NOTHING ABOUT US WITHOUT US:

Growing Meaningful Youth Involvement in Your Organization

Tania Duperoy, BA Marsha Langer Ellison, PhD



The Learning and Working During the Transition to Adulthood Research and Training Center

Acknowledgements

The Transitions RTC aims to improve the supports for youth and young adults, ages 14-30, with serious mental health conditions who are trying to successfully complete their schooling and training and move into rewarding work lives. We are located at the University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Systems & Psychosocial Advances Research Center. Visit us at:

http://www.umassmed.edu/TransitionsRTC

The contents of this presentation were developed under a grant with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research, and from the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (ACL GRANT # 90RT5031, The Learning and Working Transitions RRTC). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). Additional funding provided by UMass Medical School's Commonwealth Medicine division. The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, SAMHSA, and you should not assume endorsement by the Federal Government.











Workshop Overview

Part 1	Overview/Introductions
Part 2	Overview of meaningful youth involvement
Part 3	Effective Approaches for Engaging Young Adults
Part 4	Wrap-Up Discussion



COURSE GOAL

 TO PREPARE SERVICE PROVIDERS TO BETTER SERVE YOUNG ADULTS WITH BEHAVIORAL HEALTH CONDITIONS





Disclaimer

- Just our experience (what we have learned...)
- Different organizations envision youth engagement in different ways, there is no "one size fits all", all have strengths and weaknesses
- Youth are heterogeneous no "one size fits all" here either
- Youth Engagement is continuous— expect lots of trial and error
- Quotes used in this entire presentation: youth who wished to remain anonymous



Learning Objectives

- Define ways youth can be meaningfully involved in different aspects of mental health work
- Identify and implement effective approaches to partnering with youth
- Identify common barriers and facilitators to youth involvement
- Learn how to overcome barriers to effective youth involvement
- Think of specific goals for involving young adults based on individual work

PART 2: OVERVIEW OF MEANINGFUL YOUTH INVOLVEMENT





Mechanisms of Youth Voice

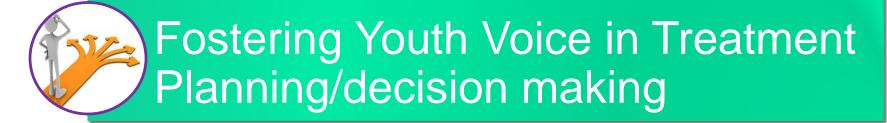


1. Treatment planning/decision making



2. Peer Worker Roles





- "Nothing about us without us"
- Important for self-determination skills
- Improves decision-making & planning skills
- Ensures treatment plan is culturally appropriate
- All models to increase youth voice in own care: respectful and value active listening





Team Approaches

Achieve My Plan³

- A structured process for implementing
 - Organizational commitment
 - Preparation for youth
 - During the meeting: meeting structures and interactions that promote youth participation
 - Mutual-Accountability

http://www.pathwaysrtc.pdx.edu/proj-3-amp



AMP Ground Rules

- √Stick to the agenda (use the parking lot)
- ✓ Speak directly to each other, not about one another
- ✓One person talks at a time
- ✓ Be respectful of everyone's voice and ideas
- ✓AJAA Avoid Jargon and Acronyms
- √ Focus on strengths and solutions
- End the meeting with everyone clear about commitments and next steps





Fostering Youth Voice Through Peer Worker Roles





Peer Support Workers

- People with lived experience providing services and supports directly to their peers
- Existing positions: "Peer Specialists", "Peer Mentors"
- Near-age or same age, shared experience
- Group settings or 1-on-1
- Can mentor on various life skills/domains
- Utilized in a variety of settings: DMH, Hospitals, Drop-in Centers, etc.



Why Peer Support?

- Research shows natural and near-age mentoring has positive effects
- Can increase social network
- Serve as a role model
- Instant credibility
- Recovery is a shared experience



Example: Vocational Peer Mentors

- Test feasibility of adapted Individualized Placement and Supports (IPS)⁴:
 - Supported employment + supported education with the use of near-age vocational peer mentors
- Near-age peer mentors with SMHC, service experience and were HS grads with school/work history
- Thresholds Young Adult Program (YAP) in Chicago



Vocational Peer Mentors

Received 40 hours of training:

- Increase knowledge of IPS model
- Learn how to share story
- Build active-listening skills



Role of Vocational Peer Mentors:

- Work closely with education/employment specialists
- Provide emotional support & validation
- Support young people in exploring work & school
- Model professionalism



Value of Vocational Peer Mentors

Valued Experiences:

- Receipt of advice
- Feeling related to & understood
- Opportunity to "talk" & be heard
- Trust & Safety

Valued Characteristics:

- Strong, positive, honest, trustworthy
- Similar life experiences and ability to empathize

"someone who was one of us... they can talk about their life, how they get through it and show us how to do it." – Sam





4. Partnering With Youth to Produce Systems & Service Change





What is Systems Change?

"Systems change" is a shift in the way that a community makes decisions about policies, programs, and the allocation of its resources — and, ultimately, in the way it delivers services to its citizens⁷.





Systems change

- Change systems to change the way a service is delivered to its target audience!
- Change underlying structures and supporting mechanisms

"In Headstrong, we have young people participating at all levels including board level. We get expenses paid and accommodation if we need it. Things like that enable everyone to participate"- Laura



Continuum of Youth Involvement⁸

Ad Hoc Input

Environment where young people can contribute ideas/ information about their needs

Influence

Formal structured input in order to ensure at least a minimal influence on the organization

Negotiation

Young people and rest of organisation each contribute their ideas, information and perspectives and decisions are reached by compromise













Structured Consultation

Deliberately
develop a
strategy to seek
young people's
opinions about
what they need,
what problems
they face or what
strategies to
employ

Delegation

Real responsibility for undertaking particular tasks of the organisation

Control

Young people make many or all of crucial decisions within the organisation, from policy, programming, financial management, hiring and firing of staff



Youth Council Involvement



DMH Statewide Youth Advisory Council

- Monthly young adult led meeting
- Reviews
 systems/services across
 MA to ensure young
 adult friendly/culturally
 appropriate
- Advocates for young adult voice in delivery and development



PART 3: EFFECTIVE APPROACHES FOR ENGAGING YOUNG ADULTS



Effective Approaches



1.Paid vs. Unpaid Young Adult Roles



2. Preparing Your Team/Young Adults



3. Accommodations and Support



4. Employer Challenges



1.Paid vs. Unpaid Young Adult Roles

- Remuneration sends a message of appreciation for time and expertise
- Allows for ongoing learning opportunities
- Shift in organizational power
- Creates a career ladder vs. stagnant positions





Paid Consultant vs Volunteer

- Should feel as if they can leave at any time
- Put strategies in place to ensure transition and continuity of work
- Encourage self-care, and importance of advocating for one's needs
- Re-assess position every few months
- Provide other incentives (resume building, trainings)



Paid/voluntary

"[...] So to speak to the paid part: paying youth is a discussion of equality. The adults are usually paid by an organization to spend time working on a project. If a youth is volunteering they can't have as much say in it. When you ask someone to volunteer: understand that you are on their time."- Mike





2. Preparing Your Team/Young Adults

- Ensure clarity <u>across the organization</u> on roles & responsibilities of young adult positions
- Establish levels of mental health disclosure required for being employed in YA positions
- Train staff on effectively working with YA staff



Preparing Young Adults

- Provide thorough and comprehensive training
- Ongoing supervision & mentoring
- Support ongoing professional development
- Decide on mutually agreed upon strength-based roles
- Little things may not seem important to a "seasoned professional,"
 but can make all the difference to a young adult



Genuine/Tokenism

- Having youth just to say you have youth
- Having one youth give feedack everything youth-related
 - One young person doesn't represent the voices of all young people
- All youth members should be approached equally for opinions and decisions

Not willing to make changes: "[...] When a group knows what they want to do, and they just want to check a box that says youth engagement so they try and convince youth of their ideas rather than listening."





3. Accommodations and Support

A reasonable accommodation:

- A modification or adjustment to the work environment or in the way things are customarily done that enables a qualified person with a disability:
 - to perform the essential functions of that position.
 - to enjoy the same privileges and benefits of employment as are enjoyed by employees without disabilities



Accommodations cont...

- Utilize existing resources and expertise (e.g. ADA, AskJan)
- Work together (employer and young adult)
- Quarterly review of request/flexibility



Accommodations Worksheet:				
1.	Name:			
2.	Date of Request:			
3.	Name of Advocate (if you want one) :			
4.	What specific Job Tasks that have been workplace (DUE TO YOUR MENTAL HE			
5.	How are the Job tasks mentioned in #4 a	affected BY your mental health cor	ndition/disability2;	
6.	Ideas for accommodations to address pr	roblems mentioned in #4:		
7.	If you cannot think come up with accome what resources you've used during your their own search (e.g. websites/people/p	search so your supervisor doesn't		
8.	Supervisor/Manager Comments:			
	Signatures:		_	

Considerations for Support

- Cost-effective process (short term pain for long term gain!)
- Formal vs. informal process
- Individualize, individualize, individualize!
- Consider coaching vs. supervision







4. Employer Challenges

- Commitment from Human Resources
 - Find a champion
 - Stress value of lived experience as a unique "qualification"
- Commitment from all levels of organization
 - Fear of "minimizing rigor"
 - Use examples to highlight value of youth voice



Challenges and Solutions

Challenge Employer Action YA Action

Mismatch of cultures

Think outside the box; embrace differences as strengths

Showcase strengths; let your voice be heard

Lack of professional skills

Mentor; give constructive feedback; seek guidance

Seek out supports; take initiative



Wrap-Up Discussion

- What do your goals look like?
- What resources will you look into moving forward?
- How can you keep up the stamina?





Confidentiality Statement

By receipt of this presentation, each recipient agrees that the information contained herein will be kept confidential and that the information will not be photocopied, reproduced, or distributed to or disclosed to others at any time without the prior written consent of Magellan Health, Inc.

The information contained in this presentation is intended for educational purposes only and is not intended to define a standard of care or exclusive course of treatment, nor be a substitute for treatment.





Thank You!

Want More Information?

Marsha Ellison: marsha.ellison@umassmed.edu
Tania Duperoy: tania.duperoy@umassmed.edu



Transitions RTC Website: www.umassmed.edu/transitionsRTC

References

- 1. Kirby P, Lanyon C, Cronin K, Sinclair R. *Handbook Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation.* Nottingham: Department for Education and Skills;2003.
- 2. Oliver K, Collin P, Burns J, Nicholas J. Building resilience in young people through meaningful participation. *Adv Mental Health.* 2006;5(1):34-40
- 3. Moser C, Walker J, Allen J, Bogner S. Achieve My Plan (AMP!): Youth Participation in Planning Teams. Retrieved from http://www.pathwaysrtc.pdx.edu/pdf/Webinar_AMP.pdf
- 4. Klodnick, V.V., Sabella, K., Brenner, C., Krzos, I., Ellison, M, Kaiser, S., Davis, M. and Fagan, M. *In press.* "Perspectives of Young Emerging Adults with Serious Mental Health Conditions on Vocational Peer Mentors". *Journal of Emotional and Behavioral Disorders.* (Published online, December 30, 2014)
- 5. Danley, K. S., & Ellison, M. L. (1999). A handbook for participatory action researchers.
- 6. Salzer, M. S., Wick, L. C., & Rogers, J. A. (2008). Familiarity with and use of accommodations and supports among postsecondary students with mental illnesses. *Psychiatric Services*.
- 7. Comprehensive Community Initiatives. (2008). Learn the Basics/What is a Systems Change. Retrieved from http://www.ccitoolsforfeds.org/systems_change.asp
- 8. Westhorp, G. (1987). Planning for youth participation: A resource kit. *Adelaide, Youth Sector Training Council of South Australia*.

