WELCOME!

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 <u>benefits</u> of having young adults involved in research/service design/their own treatment planning?

2. What are the <u>challenges</u> of having young adults involved in research/service design/their own treatment planning?

2016 Recovery Workforce Summit
Presented by PRA & PRF, in partnership with MassPRA

The State of Recovery in the World of Psychiatric Rehabilitation:
Our Collective Vision Put into Action

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

Psychiatric Rehabilitation Association

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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

Workshop Overview

Part 1	Overview/Introductions
Part 2	Overview of meaningful youth involvement • Treatment planning/Decision Making • Peer Worker Roles • Participatory Research/Evaluation • Systems & Service Change
Part 3	Effective Approaches for Engaging Young Adults
Part 4	Wrap-Up Discussion

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

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 <u>active voice</u> in [1, 2]

Team Approaches

Achieve My Plan [3]

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

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**

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 [6]

- 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[7].
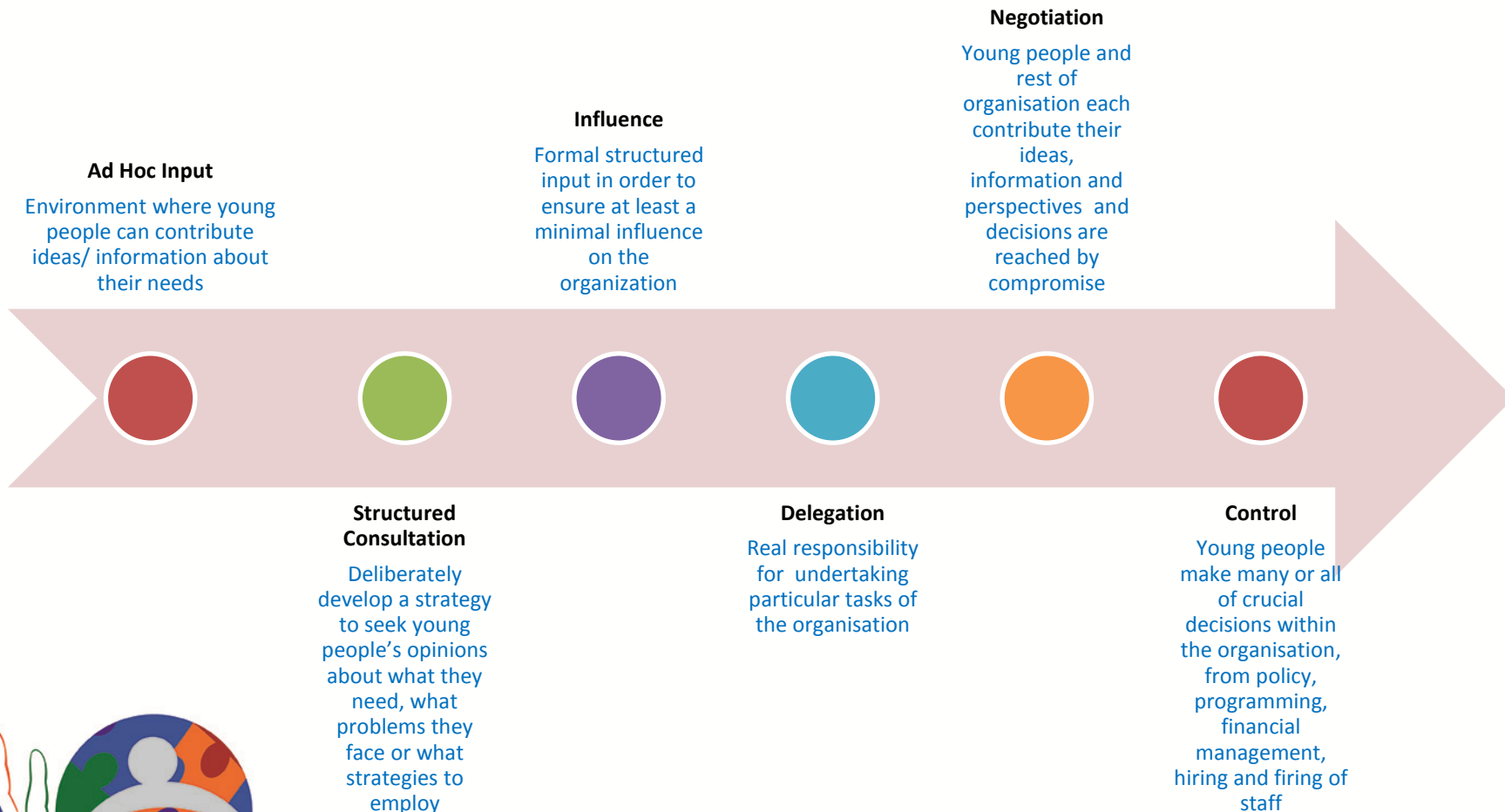
Systems change

- 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[8]

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

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

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

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 problematic/ overall issues you may be having in the workplace (DUE TO YOUR MENTAL HEALTH CONDITION/DISABILITY)?:
   _____
   _____

5. How are the Job tasks mentioned in #4 affected BY your mental health condition/disability?:
   _____
   _____
   _____
   _____

6. Ideas for accommodations to address problems mentioned in #4:
   _____
   _____
   _____

7. If you cannot think come up with accommodations to help address your difficulties, please list what resources you've used during your search so your supervisor doesn't use them when doing their own search (e.g. websites/people/products/etc.):
   _____
   _____

8. Supervisor/Manager Comments:
   _____
   _____

Signatures:

_____   _____
Signature of Employee   Date   Signature of Employee   Date

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

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

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*.