Portland, Oregon

Participatory Mental Health Research with Young People: Experiences and Lessons Learned

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Presentation purpose

- To present a conceptual framework for collaborating with young people with mental health needs in interpretive research

- To describe experiences working with young people with mental health needs in research

- To describe co-researchers' roles and activities, and

- To examine challenges and effective strategies for collaborative research with young people.

Rationale for youth participation in research

Youth participation is believed to result in:

- Increased relevance of questions to the needs and concerns of youth and families;
- Improved cultural appropriateness of methods;
- Increased quality of data;
- More accurate interpretations and increased validity of findings;
- Wider dissemination of findings;
- More effective utilization of findings to guide programmatic improvements; and
- Empowerment of participants

(Carey, 2011; Smith, Monaghan, & Broad, 2002; Turnbull, Friesen, & Ramirez, 1998).

Participatory research: Pros and cautions

- Participatory research can claim ethical high ground by putting research participants at the center of study and sharing control over the process (Smith, Monaghan, & Broad, 2002)

- Carey (2010) encourages skepticism regarding service user participation in research and recommends caution about claims of benefits and unrealistic descriptions of emancipatory outcomes .

Ladder of Youth Participation

Degrees of Participation

Youth-initiated, shared decisions with adults

Youth-initiated and directed

Adult-initiated, shared decisions with youth
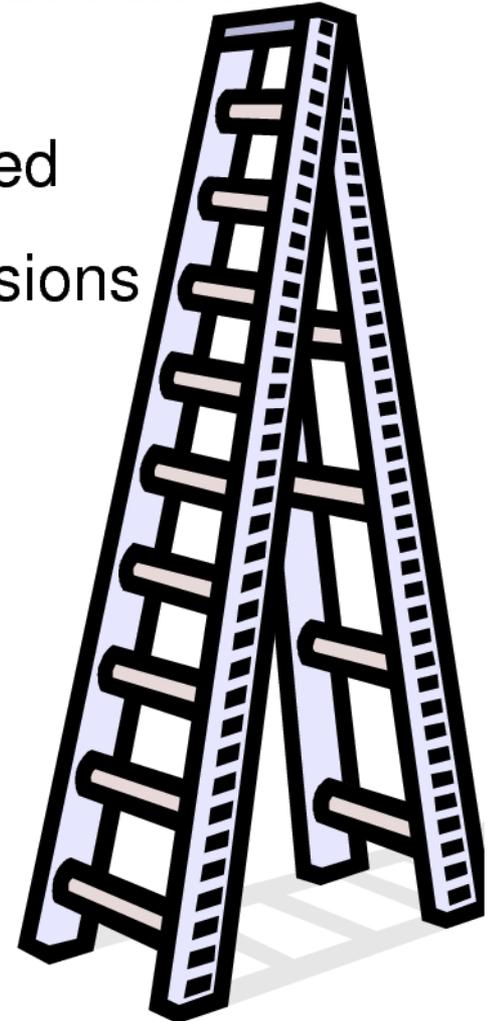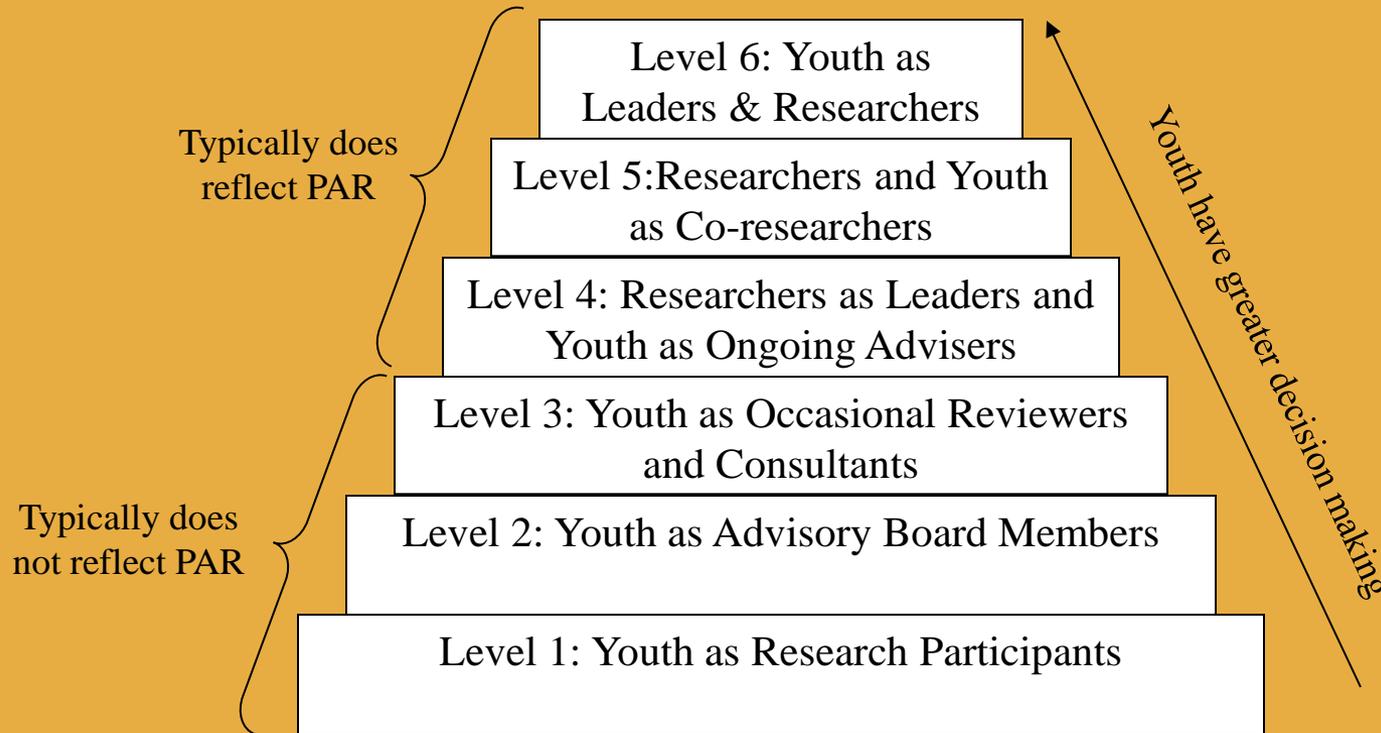
Consulted and informed

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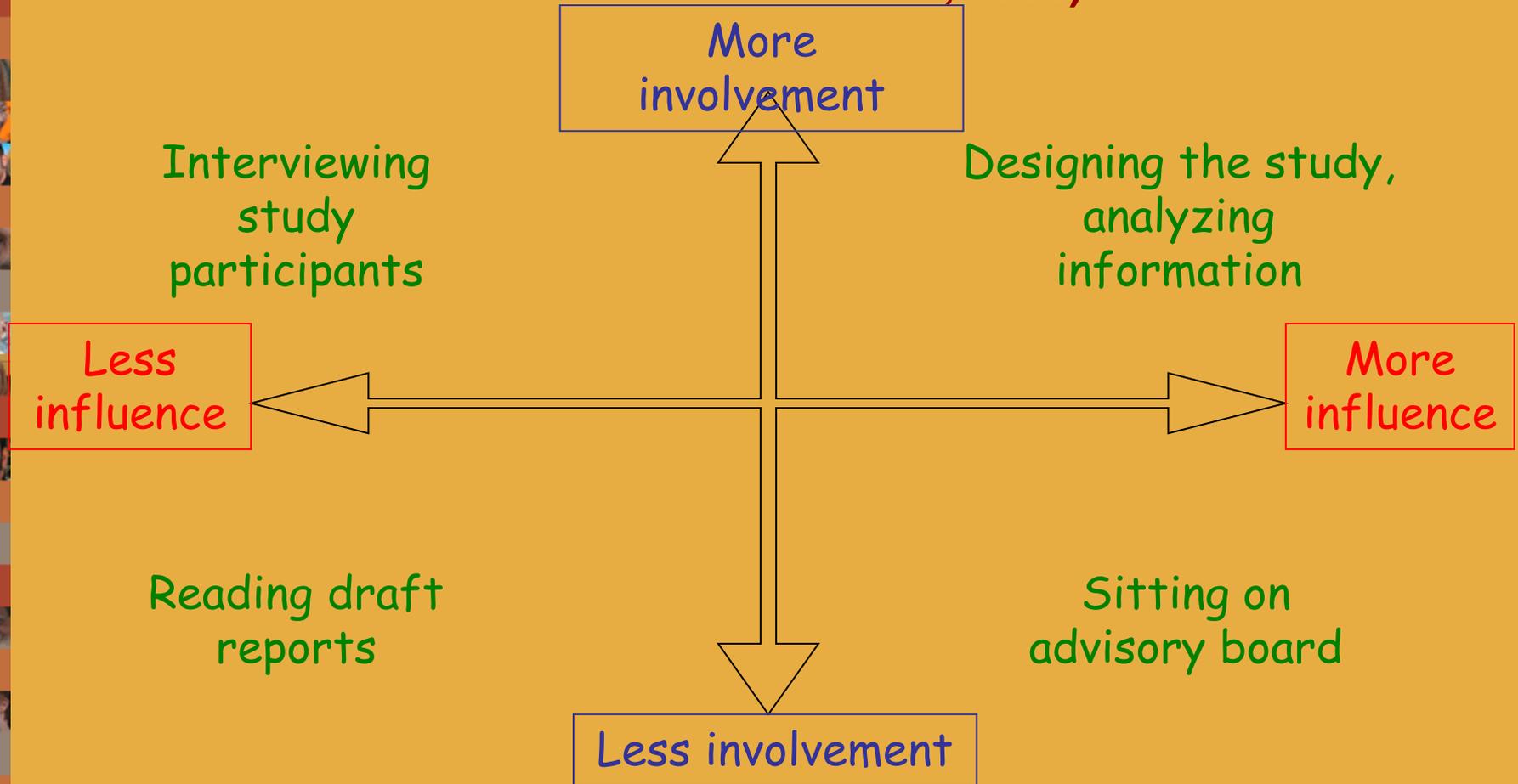
Non-Participation

Tokenism

Decoration

Manipulation

Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*
Florence: UNICEF Innocenti Research Centre.

Adaptation of continuum of involvement
(Turnbull, Friesen, & Ramirez, 1998)

Level 6: Youth as Leaders & Researchers

Level 5:Researchers and Youth as Co-researchers

Level 4: Researchers as Leaders and Youth as Ongoing Advisers

Level 3: Youth as Occasional Reviewers and Consultants

Level 2: Youth as Advisory Board Members

Level 1: Youth as Research Participants

Typically does reflect PAR

Typically does not reflect PAR

Youth have greater decision making

Youth roles and influence in research and evaluations(based on Cousins & Whitmore, 1998)

Research methods

- Formation of Portland and Seattle research teams.

- Recruitment, hiring, and training of three youth (and two family member) research assistants.

- Recruitment of youth and young adults to participate in focus groups through contacts with family support organizations, community-based agencies, colleges, and personal contacts.

Recruitment of youth and family co-researchers

- Prepared job descriptions and recruitment materials
- Criteria: Young person aged 18-24 with history of mental health difficulties or experience of using mental health services and interest in MH research
  - Available for part-time employment
- Recruitment: Advertized in college publications and via web-site
- Hiring: Two female students in early 20s who met these criteria and one "mentee".

Training of youth co-researchers

- Developed a training handbook that included:
  - A copy of the grant proposal that had been funded.
  - Copies of articles and chapters on qualitative research methods, including data collection and analysis
  - Guidelines for ethical practices in research, including confidentiality, informed consent, how to respond if a research participant becomes distressed, etc.
  - A guide to conducting focus groups which had been selected by our advisory groups as the data collection strategy.

Training youth co-researchers

- The project leaders conducted face-to-face training sessions using the handbook as a guide
- Several sessions of role play to practice conducting focus groups
- Discussion of ethical dilemmas in research and how to address them
- Training in the use of data analysis software and basic SPSS training.

Data collection

- Twelve 90-minute focus groups with 59 youth and young adults (14-24) with mental health difficulties with questions focused on community integration.

- Youth and family co-researchers took lead roles in moderating groups, with Co-PIs and project manager assisting as note-takers, equipment monitors, etc.

Data collection & analysis

- Participants also completed a pre-focus group questionnaire and received $30; quantitative data were entered into SPSS for analysis.

- Focus group discussions were audio-taped, transcribed, and entered into qualitative analysis software.

- All team members participated in data analysis.

- After we established acceptable agreement on a portion of the transcripts, transcripts were coded independently by team members to identify common and unique experiences and perspectives of participants.

Roles/activities of youth co-researchers

- Advisory group consulted at the beginning and periodically throughout the project:
  - Gave feedback on methods, questions, analysis, findings, and dissemination strategies
- Youth co-researchers:
  - Assisted in wording questions.
  - Recruited focus group participants.
  - Mailed or e-mailed information about the project and informed consent materials.

Roles/activities of youth co-researchers

- Facilitated focus groups.
- Debriefed with PIs and project manager after focus groups.
- Transcribed some audio-tapes.
- Entered demographic data in SPSS.
- Participated in qualitative data analysis.
- Reviewed written report drafts and gave feedback.
- Co-presented findings at conferences.

Challenges of participatory approach

- Took more time – for training and debriefing
- Needed to take time to examine and resolve ethical dilemmas that came up
- Need for ongoing discussions of bracketing
- Youth co-researchers had other priorities at times
- One youth co-researcher struggled with her role and issues the work brought up for her – eventually quit
- Sometimes youth researchers expressed impatience at the slow pace of research and preparation of reports – wanted to use preliminary findings in advocacy for change
- Continuing concerns: Are we being participatory enough? Might we have stifled ideas, potential criticism?

Benefits of youth participation

- More relevant questions and probes
- Co-researchers created a relaxed, yet curious environment for participants to share experiences and views – we believe that participants were more comfortable and more forthcoming
- Increased participation in study – youth modeled skills for participants by setting focus group ground rules
- Youth co-researchers were quick learners and very computer savvy.

Benefits of youth participation

- In data analysis, co-researchers noticed ideas that Co-PIs would have missed.

- Co-researchers learned new skills: greater comfort with research, developed skills in data collection and analysis, practiced public presentation skills at conferences

- Youth co-researchers continued their education (and one went to graduate school in public administration)

- PIs learned more about youth mental health experience and skills in collaboration

- More culturally grounded findings and overall, a better quality study.

Personal Reflection

- Impressed with the skills of youth co-researchers
- Strived to facilitate an egalitarian team with limited success: how to manage privilege and share power?
- Sometimes I felt impatience at time needed to explain research processes
- Sadness at the departure of a dissatisfied team member: What I could have done differently?
- Regret that we did not have $ or time to involve youth in later dissemination and advocacy
- Overall, more convinced than ever of the importance of participatory research with young people – more recent projects.

Recommendations for participatory studies

- Be clear and transparent about power dynamics in the research team, where the project leaders must:
  - Meet deadlines,
  - Be accountable to the funders,
  - Be responsible for achieving "academic" goals – publication!
- Continually examine and share power – in our study, everyone's ideas were welcomed and taken seriously and most decisions were negotiated.
- Get to know each other as people – we needed more self-disclosure than with other colleagues
- Be patient
- Embrace the roles of teacher and learner throughout all stages – welcome ideas, questions, and challenges.

Revisiting Carey's 2010 cautions

- Recognize limitations in empowerment
- Need to be explicit about action agenda or the lack thereof
- Need caution about clams of benefits of young people's participation
- Need care to avoid "a different – and probably more sophisticated – type of exploitation" (p. 240).

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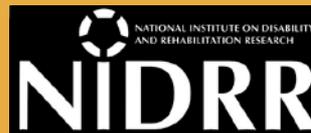
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