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Hearing a Voice: Results of a Participatory Action Research Study

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Abstract Interest in participatory action research (PAR) is rising among academics, researchers, families, and youth themselves who are involved in the system of care. PAR combines systematic research and professional guidance with the development of a practical intervention tailored to the user population in collaboration with the user population. We designed our research to sample and assess the level of interest in PAR for adolescents, gathering qualitative data about the level of understanding of, and expectations for, youth participatory action research. We present the results of a pilot study and then a survey, administered to two different conference populations during 2008. Our data offers insight into the world of service providers, beneficiaries, and advocates for children with mental health disorders. Based on the responses to our questionnaire, we identify four major themes and their underlying issues concerning the benefits and drawbacks of PAR for a young population. We also examine the concerns of each of the self-identified group to determine whether there were dominant characteristics for each group. We conclude that stakeholders do have reasonable expectations of participatory action research as a process and of the youth who could be empowered to bring about change in their system of care. Finally, we make recommendations for future research.

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Introduction

Participatory action research (PAR) combines systematic research with the development of a practical intervention. Working under professional guidance and project oversight personnel, PAR methodology draws on the knowledge of the user population to identify problems, to tailor treatments, and to disseminate the results. Full participation is achieved when the subject population also evaluates the data and understands the strengths and limitations of the project (Chen et al. 2007). While the traditional research study is "outside directed" by the scientist who tests an hypothesis on a given population, the ideal PAR study seeks to engage the subject population of the research so that the voice of the subject population is heard and respected. For marginalized populations, this type of collaboration is a powerful tool in effecting treatment outcomes. Another hallmark of PAR is empowerment of the subject participants and their active participation in treatment and rehabilitation choices as a result of the research.

PAR methodology has been applied in a broad array of fields with successful results. One PAR study examined ethnic and intergroup conflict among adolescents to encourage participants' openness to diversity, tolerance of differences, and the acquisition of conflict management skills (Garvin and Bargal 2008). Other PAR studies determined what and how youth support services should be developed (Bostock and Freeman 2003), to promote school-based mental health counseling services (Lind 2007), and to design electronic formats to engage youth in health promotion (Flicker et al. 2008).

PAR has been applied specifically in the mental health field and with youth (Matarese et al. 2005). In 2008, researchers addressed how youth integrate into a community as they transition into the adult mental health system, focusing on "stigma, recovery, youth and family participation, and empowerment from the perspectives of youth and families" (Jivanjee and Kruzich 2008, p. 1). Another study sought the expertise of youth in evaluating the effectiveness of transitional services (Powers et al. 2007). PAR has been used to help adolescents with physical or other health impairments identify a personal need, develop a goal, and then design a strategy to meet that goal (Burstein et al. 2005); to improve family-school collaboration when children have special education needs (Ditrano and Silverstein 2006); and to improve teacher responsiveness to students who are either homeless or transient when the students come to the classroom (James 2006). The collaborative methodology was employed successfully nationally and internationally to engage the community in discussions about the transmission and prevention of HIV (Mabala and Allen 2002; Gosin et al. 2003; Maglajlic 2004). In short, PAR has been used at the individual, classroom, school, and community levels to educate teachers and the public, to reduce intolerance and conflict, and to create successful service delivery systems.

PAR in the Context of System of Care

Systems of care look at the entire community of service planning and delivery available to the child and family, and organize community services as appropriate to support the child and family through all stages of need, of personal development, and of treatment with a goal of full participation in every phase of treatment planning (Stroul and Blau 2008; Rivera and Kutash 1994; Stroul and Friedman 1986). In 2003, President Bush's New Freedom Commission specifically mentions a system of care as the preferred vehicle for delivering care and services to children, youth, and families (President's New Freedom Commission on Mental Health 2003). The Substance Abuse and Mental Health Services Administration (SAMHSA), a federal agency, states in its conceptualization of systems of care,

> Families and youth work in partnership with public and private organizations to design mental health services and supports that are effective, that build on the strengths of individuals, and that address each person's cultural and linguistic needs (Substance Abuse and Mental Health Services Administration [SAMSHA] 2007).

The continued emphasis on partnerships between families, youth, and private and public providers moves PAR from a theoretical model to practical application; hence, our question on how PAR is viewed within that community.

Method

We designed this exploratory study to gain an understanding of the expectations of the various stakeholders in the system of care for children with mental health challenges: providers of services, researchers, evaluators, youth who had used services, administrators, policy-makers, family, and advocates. Our underlying question was: Do stakeholders have reasonable expectations of participatory action research as a process and of the youth who could be empowered to bring about change in their own system of care?

Since ethnographic research allows a wide range of data collection methodologies, including interviews and narratives, we chose a grounded theory approach, which is a systematic qualitative research methodology used in the social sciences. Unlike the traditional sciences that choose a theoretical framework, grounded theory is emergent, i.e., as data is collected and compared, questions about the data are formed or reformulated. Most importantly, the use of comparative analysis allows the researcher to look at the data, ascertain patterns, and generalize concepts that can be built into broader theoretical propositions, evaluated, and compared to other groups.

We also chose Baker's membership categorization framework as an additional lens of analysis (Baker 2004). Baker contends that each individual identifies with numerous groups, and that identification can be determined by the way individuals talk about their concerns. In our study, the way people express their concerns is important to understanding what they expect and want from PAR. Respondents self-selected the groups to which they belonged, and they could select more than one group. For example, people self-selected the group, "Family member" [of a young person who has received services], while others self-selected the group, "Advocate." Other respondents identified with both groups by self-selecting for "Family member" + "Advocate." We then analyzed the concerns identified by the self-selected groups. We also examined the combinations of self-selected roles to determine whether there were constellations of concerns identified by these combination groups that were different from the concerns expressed by the individual elements in the group combination. For example, if Group A was concerned about X and Group B was concerned about Y, what was Group AB concerned about? Was it more of X and Y, or was it something different from or in addition to X and Y?

The Survey Instrument

In 2008, a collaboration was initiated at the University of South Florida-Tampa to discuss the system of care in place for youth with mental health challenges. Our research focused on the expectations of the user community concerning the application of PAR methodology to adolescents who are challenged by emotional and behavioral disorders. To assess that interest, we chose two national conferences as sites for our survey: the annual meeting of the Research and Training Center for Children's Mental Health System of Care conference (RTC) held in Tampa, Florida in February 2008, and the annual meeting of the National Federation of Families for Children's Mental Health (NFFCMH) in Atlanta, Georgia in November 2008. Both conferences were chosen due to their national stature and to ensure a diverse sampling population.

Five questions comprise the survey. The survey was intentionally short so it could be filled out immediately and quickly by interested conference attendees during the poster session. The same questionnaire was administered at both venues (See Appendix).

Survey Populations

The attendees at these conferences do not represent a cross-section of society for two reasons. First, by the very nature of the organizations that hold these conferences, the attendees are interested in services to children with mental health challenges. Second, respondents volunteered to participate in our survey. We compiled their responses and identified a number of groups among the attendees, based on their self-identified affiliation and on their responses on the questionnaire.

Procedure

The survey was available to all conference participants who attended the poster session at each of the venues. We chose the poster session since it allowed individuals to self-select for our survey and to engage with researchers in a casual setting. The consent form and the survey were printed side-by-side with researchers' emails clearly visible on the consent form. This layout permitted the respondents to tear off and retain the consent form for possible future contact with us; none did. Of the individuals who attended the poster session at the conferences, 21 persons in Tampa and 62 individuals in Atlanta completed the survey. There is no count available of the number of people who attended the poster sessions and no inferences are drawn.

After each event, the survey response sheets were numbered consecutively so the data could be tracked for research purposes to the venue while ensuring that there would be no audit trail leading back to the respondent. Two ranges of numbers were used: the Tampa responses were numbered starting with 1; the Atlanta responses were numbered starting with 101. In the sections following, for example, the designation (9) refers to Survey Respondent 9, who was in the Tampa group. The responses were transcribed to an Excel spreadsheet and then examined for emerging themes. These themes were coded and tabulated to determine the frequency of the theme and the number of themes that emerged from each of the two sets of data.

Results

Who Attended

Both conferences offer a forum to share findings, suggest solutions, and identify strategies for promoting positive child, family, and community outcomes through implementing effective systems of care. Because participants were allowed to mark more than one response to the demographic data question, the number of self-identified roles for the respondents was greater than the number of respondents.

The responses reveal a different mix of self-identified roles among participants in the two populations. Although the majority of respondents in each venue identified with only one role in the system of care, the remainder of respondents identified with more than one role. The majority of respondents at the Tampa conference were academically-oriented researchers or evaluators; the majority of respondents at the Atlanta conference were more personally-involved advocates or family members of a young person who had received services. These different proportions in the constellation of concerned persons at the two venues inform our range of self-reported user expectations (Table 1).

Table 1 Respondent roles across the two conferences

Role	Tampa #	Atlanta #
Researchers or evaluators	11	8
Providers of service	8	14
Administrators or policy makers	7	13
Family members of youth who received services	3	27
Advocates	5	38
Youths who have used services	–	5
Other or [None]	–	3
Completed Surveys	21	62

Analysis of Response Themes

We identified four themes among the responses concerning the benefits and drawbacks of PAR. The first theme concerns empowerment of youth as a group, making their voice heard in the design of treatments and services. Within the empowerment theme was the issue of education. Education encompassed ideas about youth learning what services are available to them, how data is used and how it affects policy, program development, and marketing. Empowerment was clearly considered a benefit of the PAR process, "giving youth more involvement in system change and treatment plans" (9), and "guiding social development toward practices effective for youth" (18). One respondent observed, "youth would learn how data is derived and how it affects policy and program development." Further, PAR "empowers youth to participate in framing the questions that should be asked … educates them about [how] data is derived and how it affects policy and program development" (132). Another respondent (163) wrote, "When youth understand the data and marketing, they can have their voice heard thru-out the system in a different way." Respondent 132 also recognized the need to educate them about the process, answer their questions, and manage their expectations about change as a result of the research and evaluation process. Other benefits included giving worth to the process (143), developing awareness of self (154), ensuring that the youth perspective is accurately represented (120), and leading to accurate and pertinent research (138). One respondent said, "We can learn firsthand from them" (158). From this perspective, education can be a mutual benefit to both youth and their circle of concerned adults.

The second theme concerns investment by youth in PAR as a measure of their commitment to the process. Ownership and participation were the two issues that supported the investment theme. Ownership addressed concerns about buy-in and recognition by the target youth, that services are designed for their population. Participation included the idea of engagement in the process of determining the input to and output of services. While many responses echoed the ones who said, "Youth know what works for them" (139), and "young people will do better if they have a say in their treatment" (155), others spoke about the need to make the work interesting to keep youths' attention (4) (16) (104) (146). Several respondents wanted to make sure youth and adults understood the terminology of the field and of each other to ensure accurate communication. Respondent 126 observed, "It may be difficult for some community partners/stakeholders to slow-down and make their language more accessible to young folks." Another facet of the investment theme was the perception that participation would lead to buy-in. One respondent (5)

noted that youth improve interpretation by using youth language, by asking the relevant questions that other youth understand. There were both positive (126) and negative (134) comments about youth being able to meet the demands of responsibility and work at the cognitive level required (122). Since neither the age range of youth nor the level of investment expected was defined, the responses reflect a wide range of concerns but not necessarily a negative perspective. Taken all together, the concerns expressed seem to be those typical of any concerned adult for any child.

The third theme, recognition, concerns how figures of authority view the youth contribution and reflects the reasonableness of expectations of performance. Concerns about recognition included, on the one hand, the occasional unwillingness of people to accept the capabilities of youth, their potential for leadership and the usefulness of their input, and on the other hand, the limited experience and education levels of typical youths. Respondents voiced concern about collaboration in terms of the "acceptance by the formal provider systems" (10), and the challenge "for researchers to suspend their opinions and really listen to what youth say" (101). Many respondents recognized the importance of listening to the youth voice. Authenticity reflected the recognition that youth with mental health challenges speak with authority on their own condition: "they know how they feel" (114); "they know what they need" (149); and "Youth are experts on the issues they face—it is crucial to get their input" (2). Youth improve data collection from their peer groups by exhibiting and encouraging "buy-in." Another respondent (121) noted that youth know how to ask the questions in a youth-friendly manner to get good data.

Validation issues addressed the recognition of the youth voice by youth themselves and by the world-at-large as a valuable component of the development and delivery of youth services. Comments on this issue included: "They need to have their voice heard" (116) "to let people know they have a voice" (133).

The fourth theme concerns barriers to youth in the PAR process as expressed in concerns about the logistics of transportation, scheduling, and out-of-pocket money. Respondent 102 was concerned about possible legal ramifications. There were also concerns about the level of education required and the possible stress load (16). These concerns centered on the fact that the youth are young people and may need additional services to perform this work.

Drawbacks are not barriers, of course, but they may impede the process and derail motivation. One respondent (19) questioned whether researchers would deal with or react to the participating youth as "prima donnas," which could lead to "softball evaluation of feelings versus real

outcomes measurement." There was an underlying concern that the youth would become poster children for their condition instead of respected colleagues in the research process.

Other drawbacks included the opinions about youth being unwilling to share their opinion (7) and other confidentiality concerns (110) (140), moodiness (3), limited life knowledge (17), and the possibility that they are not sure what they want and need (108). Three responses addressed adult bias (102) and its negative effect on the willingness of youth to speak up (107) (120). A surprisingly large number, twenty respondents, stated that they did not see any drawbacks to youth involvement in participatory action research.

The survey sought recommendations from the respondents as to how to increase the involvement of youth with mental health challenges in research and evaluation. Many of the previously-cited themes were echoed in these responses. Youth need to be encouraged to participate and be welcomed to participate. Youth participation could only improve when logistics are planned as part of a study design. Concern focused on the time management aspects of both the principal investigators and also of the youth. Training was considered essential across the board and at all levels. Youth need to be trained in analytic techniques so they may advocate for themselves. The world-at-large needs to understand its kinship with youth-with-challenges and with youth-without-challenges. Policymakers need to be aware of the importance of inclusion for those persons affected by proposed governmental policies.

In a separate but related line of inquiry, the questionnaire also addressed the frequency with which the respondents saw youth with mental health challenges participate in research or evaluation as an informant, as a research assistant, or as a research partner. On the one hand, 42% of the survey responders indicated that they had not seen youth engaged in research in any capacity. On the other hand, 35% had indeed seen youth with mental health challenges involved in some manner, and 16% had seen them involved often. Seven percent of the population left this question unanswered. Of those 30 responses that indicated frequent participation, 20 saw participation at the informant level, five at the research assistant level, and five at the research partner level. In short, the responders saw youth sometimes involved in research or evaluation and mostly at a modestly collaborative level.

Roles As Identification

Given these themes, the next phase of analysis examined the concerns of each of the self-identified single-role responder groups. The data were examined for clusters of responses to each of the questions to determine whether

Table 2 Single identity roles

Role	#
Services provider	5
Researcher/evaluator	8
Youth who has used services	1
Administrator/policymaker	12
Family member	6
Advocate	13

there were dominant characteristics for each group. Table 2 shows the responses for those respondents who self-identified with one role. Two roles in this category had a dual definition: "Researcher" or "Evaluator", and "Administrator" or "Policymaker".

"Providers of services" as a group generally did not see these youth participating in research or evaluation, and the respondents viewed training as their recommendation to increase youth participation. "Researchers and/or evaluators" also reported not seeing youth involved in research or evaluation. Only one respondent (150) self-identified as a "youth with mental health challenges." That person occasionally saw youth with mental health challenges involved in research and/or evaluation as a participant. "Administrators and/or policymakers" recognized the importance of the authentic voice of youth with mental health challenges as a valuable facet of involving these same youth in research and evaluation. They also noted that recognition of the youth contribution was a major drawback. The group, "Family members of a young person who has received services," identified the major strength of involving these youth in mental health research as being the guidance that youth could offer on policy formulation and influence on delivery. The drawback for this group of respondents was the lack of recognition they anticipated for the youth who did indeed participate. "Advocates" responded strongly to the need for training as the means to increase participation by youth with mental health challenges in research and evaluation. For them, the overriding benefit of PAR is the recognition of the youth voice: Youth know best what they want and what works for them, and their input is valuable in designing and delivering successful services.

One individual chose a role as "Other" among the choices. Two individuals chose roles outside those offered on the survey instrument: One person wrote in "social marketer"; another person left the role blank. Another individual selected all six roles. These unexpected responses point out the need to improve the design of the classification system.

The final phase of the research addressed the evaluation of the comments of those respondents who self-identified with more than one role, again to look for clusters of

Table 3 Multiple identity roles

Role	#
Service provider + researcher/evaluator	2
Service provider + family member	1
Service provider + advocate	1
Researcher/evaluator + administrator/policymaker	2
Researcher/evaluator + advocate	1
Youth who has used services + advocate	3
Administrator/policymaker + Advocate	3
Family member + advocate	9
Service provider + family member + advocate	7
Researcher/evaluator + administrator/policymaker + advocate	1
Administrator/policymaker + family member + advocate	1
Service provider + researcher/evaluator + administrator/policymaker + advocate	1
Service provider + researcher/evaluator + family member + advocate	3
Service provider + researcher/evaluator + youth who has used services + administrator/policymaker + family member + advocate	1
Other	1
"Social marketer"	1
[None]	1

concerns. This data is summarized in Table 3. Two groups stood out. The first significant compound group comprised "Family member [of a young person who has received services] + Advocate" [nine respondents]. This compound group identified two benefits when youth engage in research and evaluation: first, the authentic voice of youth with mental health challenges and second, the potential influence of these youth. These same nine respondents indicated unanimously that they did not see any drawbacks to engaging this youth population in research and evaluation. The second significant compound group, "Service provider + Family member [of a young person who has received services] + Advocate" [seven respondents] echoed the same benefits as the first compound group, with the recommendation that increasing youth involvement in research and evaluation is best achieved by engaging youth with mental health challenges. Their recommendation for engagement was simply getting the youth to participate in the process. When comparing the responses of the compound groups to their corresponding single-role groups, a new dynamic emerges in the first compound group concerning the drawbacks of youth participation in research and evaluation: the single-role respondents were concerned about recognition issues, while the compound-respondent groups indicated no drawbacks at all. In the second compound group, the training component of the recommendation identified in the simple role analysis is ignored, although training of the youth would presumably increase their participation, investment, and effectiveness in the PAR process. The analyses of groups of single role definition and then of compound role definition brings to light new groups in the constellation of concerned persons that would have been ignored under a less rigorous examination of the data.

Discussion

Several general observations may be drawn from the analyses. First, the venue can have a significant effect on the self-identified roles of the attendees, even when the field of interest seems similar. In our case, the Tampa respondents were largely concerned with logistics and other "project management" facets of implementing participatory action research methodology to a study. The Atlanta respondents expressed greater interest in encouraging youth to reach out to engage in participatory action research, for their learning how the tools work, and how to use them to shape the future for other youth with mental health challenges. This divergence of responses correlates to the academically-minded Tampa conference attendees and the more family-centered, personally-engaged population in Atlanta.

Second, the survey design has implications for the utility of the data analysis. Our hope was that respondents would select the roles that corresponded to their interests in the system of care. "Other" is not a useful category, just as having someone check all the boxes or none of the boxes. The data from all respondents was included in the study; however, the four named situations in which the role selection was weak introduce some awkwardness in the data analysis.

Third, those people who see themselves in a combination of roles may offer different perspectives when examined against the single-role respondents for the same roles. In effect, they become a new population with a unique combination of concerns and considerations. This observation confirms the validity of Baker's categorization model in this context. By asking users to write in their comments on the survey instrument, we have their authentic voices in the data with which to associate their point of view and interests with their self-identified roles. Those people who self-identified with more than one role in our questionnaire demonstrated their additional concerns, beyond the dominant concerns of each of the single-role respondents. The implications for services development and delivery are profound since both the provider and the user may have multiple concerns that are not readily identifiable from a single description analysis.

Our research supports the notion that youth involvement in research through a participatory research model provides them the opportunity to engage with a larger community, to build self-confidence, and to develop effective problem-solving skills (Zeldin et al. 2006). We see this engagement as a manifestation of system of care values and principles. The respondents support the idea that involvement brings multiple benefits to the youth and offers important perspectives for the intervention team.

We conclude that stakeholders do have reasonable expectations of participatory action research as a process, and of the youth who could be empowered to bring about change in their system of care. Our respondents were enthusiastic about PAR for this population but also realistic about the extent of the youths' commitment, ability, and disposable time to create a successful change. There was widespread understanding of the importance of collaboration and respect between the principal investigators and the youth. The consensus was that the data would be improved if youth took ownership of their active role in the collaboration, and they could indeed create change. Despite concerns about the logistics of organizing youth into a working group, there was general recognition of the potential for skills improvement, for new knowledge of the inner workings of care provider systems, and for increased power as advocates for themselves when youth understood the importance of data evaluation and presentation that is part of academic research.

Our research also shows that building bridges between interested parties may identify new areas of mutual concern among the parties interested in PAR. New opportunities for PAR can then lead to new research and targeted services. For example, a PAR collaboration that solves the logistic issues that concern advocates and family members could remove a drawback and increase opportunities for

researchers and evaluators to engage with youth in a PAR population. Perhaps more work could be done over the internet with virtual meetings rather than compulsory attendance. Recognizing the limitations of youth as unskilled but potential researchers and evaluators could influence the design of PAR studies that researchers are willing to undertake. Crunching numbers can be a rigorous task, but collecting attitudes about services and preferences may be within the skill set of youth, and the active participation of youth in the product is consistent with the service design and delivery goals of PAR. Researchers and evaluators could promote imaginative projects that capitalize on youth skills, especially the ability of youth to engage with other youth.

The respondent groups offered suggestions for improved youth involvement in PAR. Service providers wanted to see more youth participation in PAR, as did administrators and policymakers. The two groups "Researchers and Evaluators" and "Family members" did not offer many suggestions for improving youth involvement in PAR and no one recommendation stood out for either group. The sole respondent in the group, "Youth who had received services," wrote "None" in the response field. The "Advocate" group offered the clearest profile. The advocates wanted recognition for the authority of this youth voice, and their recommendation was training at all levels and across the board.

We conclude that the constellation of persons that surround a youth in systems of care has a realistic understanding of the PAR methodology and its benefits. They would like to see more work in this area so change could be effected. They are passionate advocates for their youth, and they recognize the potential of PAR as a methodology and a force for change.

Further research could improve upon this study in several ways. First, further qualitative research that addresses a larger survey population would offer a broader spectrum of views on the topic, help situate the response clusters from the surveys already compiled, and clarify the main concerns that emerge from a larger population. Second, a large quantitative survey that lends itself to statistical evaluation could complement the results of the qualitative study. Q methodology has been applied to a PAR study to identify clusters of respondents (Goto 2008). Finally, the survey could be modified to let the respondent include his/her email address voluntarily for follow-up. Follow-up could be something as simple as making sense of an illegible word and as extensive as using a refined set of questions targeted to a specific participant response. We recommend implementation of PAR as a means to hear the voices most closely concerned with youth with mental health challenges in the systems of care context.

Appendix: The Survey Instrument

We are interested in your experience and perspective about the involvement of youth who have received services from the mental health system, with research and evaluation about that system. Please help us by completing this brief survey. Thank you very much.

1. How are you involved in the system of care? [circle all that apply]:

As a provider of services;
As a researcher or evaluator;
As a youth who has used services;
As an administrator or policy-maker;
As a family member of a young person who has received services;
As an advocate.

2. What do you see as the main benefits of involving youth with mental health challenges in research and evaluation?

3. What do you see as the main drawbacks of involving youth with mental health challenges in research and evaluation?

4. How often have you seen youth with mental health challenges participate in research or evaluation in each of these roles? [Circle the answer that applies]

As an informant	Never	Occasionally	Often
As a research assistant	Never	Occasionally	Often
As a research partner	Never	Occasionally	Often

5. Do you have any recommendations for how to increase the involvement of youth with mental health challenges in research and evaluation?

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