

Portland, Oregon

Involving Young People with Mental Health Needs and Parents in Qualitative Research

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Research and Training Center
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Presentation purpose

- To present a conceptual framework for collaborating with young people with mental health needs and parents in qualitative research
- To describe experiences working with young people with mental health needs and parents in qualitative research
- To examine challenges and benefits of collaborative research
- To describe lessons learned and effective strategies for collaboration



The policy context

- Since 1994, SAMHSA's Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families Program has funded systems of care for children's mental health around the U.S.
- Communities required to:
 - **involve families as partners in the development, implementation, and evaluation of systems of care.**
 - **since 2003 describe "how family members and youth will be incorporated in evaluation activities"**



Additional support for family and youth participation in research

- Family involvement in research and evaluations in children's mental health services is also recommended by:
 - The Surgeon General's Report on Mental Health,
 - The National Agenda on Children's Mental Health,
 - The President's New Freedom Commission on Mental Health, and
 - Our funding agency -- NIDRR.



Rationale for youth and family participation in research

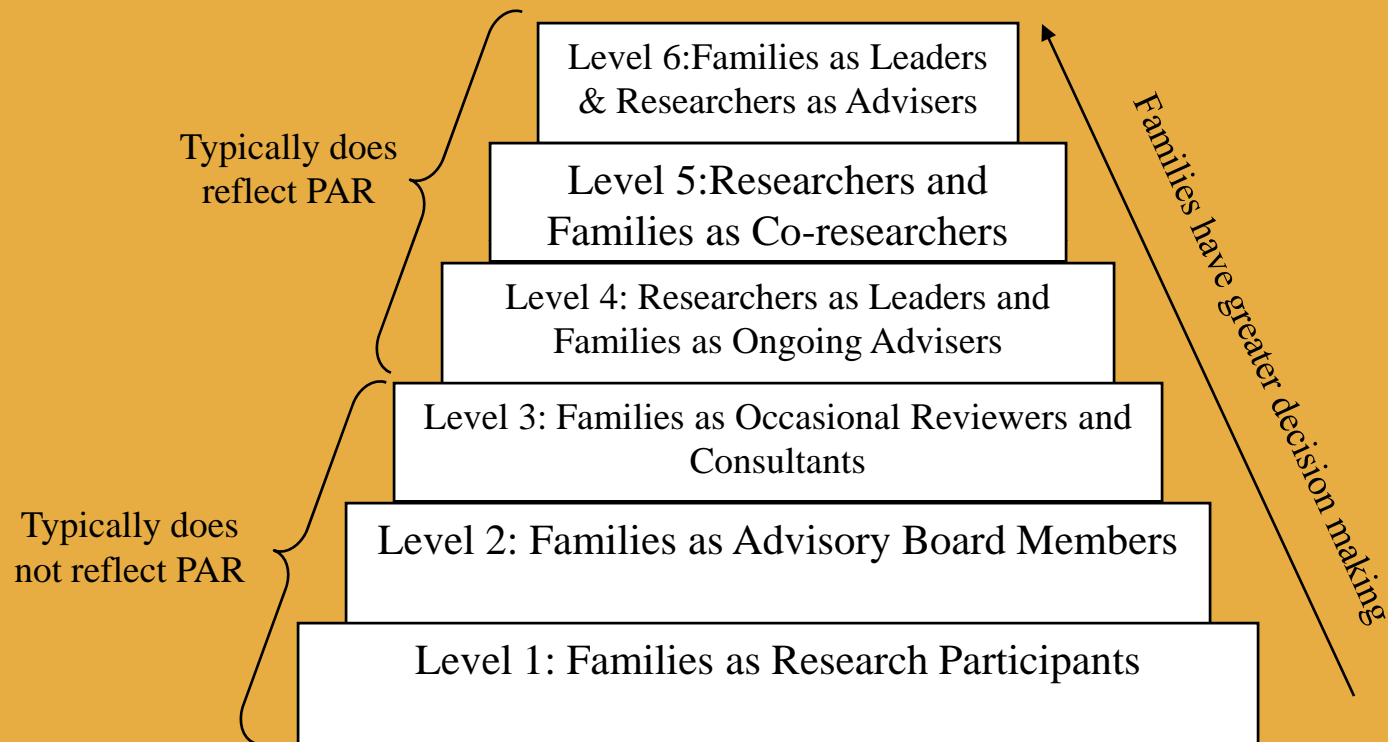
Family and youth participation in research is believed to result in:

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

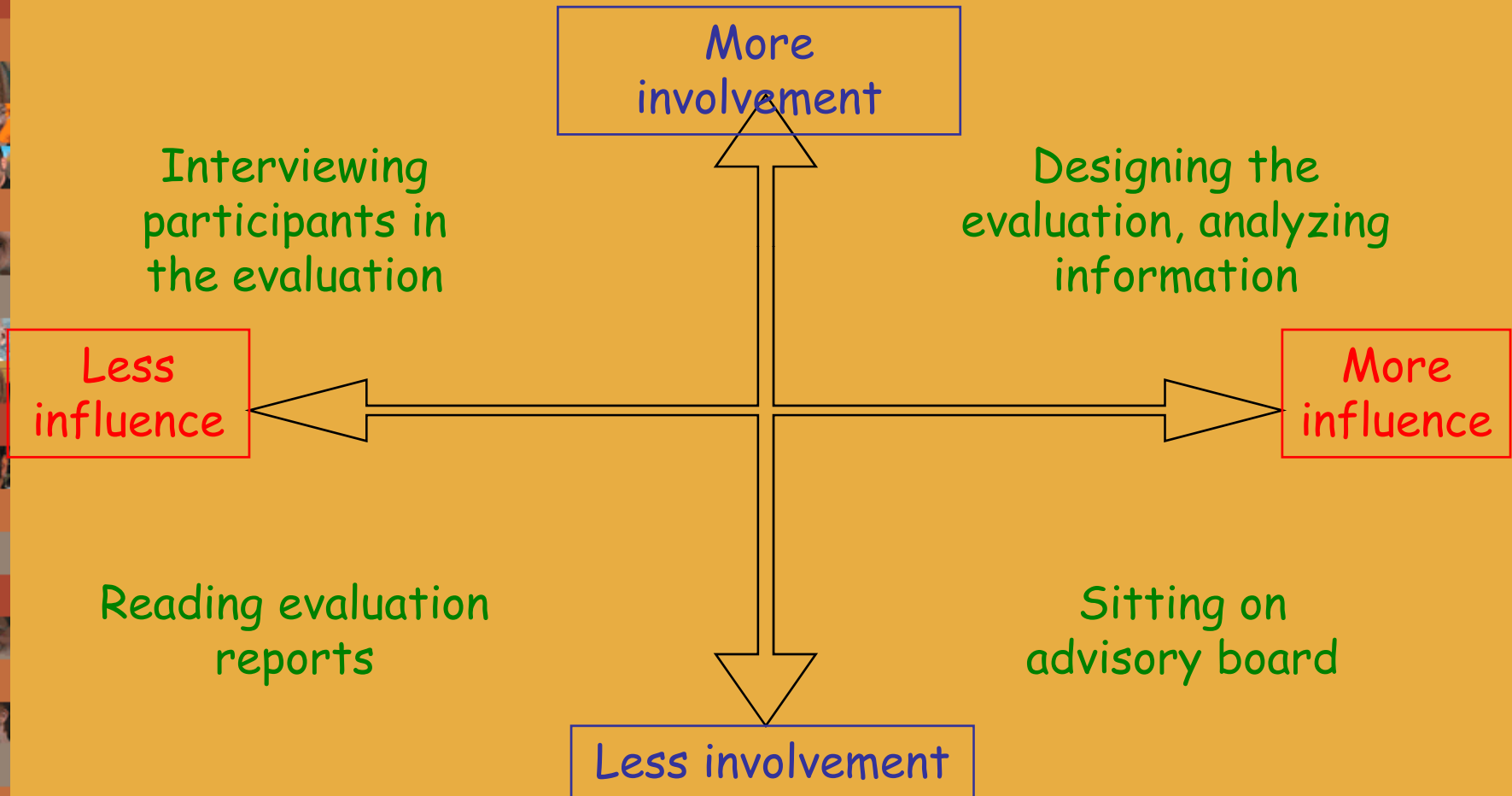
(Fetterman, 1995; Koroloff & Friesen, 1997; Turnbull, Friesen, & Ramirez, 1998; Vander Stoep, Williams, Jones, Green, & Trupin, 1999).

Continuum of family/youth involvement

(Turnbull, Friesen, & Ramirez, 1998)



Family/youth roles and influence in evaluations (based on Cousins & Whitmore, 1998)





Background work

- Earlier participatory evaluation of training for family members to be research partners
- Qualitative study of experiences of evaluators and family members in System of Care evaluations:
 - Identified roles and activities of family members in evaluation studies
 - Described challenges, lessons learned, and strategies for collaborative evaluation
 - Other projects conducted with family and youth advisors and consultants.



Development of the study

- Partnership of three former colleagues with interest in the needs of transition-age youth with mental health conditions (all with previous involvement in mental health services as consumers and/or professionals).
- Response to priorities of National Institute of Disability & Rehabilitation Research.
- Identification of and consultation with youth and family advisory groups to develop focus group questions and plan recruitment.



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 family members 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 for youth and family co-researchers.
- Criteria:
 - Young person aged 18-24 with history of mental health difficulties or experience of using mental health services and interest in MH research
 - Family member of a youth or young adult with history of using mental health services and interest in MH research
 - Available for part-time employment



Recruitment of youth and family co-researchers

- Recruitment:
 - Youth researchers: Advertized in college publications and via web-site
 - Family members: Recruited via local family advocacy organizations
- Hiring:
 - Two female students in early 20s who met these criteria and one “mentee”; group included ethnic diversity
 - Two mothers of young people with long histories of mental health challenges

Training of youth and family co-researchers

- Developed a 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 of youth and family co-researchers

- The project PIs and project manager conducted training several face-to-face training sessions using this handbook as a guide
- Several sessions of role play to practice conducting focus groups
- We also traveled to Seattle so that the entire team could participate together in a training in the use of N6 data analysis software.
- Youth co-researchers also received basic SPSS training.



Research methods & analysis

- Twelve 90-minute focus groups for young adults with mental health difficulties and eight focus groups for family members of youth and young adults (N = 102).
- Youth and family co-researchers took lead roles in moderating groups, with PIs and project manager assisting as note-takers, equipment monitors, etc.



Research methods & 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 *N6* qualitative analysis software.
- All team members participated in data analysis. After establishing acceptable agreement among coders on a portion of the transcripts, all were coded independently by team members to identify common and unique experiences and perspectives.



Focus group questions


We asked youth, young adults, and family members about their views of:

- The meaning of community integration and a successful life in the community for transition-age youth with mental health difficulties.
- Hopes, goals, and dreams for transition-age youth with mental health difficulties.
- Barriers to and supports for community integration.
- Advice to other young adults/family members in similar situations.



Roles/activities of youth and parent co-researchers

- Advisory group members consulted at the beginning and periodically throughout the project:
 - Gave feedback on methods, questions, analysis, findings, and dissemination strategies
- Youth and family 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 and parent 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 – she eventually quit
- Family members were interested in the job because of their work as advocates – they experienced tension between their roles as advocates and researchers



Benefits of youth and family participation

- More relevant questions and probes
- Increased participation in study – youth modeled skills for participants by setting focus group ground rules
- More easily engaged with focus group participants, esp. youth participants – we believe that participants were more comfortable and more forthcoming
- Youth co-researchers were quick learners and very computer savvy.



Benefits of youth and family participation

- Co-researchers were very helpful in qualitative analysis – noticed ideas that PIs might have passed over
- 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.



Recommendations for participatory studies

- Be clear and transparent about power dynamics in the research team – where the PIs must meet deadlines, are accountable to the funders
- Share power to the extent possible – in our study, everyone's ideas were welcomed and taken seriously and most decisions were negotiated
- Get to know each other as people – 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



Acknowledgements

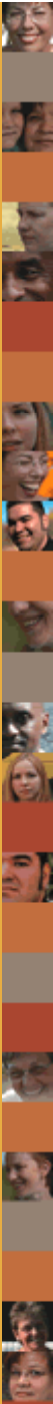
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