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Acknowledgments/Funders



National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
<http://acl.gov/programs/NIDILRR>

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Pathways Webinar | September 2015

RESEARCH & TRAINING CENTER FOR PATHWAYS TO POSITIVE FUTURES



Family Support for Transition-Aged Youth



September 29,
2015



Objectives

Participants in this webinar will be able to

- Use their research-based knowledge of family experiences to better support young adults with mental health challenges.
- Assess the impact of cultural background on the experiences of these families.
- Better support families including young adults with mental health lived experience.
- Access training opportunities and resources that will help families better support young people.
- Identify needed research and training that will help participants better address the needs of young adults and their families.



Presenters



Ana Maria Brannan
*Associate Professor,
Indiana University*



Lori Cerar
*Executive Director,
Allies with Families,
Utah*



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*Research
Professor
Pathways to
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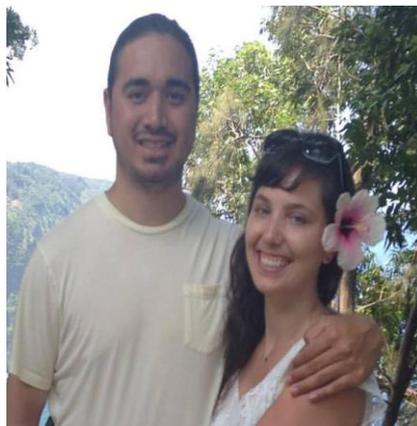


John Ossowski
*Dissemination
Manager, Pathways
to Positive Futures,
Portland*



Perspectives of a young adult with lived experience

Conversation between Nicholas Buekea and John Ossowski





Early Assessment and Support Alliance (EASA)

EASA provides information and support to young people who are experiencing symptoms of psychosis for the first time. Most people don't realize just how common and treatable psychosis is!

Email Tamara Sale for more information: tsale@pdx.edu

Visit the website at: www.easacommunity.org



Caregiver Strain

Ana Maria Brannan, Ph.D.
Indiana University





Purpose

- Review the research literature on the experience of families of transition-aged youth with behavioral health challenges
- Highlight what is known and where there are gaps in knowledge
- Recommend future directions
 - Practice
 - Policy
 - Research



Background

- This topic is positioned between the fields of child and adult mental health services research
- A good deal of work has been covered both fields, but little has focused on transition-aged youth



Positive and Negative

- Caring for a child with emotional and behavioral difficulties can be enriching
 - Better view of life and the world
 - Closer family relationships
 - Rewarding spiritual life
- More focus has been on challenges experience by caregivers families



Caregiver Strain

- It is well documented that extra caregiving responsibilities can be difficult
 - Financial strain
 - Disrupted relationships
 - Worry, guilt, and fatigue
 - Fear for the future of relative with challenges
- “Caregiver strain” is a term used to describe the impact of these additional demands on caregivers and families



Influences on Strain

- Symptom severity is greatest contributor to caregiver strain
 - Caregivers of older adolescents report greater strain in some areas
- Having adequate resources can be protective
- Barriers to care increase strain
- More family empowerment associated with less caregiver strain



Caregiver Strain and Parental Employment

- Caring for school-age children with emotional and behavioral difficulties impacts caregiver employment
- Caregivers are
 - Less likely to work outside of home
 - More likely to reduce hours, change jobs, quit or be dismissed



Caregiver Strain and Service Use

- Strain impacts child service use patterns
 - Increases risk of residential placement
 - Increases likelihood child will receive any MH services
 - Positively related to amount of services received and costs of care



Race and Ethnicity

- African-Americans report less strain
- Some think this is related to having better social support
- Appears to be related to severity of child internalizing problems (e.g., depression, anxiety, mood)
- Partially explains differential service use across racial/ethnic groups



Caregiver Strain and Child and Family Outcomes

- Children of caregivers who reported more strain at intake were less likely to experience clinical deterioration
- School-based parent-to-parent peer support program realized
 - Reduced caregiver strain
 - Improved child reading achievement
 - This was found only for most strained caregivers



Conclusion

- Supporting families is likely to result in better service processes and improved outcomes for young people with emotional and behavioral difficulties
- More research is needed on the unique needs of families as they try to support their transition-age youth and young adults



Growing up without growing apart

Lori Cerar

Executive Director Allies with Families

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





GROWING UP WITHOUT GROWING APART

*Finding your way
to your Child's Adulthood*

A curriculum designed by parents for parents and caregivers who have a youth/young adult transitioning into adulthood.



Section 1:

- INDEPENDENCE VS. INTERDEPENDENCE
 - Defining Healthy Relationships
- Taking Care of Yourself
 - Managing stress and
 - Time management
- Understanding the Grief Process
 - Stages of emotional response



Section 2:

- PERSON CENTERED PLANNING or Youth Guided Wraparound
 - What it is ...
 - Why do it ...
 - When to begin ...
 - Who should be involved ...



Section 3:

- **EDUCATION**
 - The IEP for Transition-Aged Students
 - IDEA Transition Requirements
 - Special Factors for the IEP Team to consider
 - SECTION 504 guidelines and implementation.
- Who is the parent - parenting tips



Section 4:

- **LEGAL ISSUES**
 - What is this thing called Guardianship?
 - What are Advance Directives and how to use them?
 - Why is HIPAA important?
 - What you need to know about Estate Planning?



Section 5:

- Dreaming New Dreams/Loosening Up
 - What is loosening up?
 - Why is it necessary?
 - When is it appropriate?
 - Who is this for?
 - How to get there.
 - The need for support groups.
 - The need for prevention planning.



When is Loosening Up Appropriate?

Greater independence means
greater risk.

...risk taking is essential for the
long term development of
social and personal
competence.



Section 6:

- DEVELOPMENTAL MILESTONES
 - What are they?
 - When do developmental changes happen?
 - Why should we know about developmental milestones?



Section 8 (optional class)

- **FOSTER CARE**
 - What is “foster care” or “out-of-home” placement?
 - Why would my child be placed in foster care?
 - Who are the people who will take care of my child?
 - What information do I need to give to the child welfare agency about my child?
 - Who advocates for the best interests of my child?
 - What is a guardian ad litem?



I SEE CHILDREN AS KITES

You spend a lifetime trying to get them off the ground.

You run with them until you are both breathless.

They crash, they hit the rooftop,

You patch and you comfort,

You adjust and you teach.

You watch them lifted by the wind and assure them that someday they'll fly.

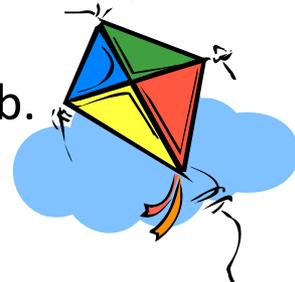
Finally they are airborne, and they need more string and you keep letting it out.

But with each twist of the ball of twine there is a sadness that goes with the joy.

The kite becomes more distant and you know that it won't be long before that string will snap and the lifeline that holds you together will no longer be the same.

A child, as a kite, must be prepared to soar, as they are meant to soar, free and alone, to the greatest extent possible.

And only then can we collectively say that we have done our job.



Anonymous



Moving to Young Adult Life: A Legal Guide for Parents

RESEARCH & TRAINING CENTER FOR PATHWAYS TO POSITIVE FUTURES

Lisa Lambert

Executive Director Parent/ Professional Advocacy League

<http://ppal.net/>





Parent role during transition

- Parents can have many roles during a youth's transition to adulthood – some substantial, some supporting
- Sometimes the culture of the youth and family will influence the role
- Parents can agree or disagree with the choice the youth makes but respect their right to choose
- Parents make decisions for the whole family not just for one child

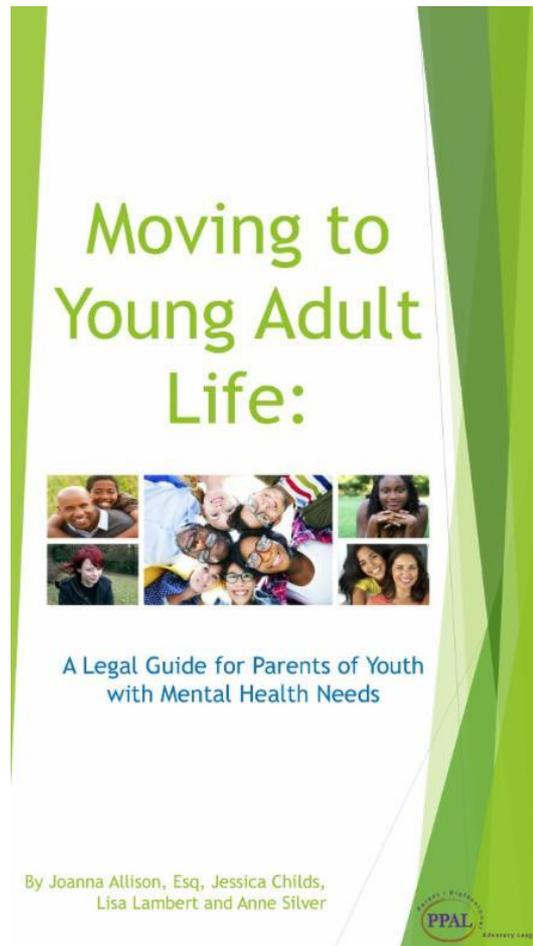


Roles parents can play

Roles
Create space for youth to take the lead
Emotional support
Financial support
Insurance advocacy
Special education/higher education advocacy
Keep adjusting the relationship
Personalized brainstorming, feedback
Promote youth voice/involvement
Provide personal medical history
Using youth-friendly language
Value family involvement



Legal guide



- Many legal guides for parents of youth with other special needs
- Quick guide focused on legal decision making
- Landscape has changed with Affordable Care Act, reauthorization of ABLE Act

Download the Legal Guide

<http://ppal.net/publications/guides>



Health care options

- Affordable Care Act allows young adults to stay on their parents insurance until age 26
- Many parents have taken on the role of insurance advocate (prior authorizations, appeals)
- Some youth/young adults are happy to hand over making appointments, arguing with insurers while taking charge of health care decisions
- Recommendation: think about Health Care Proxys and releases, which can be limited in scope



Financial decision-making

- Custodial/joint bank accounts
- Some youth can sustain employment but need an assist in managing finances
- In custodial account, parent or custodian has control; in joint account both parties have equal control
- Supplemental needs trusts in order not to jeopardize benefits
- Parent as representative payee for SSI if son/daughter is unable to manage money or pay bills



Achieving a Better Life Experience (ABLE) Act

- New legislation passed in December 2014
- Allows families to establish tax-free savings accounts (similar to 529 plans) for qualified persons with blindness, physical or mental disabilities incurred before age 26
- Does not jeopardize Medicaid, SSI or other benefits
- Accounts up to \$14K annually/up to \$100K
- Funds to be used for health care, education, housing and other expenses



HIPAA and HHS guidance

- More than 34% of young adults 18-34 are living at home
- Interpretation of HIPAA rules about communication are often quite restrictive
- U.S. Dept. of Health and Human Services issued a guide which clarifies communication with family, friends, others involved in care
- Personal HIPAA releases can allow family or friends to make appointments or receive information during a crisis, instead of law enforcement



Making meaningful decisions

- Decision making (who, how, what) changes as youth grow older
- Youth may assume complete responsibility in one area yet wait to assume responsibility for another
- Framing the role of family can be essential
- Having a clear understanding of the legal challenges and options is important



Promoting Positive Pathways to Adulthood



Pathways Transition Training Partnership (PTTP) Online Training Program

<http://www.pathwaysrtc.pdx.edu/proj-pttp>

Eileen Brennan,
Pauline Jivanjee,
Claudia Sellmaier
Maria Carolina
Gonzalez-Prats





Focus of Training Program

- Support service providers working with young people (14-29) with serious mental health conditions, and their families.
- Provide specialized, research-based, interactive training experiences.
- Move participant knowledge and skill development into improved practices.





Ten Hour-Long Training Modules

Module 1 - Partnering with Youth and Young Adults	Module 6--Providing Individualized and Developmentally Appropriate Services
Module 2 – Promoting Recovery	Module 7—Developing Healthy Relationships
Module 3 – Increasing Cultural Awareness and Building Community Support	Module 8—Planning Partnerships with Providers of Other Services and Collaborating to Bridge Service Gaps
Module 4 – Fostering Resilience and Family Supports	Module 9—Promoting Support from Family, Peers, and Mentors
Module 5 - Promoting Cross-Cultural and Intergenerational Relationships	Module 10—Using Evidence-supported Practices and Individualizing Interventions



The Training Experience



- Access free online training through your organization or team or the Pathways website.
- Engage in an hour-long learning experience including video segments, interactive exercises, and a brief knowledge check.
- Print out a certificate of completion at the end of each module.



Pathways Transition Training Partnership

- Beginning this fall, partnerships are being formed with organizations serving youth and young adults and their families.
- PTTP members will participate in testing the effectiveness of the training.
- Additional training supports will be available for PTTP member organizations and teams.
- If interested please contact: Eileen Brennan at eileen@pdx.edu or 503-725-5003.



Question and Answer Session

Q & A

Moderator: John Ossowski



Slides and References

Today's slides and references are available at:

The screenshot shows the website for the Pathways Transition Training Collaborative (PTTC). The header includes the logo 'PATHWAYS 2 POSITIVE FUTURES' and a search bar. The main content area features a navigation menu on the left with options like Home, About, Research, Training, Publications, Connect, and Resources. The central text reads 'TRAINING COLLABORATIVE' and lists project staff: Pauline Jivanjee (Co-Principal Investigator), Eileen Brennan (Co-Principal Investigator), and Michael Walker (Summer Intern). A description follows, stating the PTTC is designed to enhance the skills of service providers working with young people with serious mental health conditions. Below the description is a photo of a young woman in a graduation cap and gown. At the bottom of the page, there are social media sharing options and a footer with the Pathways RTC logo and website address.

<http://www.pathwaysrtc.pdx.edu/webinars-previous.shtml>



Additional Questions

**If you have additional questions
or feedback, please contact us**

John Ossowski, Dissemination Manager:

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Eileen Brennan, Co-Principal Investigator:

brennane@pdx.edu

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Maria Carolina Gonzalez-Prats, Graduate Research Assistant:

mgonza2@pdx.edu

Our project website

<http://www.pathwaysrtc.pdx.edu>



Resources (1 of 3)

Allies with Families a non-profit organization in Utah working on empowering families with voice, access and ownership through training, education and advocacy: <http://allieswithfamilies.org>
Training by parents for parents/caregivers who have a youth/young adult transitioning into adulthood: http://www.pathwaysrtc.pdx.edu/HTItoolkit/files/08-Family_Support_and_Roles/2-System_Navigation/B_Growing_Up_Without_Growing_Apart-Parent_Curriculum.pdf

Balancing work & family responsibilities: A guidebook for parent support providers. (2015).
Portland, OR: Research and Training Center for Pathways to Positive Futures, Portland State University.
<http://pathwaysrtc.pdx.edu/pdf/work-life/BalancingWorkandFamilyGuide.pdf>

Beyond Blue: *beyondblue's* youth program, Youthbeyondblue, aims to empower young people aged 12–25, their friends and those who care for them to respond to anxiety and depression by providing online information and support: <https://www.youthbeyondblue.com>

Center for Parent Information and Resources (CPIR) serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs), so that they can focus their efforts on serving families of children with disabilities. <http://www.parentcenterhub.org/>

The Family-Run Executive Director Leadership Association (FREDLA) is dedicated to *building leadership and organizational capacity of state and local family-run organizations focused on the well-being of children and youth with mental health, emotional or behavioral challenges and their families.* <http://fredla.org/>

NAMI is the largest U.S. grassroots mental health organization dedicated to improving the lives of people who suffer from mental illness through education, advocacy and support through local chapters and online resources: www.nami.org



Resources (2 of 3)

NAMI Strength of Us is an online community developed by NAMI and young adults to inspire young adults to achieve their goals through peer support and resource sharing: <http://strengthofus.org/>

National Federation of Families for Children’s Mental Health a family-run organization with more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and their families: <http://www.ffcmh.org/>

Parents, Families and Friends of Lesbians and Gays (PFLAG) is a national organization with local chapters that provides support education, and advocacy on behalf of LGBTQ people: <https://community.pflag.org/>

Parent/Professional Advocacy League (PPAL) the family voice for children’s mental health in Massachusetts: <http://ppal.net>

A legal guide for parents of youth with mental health needs: <http://ppal.net/publications/guides>

Pathways Transition Training Partnership (PTTP) develops trainings to enhance the skills of service providers working with young adults with mental health conditions and provides information and tools for young people, family members, service providers, policy makers, and researchers:

<http://www.pathwaysrtc.pdx.edu/proj-pttp>

Promoting Positive Pathways to Adulthood, a collaborative project of PTTP, is a free online training series of 10 modules for service providers to increase their skills in engaging and supporting youth and young adults in the transition years who have mental health conditions.

<http://www.pathwaysrtc.pdx.edu/proj-pttp#modules>



Resources (3 of 3)

Statewide Parent Advocacy Network of New Jersey has published *Children's mental health services: A family guide*:

<http://www.spanadvocacy.org/sites/g/files/g524681/f/documents/Children%27s%20Mental%20Health-Family%20Guide-FINAL.pdf>

TeenMentalHealth.org is a Canadian organization developed to help improve the mental health of youth by the effective transfer of scientific knowledge into training programs, publications, tools and resources to enhance the understanding of adolescent mental health and mental disorders: <http://teenmentalhealth.org>

Youth M.O.V.E National is a youth-led national organization with local chapters devoted to improving services and systems that support positive growth and development by uniting the voices of youth and young adults who have lived experience in the mental health, juvenile justice, education, and/or child welfare systems: <http://www.youthmovenational.org/>



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