for support that family members offer them as they work toward recovery and independence (Preyde, Cameron, Frensch, & Adams, 2011).
- Other young people may want to strike out on their own and not want other family members in their business (Arnett, 2000).
- Families are a resource and generally want to be helpful. Youth in crisis may not see what families have to offer; providers should be prepared to speak about the value of involving families.

Providers are encouraged to:

- Recognize social and emotional supports, including siblings.



- Ask family members questions to find out about the challenges they face.
- Recognize isolation, fear, and loss of control in parents.
- Ask questions about the important systems that affect the family’s ability to support their young person (e.g. school, transportation, employment, family support).
- Recognize the practical assistance families provide: financial help (housing, bills, access to health care); treatment; education.
- Avoid jargon and talk clearly to families.
- Support families finding a balance between wanting to protect their children and needing to let them make mistakes.
- Support families to encourage their children to take responsibility for their own care in new environments (college, first apartment, supported housing).
- Offer assistance to families to get their young people ready to make their own decisions and to advocate for themselves.
- Avoid blaming families if their children make mistakes.
- Help families to get connected with Family Support Organizations and link them with Family/Parent Advocates.

The following questions about mental health issues could be useful for family discussion:

- Is the young person able to discuss her/his condition with significant people?

- Can the young adult articulate her/his mental health and other needs? Does s/he know how to access health/mental health information?
- Does the young person know how to access community resources and agencies?
- Does the young person understand when to discuss her/his condition?
- Can the young person advocate for her/himself? (Holmbeck et al, 2010)

New service approaches are needed with diverse families and communities:

- Young people live in many different family structures, so it is important to:
 - » Ask young people who they define as family and what are their preferences for family involvement in services.
 - » Seek information and advice about the racial and ethnic diversity of families you are serving and seek opportunities to develop skills in providing culturally responsive services.
 - » Reach out to the families of youth of color who are over-represented in more restrictive settings and who face additional challenges in trying to participate in their children's treatment.
 - » For effective work with immigrant families, think about protective factors such as respect, loyalty to family, and the development of biculturalism.
 - » Focus interventions on promoting a strong sense of positive cultural identity to reduce the depressive effects of discrimination.
 - » Involvement of community supports such as churches can be valuable, although not all families want this (Lindsey et al., 2006).
 - » Seek to connect Native American youth and families to culturally-specific agencies that use holistic approaches rooted in traditional teachings, promote the

development of positive cultural identity, and encourage families to draw from traditional culture and spiritual teachings to guide their relationships with young people (Cross et al., 2007).

- » Emphasize health promotion involving family, friends, peer supports, and other community supports that young people trust (Garcia & Saewyc, 2007).
- » Seek ways to facilitate youth-family communication to build understanding and appreciation of strengths (Chapman & Pereira, 2005).
- » Reach out to community resources and engage in advocacy on behalf of vulnerable families.
- » Use asset-based approaches to promote LGBTQIQ2-S resiliency through building positive identity, reducing stigma, and promoting strong relationships with peers, supportive families, positive role models, and adult allies (Gamache & Lazear, 2009).
- » Know about policies and supports in all areas of living, obstacles to success, and strategies for young people to achieve their goals.



Self-assessment of preparedness to work with diverse families:

- Do I understand and respect those whom young people define as family?
- Am I aware of families' different cultural

beliefs about mental health and have I clarified their expectations of treatment outcomes?

- Do I respond with humility and reflection and seek clarity where I don't understand?
- Do I know where to seek culturally relevant and specific services and supports?
- Am I working to support the development of positive ethnic and cultural identity as a protective factor?
- Have I sought mentors to bring knowledge of youth culture to adult family members?
- Do I know how to connect families with Family Support Organizations, family support and advocacy groups, and parent advocates who can:
 - Help parents navigate the system and access traditional and non-traditional services?
 - Translate the content and process of meetings with service providers into understandable language (Munson et al., 2009)?
 - Work to empower parents and youth so that their voices are heard in service systems?
 - Serve as networking agents to link parents with others with similar experiences?
 - Bring their valuable personal experiences to bear, and offer hope (Hoagwood, 2005; Munson et al., 2009, Robbins et al, 2008)?

National Family Support Organizations

National Federation of Families for Children's Mental Health—also check for state/local chapters

<http://www.ffcmh.org/>

National Alliance for the Mentally Ill (NAMI) – also check for state/local chapters

<http://www.nami.org/>

PACER center

<http://pacer.org>

Parents, Families and Friends of Lesbians and Gays (PFLAG) has over 500 chapters nationwide and provides community-based support and advocacy for families

<http://community.pflag.org/>

Please visit our project web page at:

www.pathwaysrtc.pdx.edu/proj-trainingcollaborative.shtml



Tipsheet produced by Pathways Transition Training Collaborative, Research and Training Center for Pathways to Positive Futures, Portland State University, Portland, OR.

www.pathwaysrtc.pdx.edu



Project funded by National Institute of Disability and Rehabilitation Research, United States Department of Education, and the Center for Mental Health Services Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (NIDRR grant H133B090019).