Participatory Action Research with Young Adults: Experiences and Lessons Learned

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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, Dept of Psychiatry, Center for Mental Health Services Research. Visit us at:

http://labs.umassmed.edu/TransitionsRTC

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Benefits of Active Participation in Research

- Relevance of topic
- Quality of Research (Viswanathan et al, 2004)
- Dissemination and diffusion
- Researcher Education
- Young Adult Consumer
- Community capacity to partner in research
Challenges to active participation in research

• Achieving sufficient level of trust
• Challenges researcher education and experience
• Lack of infrastructure and/or funding for bridging the gap
• Unrealistic consumer expectations
Unique to Youth/Young Adults

- Developmental Turbulence
- Lack of awareness of the concepts of empowerment and recovery
- Adults and the generation(s) gap(s)
- Lack of experience
Our Experience at the RTC
Obstacles

• Lack of professional experience
  – Professional interactions
  – Independence, opportunity to take initiative
  – Dress code

• Psychosocial/developmental turbulence
  – Emotional turbulence
  – Housing
  – Personal relationships
Obstacles

• Young adult’s limited resources
  – Transportation
  – Wardrobe
  – Limited support network

• Medications and treatment side effects
  – ECT and memory loss
  – Medication transitions, cognitive function
Obstacles

• Lack of empowerment
  – Result of child mental health system
  – Lack of ownership of their mental health condition and how it might affect their work
Best Practices (Lessons Learned)

• Communication
  – Training
  – Be patient, be concrete
  – Consistent encouragement without being patronizing
  – Feedback: it is about the job, best employee

• Consistency
  – Be firm with schedule
  – Regular group meetings
Best Practices (Lessons Learned)

- **Strengths-based approach**
  - Task matching
  - Voices4Hope example
  - Ongoing conversation
Best Practices (Lessons Learned)

- Supports and reasonable accommodations
  - Physical space
  - Recording meetings, note taking
  - Employment specialists
  - Internal mentoring
  - Support without “mothering”

- Handling times of crisis
  - Hospitalization
  - Emergency contact, know their treatment team
Nadia’s Story

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