

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

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>

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Webinar Overview

Part 1 Overview/Introductions

Part 2 Overview of Meaningful Youth Involvement

Part 3 Effective Approaches for Engaging Young Adults

Part 4 Interactive Live Q&A

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



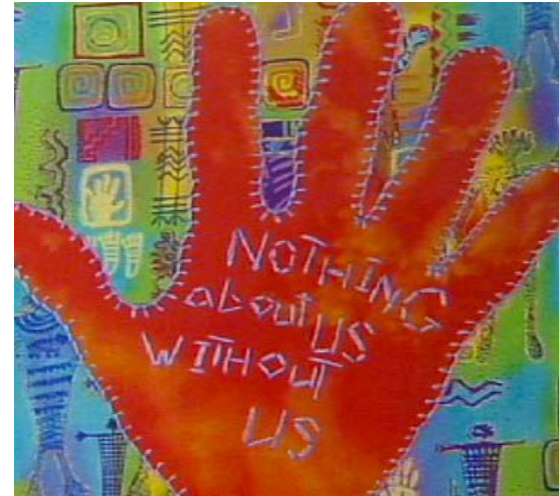
4. Systems & Service Change



Fostering Youth Voice in Treatment Planning and Decision-making

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 the 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>

Open Dialogue

https://www.power2u.org/downloads/becomingdialogic_ANZJFT11.pdf

Transition to Independence (TIP) <http://www.tipstars.org/>

Project RENEW http://www.iod.unh.edu/Projects/renew/renew_main.aspx

1-on-1 Models

Motivational Interviewing <http://www.motivationalinterviewing.org/>

Shared Decision-Making

- <https://store.samhsa.gov/shin/content/SMA09-4371/SMA09-4371.pdf>
- <https://www.patdeegan.com/commonground>

Person-Centered Planning <http://www.personcenteredplanning.org/>



Fostering Youth Voice Through Peer Worker Roles



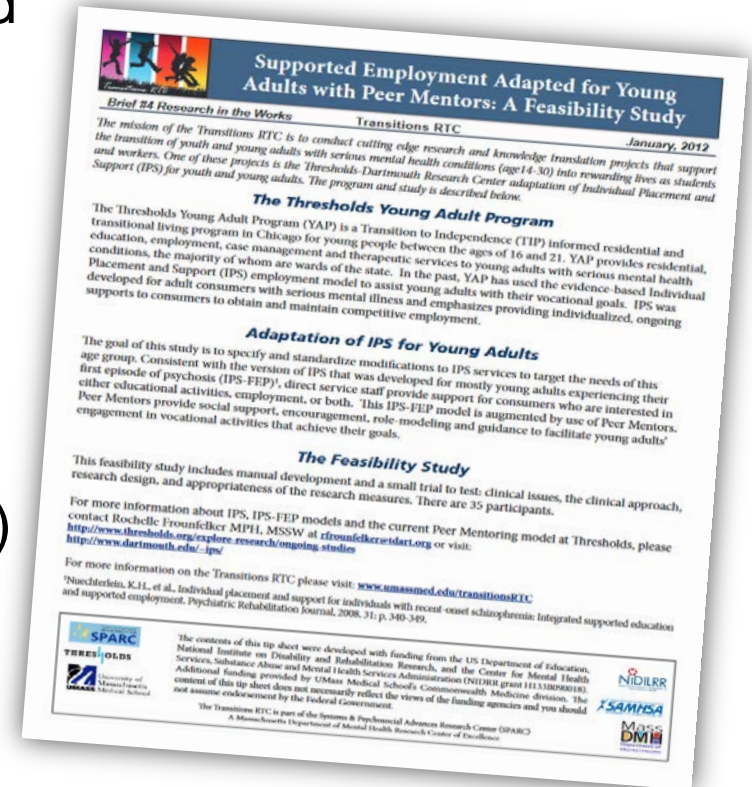
Peer Support Workers

- 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



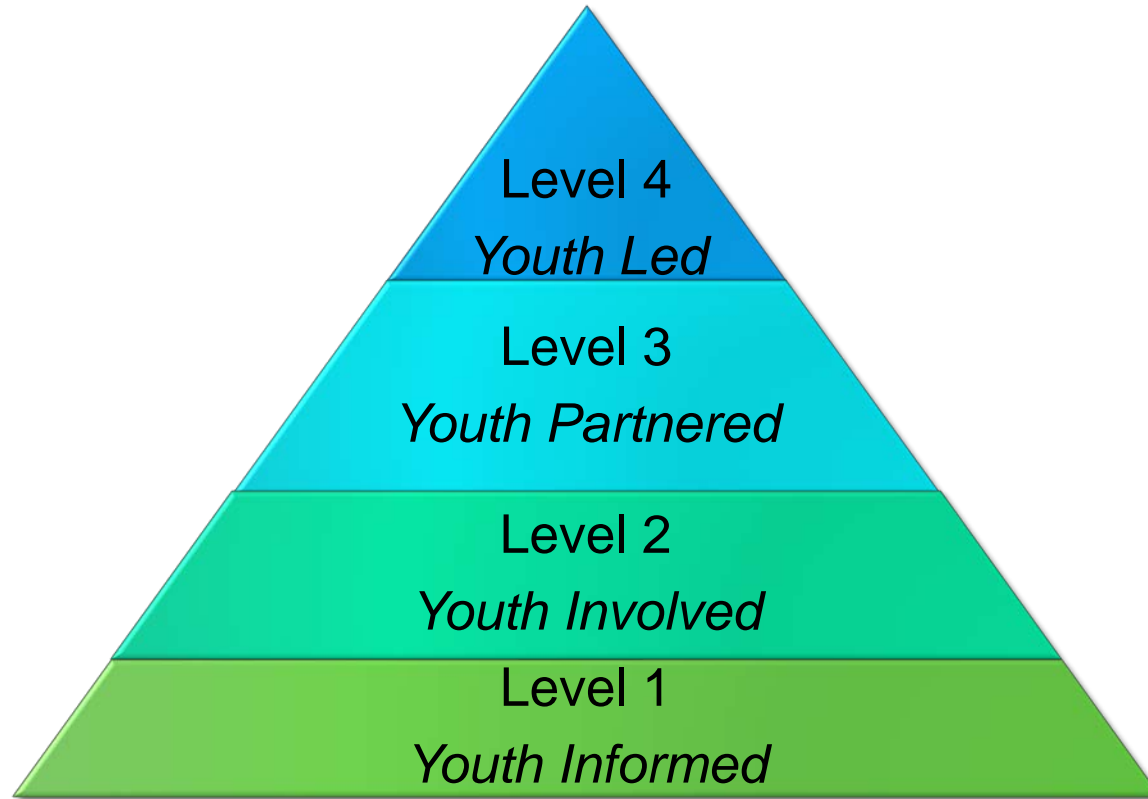
Young Adult Participatory Action Research (PAR)

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



**YOUTH
DECIDE**

PAR Levels of Involvement



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 ⁶



- 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 citizens⁷.



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.**”





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..

- Get Creative!
- Utilize existing resources (e.g. ADA, AskJan.org)
- 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

- **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?

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Live Q&A



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