



What Constitutes Youth Involvement in Systems of Care?

Source: Gyamfi, P., Keens-Douglas, A., & Medin, E. Youth and youth coordinators' perspectives on youth involvement in systems of care. *Journal of Behavioral Health Services & Research*. [Online early access]. DOI: 10.1007/s11414-007-9068-0. Published Online: June 16, 2007.

This paper examines how youth and youth coordinators perceive youth involvement in their mental health care. The presence or absence of involvement, along with challenges and barriers to youth involvement, are addressed.

Method

This study used a two-phase process of collecting data using focus groups between May and October of 2004. An initial exploratory focus group was conducted via teleconference to “examine an issue where little information is available” (Gyamfi, Keens-Douglas, & Medin); thus its primary goal was to generate and prioritize key concepts for the second phase of data collection. This focus group consisted of three youth coordinators and one youth serving in the role of youth coordinator, all of whom were former consumers of mental health services. A larger sample was sought; however, few agreed to participate. The questions for this group focused on the role of youth coordinators and their perceptions of youth involvement in systems of care.

In the second (explanatory) phase of data collection, five focus groups were conducted – two consisted of youth coordinators and three were comprised of youth receiving services in a system of care. Efforts were made to select groups with racial and ethnic diversity. The purpose of this phase was to add meaning and context to the themes generated from the initial focus group. Youth coordinator participants were recruited through a national technical assistance coordinator for youth issues. A total of 11 youth coordinators – four White, three African-American, one Hispanic, one American Indian, and two Asian – participated in the discussions. Focus groups were organized around the following topics: the role of youth coordinators and youth in systems of care, the challenges that youth coordinators face trying to get youth involved, and strategies for addressing these challenges.

Youth participants were recruited by youth coordinators. To be eligible for the study, youth needed to be 13-22 years old and currently receiving services for serious emotional disturbances from a federally funded system-of-care community. A total of 22 youth – six white and sixteen African-American – participated. Focus groups emphasized the following topics: youth groups, and youth involvement in service delivery and infrastructure of systems of care.

Data were analyzed with the assistance of Atlas.ti software. The coding scheme was developed using the system of care assessment framework.

Results

Analysis of focus groups revealed that youth groups are the key vehicle for youth participation. Youth reported feeling that these groups helped them develop coping strategies for their

problems, offered emotional support, and a place to disclose personal issues. Youth groups sometimes led to involvement in additional groups and advisory committees.

Overall, however, youth reported feeling under-used and under-empowered by the limited opportunities they had to both inform and be informed by their system of care. Outside the youth groups, youth involvement was limited and there was little evidence that youth were participating in the decision-making process related to their care. In cases where youth mentioned participating in advisory boards, they believed they did not have any real effect in shaping their care. Furthermore, it was evident that many youth were not aware of opportunities they had to be involved in service delivery activities.

Results from the youth coordinator focus group echoed these findings. Coordinators identified several barriers to youth involvement including the lack of true commitment by administrators to create specific opportunities for youth to participate in their care. This sentiment made it difficult for youth to feel welcome or able to become involved. For example, meetings were often held during school hours or in locations that were not close to public transportation. One youth coordinator stated: “I still feel that the position and the idea of youth involvement is exactly that: an idea” (Gyamfi, et al.).

Discussion & Conclusions

This study is one of the first to elicit youth perspective while researching the potential benefits of youth involvement in systems of care. One of the main findings, that “youth appeared to not have much understanding on if and how they could be more involved” (Gyamfi, et al.) and yet felt under-represented, signals a need for more of this work on both the research and community levels. Youth coordinators supported this finding by stating that there was an overall absence of youth voice during decision-making processes. Both groups mentioned youth groups as the primary mechanism of youth participation. The overall conclusion is that communities do not consistently involve youth in the planning, implementation, and evolution of the services they receive. Considerable training, technical assistance, and support to youth, youth coordinators, and the larger system of care may be needed to substantially improve this situation.

Although it addresses a very important topic, there were many limitations to this study. First, the authors state they had difficulty recruiting subjects, especially youth coordinators. Since these persons were also primarily responsible for the subsequent recruitment of youth participants, it is unclear how representative these youth are. In addition, getting permission from parents was mentioned as a challenge. Therefore, generalization of these findings to youth and youth coordinators across systems of care should be made with caution. Despite these limitations, however, the study results suggest both areas for further research and practice change in community mental health settings.



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Funds to support this activity come from the Child, Adolescent and Family Branch, Federal Center for Mental Health Services, Substance Abuse Mental Health Services Administration