NOTHING ABOUT US WITHOUT US:
Growing Meaningful Youth Involvement in Your Organization

Tania Duperoy, BA
Amanda Costa, BS

**Special Thank You to Ashley Tritt for YA quotes**

The Learning and Working During the Transition to Adulthood Research and Training Center
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.
# Webinar Overview

<table>
<thead>
<tr>
<th>Part 1</th>
<th>Overview/Introductions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part 2</td>
<td>Overview of Meaningful Youth Involvement</td>
</tr>
<tr>
<td>Part 3</td>
<td>Effective Approaches for Engaging Young Adults</td>
</tr>
<tr>
<td>Part 4</td>
<td>Interactive Live Q&amp;A</td>
</tr>
</tbody>
</table>
Disclaimer

- Just our experience/what we have learned

- There is no “one size fits all” for youth engagement in different organizations

- 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 are from youth (pseudonyms are used for anonymity)
PART 2: OVERVIEW OF MEANINGFUL YOUTH INVOLVEMENT
Mechanisms of Youth Involvement

1. Treatment planning/decision making
2. Peer Worker Roles
3. Participatory Research & Evaluation
4. Systems & Service Change
Why have young adults lead their own treatment planning?

Young adults are more engaged and committed to services & supports that they have an active voice in $^{1,2}$
Benefit to Young Adults

Young adults are naturally in a developmental period where they are learning and solidifying:

- self-determination
- self advocacy
- self-efficacy skills

Involving Young Adults in their own treatment is:

- Important for self-determination skills
- Improving decision-making & planning skills
One Size Does Not Fit All

Mental health treatment is largely tailored to older adults or children, sometimes with service gaps for young adults.

Involving young adults in their own treatment:

- Ensures standard treatment plan is culturally appropriate and can become more flexible towards the individual, age group, and current practices of their culture
- All models to increase youth voice in own care are respectful and show value towards active listening
Resources - Different Approaches

For Teams
Achieve My Plan ³ [http://www.pathwaysrtc.pdx.edu/proj-3-amp](http://www.pathwaysrtc.pdx.edu/proj-3-amp)
Open Dialogue
[https://www.power2u.org/downloads/becomingdialogiic_ANZJFT11.pdf](https://www.power2u.org/downloads/becomingdialogiic_ANZJFT11.pdf)
Transition to Independence (TIP) [http://www.tipstars.org/](http://www.tipstars.org/)
Project RENEW [http://www.iod.unh.edu/Projects/renew/renew_main.aspx](http://www.iod.unh.edu/Projects/renew/renew_main.aspx)

1-on-1 Models
Shared Decision-Making
• [https://store.samhsa.gov/shin/content/SMA09-4371/SMA09-4371.pdf](https://store.samhsa.gov/shin/content/SMA09-4371/SMA09-4371.pdf)
• [https://www.patdeegan.com/commonground](https://www.patdeegan.com/commonground)
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.
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 for young adults
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

A Peer Mentor from the program was:
“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
Fostering Youth Voice Through Participatory Research & Evaluation
Young Adult Participatory Action Research (PAR)

Active involvement of young adult research staff with serious mental health conditions (SMHC) in all phases of research and evaluation efforts from defining the problem to disseminating results.
PAR Levels of Involvement

Level 4
*Youth Led*

Level 3
*Youth Partnered*

Level 2
*Youth Involved*

Level 1
*Youth Informed*
The College Study

The Academic Experiences and Perspectives of Young Adult College Students with Mental Health Conditions

- Secondary Analysis of Data from the “National Survey of College Students With Mental Illnesses” - survey by Mark Salzer, PhD
  - Created the research questions
  - Analyzed data using SPSS Statistical software
  - Interpreted Findings
  - Developed publications
PAR at the RTC: Trial and Error

Breaking New Ground (Yrs 1-3)
- 5 Per-diem YA positions
- Generalized job description
- Separate YA meetings
- Supervisor = main support
- Only Internal Youth Voice

Steering towards Success (Yrs 3-now)
- 7 PAR staff on career trajectories
- Strengths based job descriptions
- Culture Shift
- Career Coach
- National Youth Voice
Youth Advisory Board

- 100% Young Adult Led
- Value of National voice
- Diversity in perspective
- Ongoing training & Support

“Being a part of the YAB, I could see my comments put to good use. My thoughts and opinions felt important and I was treated with respect.” – Rick
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 citizens.
Systems Change

Why change the mental health system?

- To change the way services are delivered the target audience!
- Need to accommodate for changes in Times, cultures/generations, technology, educational and work market, developments in research

How is Systems Change achieved for young adults?

- From the ground up - 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
The Power of Youth Voice in Systems Change

An Example in the Massachusetts’ Department of Mental Health Transition Age Youth (TAY) Initiative (since 2001)

The Youth Development Committee (YDC)
- Established in 2002
- Infuses Youth Voice in TAY Programming in DMH and is considered key to the initiative
- Peer-Led, monthly meeting

Statewide Young Adult Council
- Young Adult Peer-Led, monthly meeting
- Reviews services and young adult activities 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

- Payment for work conducted = ideal whenever possible
- Sends a message of appreciation for time and expertise
- Helps time commitment stick
- Allows for ongoing learning opportunities
- Shift in organizational power
- Creates a career ladder vs. stagnant positions
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.” - YA
Considerations for Volunteer Work

• Clarify role and levels of input
• Put strategies in place to ensure transition and continuity of work
• Should feel as if they can leave at any time
• Re-assess position quarterly or bi-annually
• Provide other incentives (resume building, trainings, referrals, travel stipends, meals)
Roles for YA Input/Involvement

• **Advisor**
  • Programs or initiatives are already developed, seek general feedback from young adult

• **Consultant**
  • Youth are helping to create programs, but less of a direct role than co-leadership

• **Co-Leader**
  • Youth are helping to create programs/initiatives from the beginning stages in a more direct role, have decision-making power

• **YA-Led**
  • Youth are primary leaders in project, adults help facilitate YA goals
2. Preparing Your Team/Young Adults

• Ensure clarity across the organization on roles & responsibilities of young adult positions

• Establish levels of mental health disclosure required for being employed in YA positions

• Brainstorm barriers to employment (i.e. methods of communication, travel)

• Train staff on effectively working with & engaging YA
Preparing Young Adults

- Collaborative development of roles/expectations
- Thorough and comprehensive **ONGOING** training
- Ongoing supervision & mentoring
- Support professional development
- Little things may not seem important to a “seasoned professional,” but can make all the difference to a young adult
Tokenism

• Having YA just to say you have YA input
• Having one YA give feedback everything YA-related
  • One young person doesn't represent the voices of all young people
• Assuming involvement is genuine without getting feedback from YA

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.”
Genuine Engagement

- YA input 80% of the time (vs 20% of the time)
- Put the time and resources
- Share concrete changes made based on YA feedback
- Offer written recognition/authorship (papers, art work, curriculum, etc.)
- Ask for continuous to improve young adult engagement
- Get uncomfortable! Shift of Power = change

“People who seek youth input need resources to be creative, flexible and accommodating enough to capture the voices of those who aren’t being heard.”
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..

• Get Creative!
• Utilize existing resources (e.g. ADA, AskJan.org)
• Work together (employer and young adult)
• Quarterly review of request/flexibility
Considerations for Support

- Individualize, individualize, individualize!
- Short term pain for long term gain
- Formal vs. informal process
- Consider coaching & supervision
4. Employer Challenges

- **Commitment from Human Resources**
  - Find a champion
  - Stress value of lived experience as a unique “qualification”

- **Org Commitment from top down**
  - Fear of “minimizing rigor”
  - Use examples to highlight value of YA voice

- **Genuine Recruitment/Engagement**
  - Get advice from YA’s!
  - Creative advertising vs. traditional job posting
  - Enlist Local partners (DMH/GIFT)/colleges/Clubhouses
Thank You!

Want More Information?

Amanda Costa: amanda.costa@umassmed.edu
Tania Duperoy: tania.duperoy@umassmed.edu

Transitions RTC Website: www.umassmed.edu/transitionsRTC
Live Q&A
References


