

EMBRACING YOUNG ADULT VOICE: STRATEGIES, TOOLS & RESOURCES TO ENHANCE PARTICIPATION IN MENTAL HEALTH RESEARCH

Amanda Costa

UMass Medical School, Worcester MA, USA

- Transitions to Adulthood Center for Research (ACR)
- Systems and Psychosocial Advances Research Center



The Transitions to Adulthood Center for Research

Acknowledgements

Our mission is to promote the full participation in socially valued roles of transition-age youth and young adults (ages 14-30) with serious mental health conditions. We use the tools of research and knowledge translation in partnership with this at risk population to achieve this mission. Visit us at:

<http://www.umassmed.edu/TransitionsRTC>

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Transitions to Adulthood Center for Research

- One of two federally-funded Research and Training Centers in the US focused on Young Adults with lived experience— focus on areas of school and work
- 3 distinct arms:
 - Research
 - Knowledge Translation & Dissemination
 - Technical Assistance



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Participatory Action Research (PAR)

- Conducting research in partnership with people/the community and not "about" or "for" them.
- Collaboration throughout research process:
 - ✓ Developing research questions
 - ✓ Writing grant proposals
 - ✓ Recruitment
 - ✓ Collecting and analyzing data
 - ✓ Writing up & disseminating findings



Why We Believe in Young Adult PAR?

- **Recognizing Unique:** needs, goals, values
- **Enhanced Young Adult focus:** Ensures services are YA friendly and culturally appropriate.
- **Increased engagement:** YA are more engaged (higher retention) and committed (lower premature dropout) to services they have an active voice in.
- **Pathway to:**
 - ✓ Better quality of care
 - ✓ Greater cost efficiency
 - ✓ Improved population health



PAR: MAKING IT WORK ON THE GROUND



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Our 3 Ps of Participatory Action Research with Young Adults



Prioritize



Plan



be Purposeful





Prioritize

PAR and Young Adult Culture



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SPARC PAR Initiative

- **Vision** - To lead the mental health research community to work in partnership with young adults with lived mental health experience
- **Buy-in** – Supported by Center leaders, vetted with our research Centers
- **Leadership** - Faculty/young adult co-leadership
- **Financial resource allocation** – i.e. youth advisory boards
- **Tasks** - Develop & deliver tools, resources, and technical assistance to support researchers to do YA PAR





Employ YA as Researchers

- **Hired & Trained 8** Young Adults with lived mental health experience
- **Leadership & Growth Opportunities**
 - Leading research studies
 - Leading Center-wide initiatives (e.g., PAR Initiative, social media efforts)
 - Lead Center-wide trainings (e.g., interviewer training)





Leading Advisory Councils

As **leaders** and **members** of local and national Young Adult Advisory Councils, we advise policy makers, service providers and family members on making mental health services and supports youth friendly, and foster hope in recovery.

- 100% Young Adult Led
- Safe space to build leadership skills
- Structured web based trainings
- Individualized support





Find the Right “Fit”

Young Adults want to be matched them with jobs that fit with their skill sets and disposition.⁵

- Design strengths based roles and tailor workload to individual preferences/needs
- Honest conversations occur when mismatches happen.
- Roles delineate between skills needed upon arrival vs. skills developed during employment





Encourage social wellness

Ongoing opportunities for socialization and orientation to a job are important for a smooth emotional transition for young adults.⁶

- Personalizing the onboarding process
- Encourage daily social activities (i.e. group lunch, team walks, utilizing “Chillax” space)
- Provide “lunch and learn” series to socialize and familiarize with history of the Transitions RTC/SPARC



YA need soft skills training on: assimilating to work culture, working with others setting long term career goals, etc.⁷



What Can We Do?

- ❑ Give it TIME!
- ❑ Prioritize professional development
- ❑ Weekly supervision, bi-annual goal review
- ❑ Identify free courses on time management, working with others, communicating effectively, etc.





Consider non-traditional supervision structures

Supervisors need to embrace flexibility and integrate modern approaches in their supervision styles⁸

- Encourage flexible schedules
- Ongoing discussion about informal accommodations
- Disclosure is an ongoing topic
- Matching supervisor/mentee personalities
- Job Coach supplements to Supervisor role





Plan



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Making the TIME

- PAR does not happen overnight
 - Advisory councils- staff for administration/oversight
- Adding “buffer” time for tasks
 - Reviewing paper drafts
 - Developing PAR Lead Projects
- Prioritize staff efforts for support
 - PAR Champion
 - People with lived experience on project





Plan to do PAR

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Participatory Action Research Planning Tool

Instructions: This tool is intended to support your team to implement Participatory Action Research (PAR) methods and principles into your research and dissemination activities. This tool is most successful when it is completed collaboratively with input from all members of the team.

Overview of /Baseline Snapshot of Research Study

Step 1: Title of Research Project: _____

Step 2: Identify Project Team Members: _____

Step 3: Have you purposefully included a young adult(s) on your team that has lived mental health expertise who has agreed to explicitly share their lived experience as part of their work?

- 🍏 Yes, we have a team member who will disclose outwardly (i.e., both in their research work and in the community through presentations and publications)
- 🍏 Yes, we have a team member who will disclose behind the scenes (i.e., utilize lived experience in their research activities but NOT out to the community)
- 🍏 NO
- 🍏 Other: _____

Step 4: Required Resources- What support do you need to successfully partner with young adults with lived experience in this study:

- 🍏 Ongoing consultation from PAR Experts
- 🍏 Access to an existing advisory council
- 🍏 Written training tools/resources to help keep on top of PAR efforts throughout the project
- 🍏 Funding to support staff with lived mental health experience
- Quarterly check-ins with PAR Experts



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Recognize PAR may look different at different points in time

Research – Levels of YA Involvement

DRAFT – Biebel & Costa, UMMS, 9.19.17

| | 1. No YA | 2. YA Informed | 3. YA Involvement | 4. YA Partnership | 5. YA Ownership |
|----------------------------------------------------------------------------|--------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------|
| | YA not asked for their voice; no perceived value to YA voice | Sporadic YA voice; often one off consultation; feedback may be very targeted | Non-YA directed; consistent engagement of YA; YA voice not given equal weight | YA or non-YA initiated; YA participate in all important activities in significant ways; both voices may not have equal weight | YA initiated; YA voice valued and highlighted |
| Power/Decision Making | Never | Never | Sometimes | Very Often/Always | Always |
| YA/Non-YA Power | 0/100 | 0/100 | 30/70 | 50/50 | 70/30 |
| Dose of Involvement | Never | Rarely/sometimes | Sometimes/Very Often | Very Often/Always | Always |
| Stages of Research | | | | | |
| <i>(a) Defining the problem</i> | No YA involvement | Minimally Active <i>may be asked to suggest topics via advisory board or one time consultation</i> | Somewhat Active <i>May have more regular involvement, to develop and refine topics, but not necessarily YA led</i> | Active <i>YA leading/co-leading topic creation, voice of YA and non-YA are both valued</i> | Very Active <i>YA owning and leading developing topics with consultation from non-YA advisors/partners</i> |
| <i>(b) Designing methodologies and data collection measures/strategies</i> | No YA involvement | Inconsistent <i>may provide targeted edits on recruitment methods or collection instruments (i.e. surveys)</i> | Consistent YA voice <i>Will review ongoing drafts of methods and consult on data collection measures, not given ultimate</i> | Consistent YA partnership and voice <i>Will partner with researcher to determine ultimate methodologies and co-</i> | YA Lead <i>Leading identification of audience and key messaging</i> |





be Purposeful



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Be purposeful in your PAR

- Conducting systematic review of how PAR methods are described in the literature
- Drafted PAR assessment implementation tool
- Testing with current research teams within SPARC

PAR-PAT SECTION 2: Measuring Levels of COF Involvement

Section 2 Instructions: Using the scale provided below, indicate to what level the COF will be involved in each of the activities within all phases (1-8) of the research project.

- ❖ **None:** The COF is not involved in this activity.
- ❖ **A Little:** The COF may occasionally be involved in this activity, but not on a regular basis.
- ❖ **A lot:** The COF is consistently involved in this activity, and may have leadership or co-leadership responsibilities.

| PHASE I: Identifying the Research Question(s) | Level of COF Involvement | | |
|------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| | None | A Little | A Lot |
| Define the problem/ Identifying the Research Questions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Work on proposal development | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Develop budget | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Engage community stakeholders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Get COF input/feedback on research questions/project goals | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Modify proposal based on feedback from COF | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Proposal writing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| PHASE II: Project Start Up | Level of COF Involvement | | |
| | None | A Little | A Lot |
| Develop IRB application | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Develop recruitment procedures | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Identify community | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Develop Project Schedule | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Finalize Research team/staffing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |





Documenting Methods

Implementing a “PAR” to-do list

Standing “PAR activities” agenda item for team meetings

All publications describe par methodology

Quarterly team review of PAR
Implementation toolkit



3 Key Takeaways

PAR is successful when:

1. It's **p**rioritized, **p**lanned and **p**urposeful
2. You plan the *right* PAR for the *right* project
3. Both Young Adults and other researchers
 - Recognize and prioritize PAR
 - Value open communication about what is/isn't working
 - Have the **skills** and **tools** they need to do PAR authentically



Thank You!

Contact me at: Amanda.Costa@Umassmed.edu

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