As you enter the room, please take two post it’s and write down some of your thoughts on the following questions:

1. What are the **benefits** of having young adults involved in research/service design/their own treatment planning?

2. What are the **challenges** of having young adults involved in research/service design/their own treatment planning?
Nothing About Us Without Us: Growing Meaningful Youth Involvement in Your Organization

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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

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## Workshop Overview

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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
PART 2: OVERVIEW OF MEANINGFUL YOUTH INVOLVEMENT
The Four Mechanisms of Youth Voice

1. Treatment planning/decision making
2. Peer Worker Roles
3. Participatory Research & Evaluation
4. Systems & Service Change
Fostering Youth Voice in Treatment Planning/decision making

- 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

Young adults are more engaged and committed to services & supports that they have an active voice in \(^1,^2\)
Team Approaches

Achieve My Plan

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

http://www.pathwaysrtc.pdx.edu/pdf/Webinar_AMP.pdf
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
Fostering Youth Voice Through Participatory Research & Evaluation
Definition of Participatory Action Research (PAR)

• A collaborative approach to research that equally involves all partners in the research process and recognizes the unique strengths that each brings\(^5\).

• PAR begins with a research topic that’s important to the community with the aim of combining knowledge and action for social change.

• Strong PAR history in Adult Mental Health World.
Supporting Young Adult 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
The Young Adult 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
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
# Successes & Benefits

## Research Team

- More authentic/rich interviews
- Engaging young adult research participants
- Stronger connection to media/technology
- Strengthened relationship with local MH community

## PAR Staff

- PAR staff transitioning into professional roles
- Strength based work environment
- Increased self-efficacy & self-advocacy skills
- Strengthened youth voice
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. 

Source: http://www.ccitoolsforfeds.org/systems_change.asp
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 Involvement

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

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

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

Delegation
Real responsibility for undertaking particular tasks of the organization

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

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

- 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

DMH Statewide Youth Advisory Council
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 across the organization 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 feedback 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.”
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
Considerations for Support

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

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Employer Action</th>
<th>YA Action</th>
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<tr>
<td>Mismatch of cultures</td>
<td>Think outside the box; embrace differences as strengths</td>
<td>Showcase strengths; let your voice be heard</td>
</tr>
<tr>
<td>Lack of professional skills</td>
<td>Mentor; give constructive feedback; seek guidance</td>
<td>Seek out supports; take initiative</td>
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Discussion Time!

Take a few minutes to develop a concrete goal to improve YA involvement in your work:

1. How will you build on the benefits of YA involvement described this morning?
2. How will you overcome the challenges of YA involvement we addressed today?
Thank You!

Want More Information?

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References


