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

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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





Participatory Action Research (PAR)

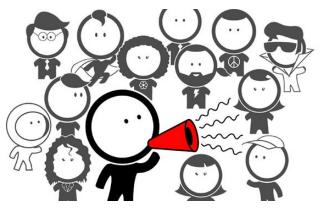
- Conducting research in partnership <u>with</u> people/the community and not "about" or "for" them.
- Collaboration throughout research process:
 - Developing research questions
 - Writing grant proposals
 - Recruitment
 - Collecting and analyzing data
 - Writing up & disseminating findings





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







PAR and Young Adult Culture



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- 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



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- 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









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 <u>upon</u> arrival vs. skills developed <u>during</u> employment







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.



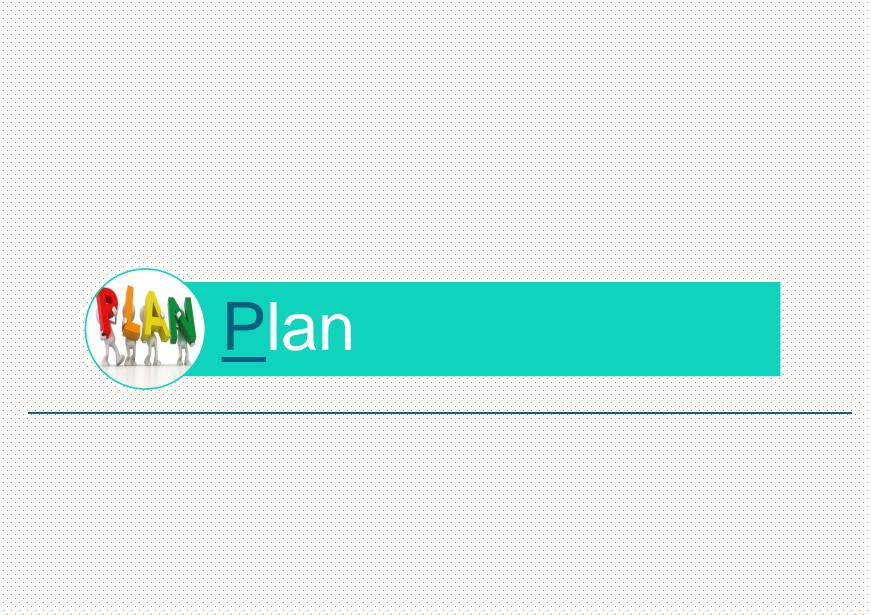


Supervisors need to embrace flexibility and integrate modern approaches in their supervision styles⁸

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









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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





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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:

- Congoing 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					
(a) Defining the problem	No YA involvement	Minimally Active	Somewhat Active	Active	Very Active
		may be asked to suggest topics via advisory board or one time consultation	May have more regular involvement, to develop and refine topics, but not necessarily YA led	YA leading/co-leading topic creation, voice of YA and non-YA are both valued	YA owning and leading developing topics with consultation from non- YA advisors/partners
(b) Designing methodologies and data collection measures/strategies	No YA involvement	Inconsistent may provide targeted edits on recruitment methods or collection instruments (i.e. surveys)	Consistent YA voice Will review ongoing drafts of methods and consult on data collection measures, not given ultimate	Consistent YA partnership and voice Will partner with researcher to determine ultimate methodologies and co-	YA Lead Leading identification of audience and key messaging



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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 coleadership responsibilities.

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





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



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3 Key Takeaways PAR is successful when:

- 1. It's prioritized, planned and purposeful
- 2. You plan the *right* PAR for the *right* project
- 3. <u>Both</u> 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: <u>Amanda.Costa@Umassmed.edu</u>

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