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6-2009

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Finding a voice: Results a participatory action research survey

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Introduction

Participatory action research [PAR] combines systematic research with the development

of a practical intervention. PAR methodology draws on the knowledge of the user population to

identify problems, to tailor treatments, and to disseminate the results, in combination with

professional guidance and project oversight. Full participation is achieved when the subject

population also evaluates the data and understands the strengths and limitations of the project.[1]

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,

collaboration is a powerful tool in effecting treatment outcomes. One of the hallmarks of PAR is

empowerment of the subject participants to change their condition as a result of the research.

Evolution of PAR Research Methodology

The definition and applications of participatory action research, sometimes

referred to as action research, have been both expanded and refined over time. The social

psychologist Kurt Lewin described action research initially as research leading to social

action guided by theory.[2]   He wanted research to be informed by the study subjects

themselves, to enlighten them, and to bring about a change in individuals' behaviors. His

particular interest was in intergroup relations and minorities. Eden & Huxham describe

action research as a "joint venture between external researchers with members over…a

matter which is of genuine interest to them".[3 p. 75] Boog describes the emancipating

nature of PAR when he writes, "action research is designed to improve the researched

subjects' capacities to solve problems, develop skills [including professional skills],

increase their chances for self-determination, and to have more influence on the

functioning and decision making processes of organizations".[4 p. 426] In Bargal's opinion,

action research was introduced to contain the scientific and systematic accumulation of

data, as well as the development of interventions that represent practical solutions to

problems experienced by people and their communities.[5] In the definition offered by

Reason and Bradbury, action research brings together action, reflection, theory, and

practice of researchers in participation with others, in the pursuit of practical solutions to

issues of pressing concern to individual persons and their communities.[6] Given all of

these views of PAR, a composite definition incorporates elements of participation,

collaboration, empowerment, and development.

PAR methodology has been applied in a broad array of fields with successful results.

Garvin and Bargal examined ethnic group conflict and intergroup conflict among adolescents

using small groups, the aim of which was to encourage in participants openness to diversity,

tolerance of differences, and the acquisition of skills to manage intergroup conflicts.[7] Another

PAR study sought youth to determine what and how youth support services should be developed.[8]

PAR was used in a Canadian high school to promote mental health counseling services[9] and to

design an electronic format to engage youth in health promotion.[10]

PAR has been applied specifically in the mental health field and with youth. For

example, two current participants in a system of care, in collaboration with a former

facilitator, wrote a step-by-step guide to using PAR to involve youth in systems of care, based upon their own experiences.[11] In 2008, Jivanjee and launched a project to address 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."[12 [p. 1]]   A study by Powers et al. sought the expertise of youth in evaluating the effectiveness of transition practices, as they age out of child services and enter the world of adult services.[13] PAR has been used to help adolescent individuals with physical or other health impairments identify a personal need, develop a goal, and then design a strategy to meet that goal;[14] to improve family-school collaboration when children have special education needs;[15] and to improve teacher responsiveness to students who are either homeless or transient when the students come to the classroom.[16] The collaborative methodology was employed successfully nationally and internationally to engage the community in discussions about the transmission and prevention of HIV.[17-19] In short, PAR has been used at the individual level, the classroom level, the school level, and at the community level 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

The idea of moving mental health care from state hospitals into community-based care, and therefore making those services more accessible than at state or private hospitals, gained momentum when former President Kennedy signed of the Community Mental Health Centers Act of 1963. The federal legislation required that care be comprehensive and available when and where it was needed. The bill also stipulated that services must be continued as long as needed,

that services include preventive measures, and that services must be coordinated for continual care.[20] Under this legislation, states were responsible for comprehensive mental health planning. Discussions revolved around creating a new system of mental health care, a unified system of care, and the continuity of care as patients moved between institutional care and community care.[21-24]

From these early initiatives on changing the adult system of care emerged parallel interest in new mental health systems for children and adolescents with mental illnesses. Hobbs et al. examined public policies affecting children with chronic mental disorders and their families and advocated for new systems of care.[25] At the 1985 annual meeting of the American Psychological Association, Heflinger and Dokecki discussed critical policy issues for standards in establishing a system of care for children and adolescents with mental illnesses.[26]

In 1986, Stroul and Friedman synthesized the then-current discussions for a transformation of children's mental health services.[27] In 2003, President Busch's New Freedom Commission on Mental Health specifically mentions a system of care as the preferred vehicle for delivering care and services to children, youth, and families.[28] Today, 'systems of care' is a philosophy of how care should be delivered to meet the needs of children with mental health needs and their families. 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.[29]

Facets of the one-point provider concept have evolved over the last fifty years. Part of the evolution of care for children with mental health needs was the inclusion, at the federal level, of youth as contributing partners in the determination of their care. Numerous government

programs, grants, and agencies, from the federal to the local level, are now based on the systems of care model as they address and monitor the care of this segment of the population. 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.[30, 31]

The vision of participatory action for youth involvement has several designers. Hart offers a comprehensive "ladder of participation" in PAR in which describes eight levels of participation. The first three rungs of the ladder are not participatory: youth are manipulated; youth are seen as decoration; youth are seen as tokens. In the next five rungs, youth participation emerges. On the fourth rung, 'youth are assigned but informed'; on the fifth rung, youth are 'consulted and informed'. On rungs 6 and 7, youth transition from 'adult-initiated, shared decisions with children' to 'child-initiated and directed' decisions. By the eighth rung, youth initiate and share decision-making with adults.[32] This schema begins at the stage where youth with mental health challenges are left out of the process; it shows a progression to where the youth are recognized as experts in their condition.

Stroul and Blau offer a collapsed version of youth participation. Their ladder of participation ranges from youth-guided care, which recognizes choices for youth concerning some of their services and activities; through youth-directed care, where the youth provide input as to their choices and preferences; to youth-driven care, in which their needs and outcomes are given priority in the design of services.[33] In the SAMHSA *Youth Guide*, this last category describes the highest level of youth impact in determining their own goals and outcomes for services, their influence on policy, and the design of systems of care.

All of the schema offer a structure to examine the extent of involvement in the PAR process. These theoretical and practice structures influenced and informed our questions surrounding the scope and implementation of participatory action research for youth with emotional and behavioral disorders.

Method

This exploratory study was designed 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. The underlying question was this: 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, such as 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 which 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 tested with other comparison groups.

We also chose Baker's membership categorization framework as an additional lens of analysis.[34] 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, we had people self-select the group, Family member [of a young person who has received services], while others self-selected the group, Advocate. In addition, we had identify with both groups by self-selecting for Family member [of a young person who has received services] + Advocate. We then analyzed the concerns identified by self-selected groups. We also we 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 research collaboration was initiated at the University of South Florida-Tampa to discuss the system of care in place for youth with mental heath 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 System of Care for Children's Mental Health held in Tampa, Florida in February 2008, and the annual meeting of the National Federation of Families for Children's Mental Health in Atlanta, Georgia in November, 2008. The Tampa conference was chosen because of its close association with the Research and Training Center for Children's Mental Health at the University of South Florida.   The Atlanta convention was selected for its national stature and its larger patron base.

Five questions comprise the survey. The survey was deliberately short so it could be filled out immediately and quickly by interested conference attendees during the time allotted during a poster session The same questionnaire was administered at both venues [see Appendix I].

Survey Populations

The attendees at these conferences do not represent a cross-section of society. By the very nature of the organizations that hold these conferences, the attendees are interested in services to children with mental health challenges. Our research identified a number of groups among the attendees, based on their self-identified affiliation and on their responses in the questionnaire.

Procedure

At each of the two venues, conference attendees at the poster session were asked to fill out a questionnaire. Their responses were voluntary and anonymous. The consent form and the survey were printed side-by-side with researchers' emails clearly visible on the consent form. If participants wanted to reach the researchers or had questions about the use of the data, they had the contact information at hand. This layout permitted the respondents to tear off and retain the consent form if they wanted to do so; none did.

The survey was available to all conference participants who attended the poster session. This venue was chosen since it allowed individuals to self-select to participate and to engage with researchers in a casual setting. Anyone who showed an interest in the poster was asked to fill out a survey. There was no obligation or inducement to participate other than goodwill. Of the individuals who attended the poster session at the conferences, 21 persons in Tampa and 62

individuals in Atlanta completed the questionnaire. There is no count available of the number of attendees 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 while ensuring that there would be no audit trail leading back to the respondent. Two ranges of numbers were used to distinguish attendees at the two venues: 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] is a reference to Survey Responder 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 and Discussion

Who Attended

The first study was conducted at the Research and Training Conference on Children's Mental Health held February 2008 in Tampa, Florida. This annual conference offers a forum to share findings, suggest solutions, and identify strategies for promoting positive child, family, and community outcomes through implementing effective systems of care. The same survey was issued to volunteer respondents at the poster session in Atlanta, Georgia at the National Federation of Families for Children's Mental Health held November 2008. Because the 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. Among the 21 respondents in Tampa, 14 identified with only one role in the system

of care. Three identified with two roles, two identified with three roles, and two identified with

four roles. Among the 63 respondents in Atlanta, 33 identified with only one role in the system

of care. Eighteen identified with two roles, eight identified with three roles, and three identified

with four roles. While 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

expand our range of self-reported user expectations.

Analysis of Response Themes

In analyzing the responses concerning the benefits and drawbacks of PAR, we identified

four themes. 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 [132] observed, "youth would learn

how data is derived and how it affects policy and program development." Another respondent

[163] wrote this: "When youth understand the data and marketing, they can have their voice

heard thru-out the system in a different way." Another said, PAR "empowers youth to participate

in framing the questions that should be asked. (PAR) educates them about [how] data is derived

and how it affects policy and program development" [132]. One researcher recognized the need

to education them about the process, answer their questions, and manage their expectations

about change as a result of the research and evaluation process [132]. 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 population that services are designed for their population. Participation included the idea

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 this theme was the perception was 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]. The 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 involved youth as "prima donnas," which resulted in "softball evaluation of feelings vs. 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 in research for those persons affected by the policies proposed by government.

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, forty-two percent of the survey responders indicated that they had not seen youth engaged in research in any capacity. On the other hand, thirty-five percent had indeed seen youth with mental health challenges involved in some manner, and sixteen percent had seen them involved often. Seven percent of the population left this question unanswered. Of those thirty responses that indicated frequent participation, twenty 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 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 youth could offer to 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 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

15

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.

<div align="center">Lessons Learned</div>

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 for engagement 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 but the four named situations in

which the role selection was weak introduces 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.

Implications for Behavioral Health

Our research supported the perspective promoted by Zeldin, O'Connor, and Camino that

youth involvement in research through a participatory research model provides youth the

opportunity to engage with a larger community, to build self-confidence, and to develop

effective problem-solving skills. [35] We see it as a manifestation of system of care values and

principles. The respondents to our survey support the idea that such 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 change

could indeed result. 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 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 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

have 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.[36] Finally, the

survey could be modified to let the respondent include his/her email address voluntarily for

follow-up. Follow-up could comprise 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.

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