



Beyond Our Borders:

The Changing Context of Constituent Involvement in Mental Health Statistics

Prepared by,

Laura Van Tosh

Consultant

This brief paper will address the changing context of constituent involvement as the Mental Health Statistics Improvement Project (MHSIP) begins to formulate a new path in mental health statistics and informatics. The MHSIP Advisory Committee will be meeting soon in a retreat setting to identify next steps for the organization and its activities over the next several years. The next millennium presents us with opportunities to re-group and inventory our past accomplishments and goals for the future.

Below are some ideas and challenges for securing the ongoing involvement of constituents who have a stake in the future of mental health statistics. Constituents, in this sense, include primary and secondary consumers. Primary consumers redefined as current or past recipients of behavioral healthcare services, and secondary consumers are defined as family members. These consumers also represent the breadth of disability status and minority perspectives. (NOTE: This paper does not address the role of the private sector, as described in Dr. Manderscheid's paper.)

MHSIP and the Survey and Analysis Branch of the Center for Mental Health Services have laid a useful framework for constituent involvement. These two entities have contributed to the sustained involvement of primary consumers in MHSIP activities, however, equal attention has not been provided to family members. It's true, as Dr. Manderscheid noted, "... consumer activities have moved into a second generation in which representation is being replaced by equal participation." Practically speaking, equal participation has not been fully realized for a host of reasons; including, financial constraints and the widening knowledge gap among many consumers and family members beyond the select number of active MHSIP consumer-participants.

Now, we're at the cusp of the next wave of involvement. The responsibilities for management information systems, data collection, and outcomes management have moved to the states. MHSIP, on a national basis, should continue to promote active constituent participation while recognizing that most activity occurs locally. MHSIP is poised, it seems, to begin to transfer knowledge to the States on a widespread basis. Could this be the next generation of activity for the MHSIP/CMHS - to expand beyond pilot projects to a forum that is national in scope?

Consumers and family members now occupy key positions at the state level, with consumers employed by state and local governments in Offices of Consumer Affairs. Consumers staff these key positions in more than 30 states. Their linkages to local, grassroots organizations cannot be overlooked. This is where the action is. MHSIP's challenge is to foster local and state technical assistance and mentoring to ensure consumers and family members are in fact impacting state-level MIS activities. MHSIP is a vehicle to promote improved data collection and analysis resulting in improved consumer quality of

life. For this goal to be realized, MHSIP must look beyond its borders to state and local environments.

With the national expansion of Offices of Consumer Affairs, might this be a good opportunity for MHSIP to form linkages with consumers in several states, rather than with a select number of consumers who are more "known" to the MHSIP family?

Regardless of the mechanism, it appears MHSIP must re-tool and rethink constituent involvement. MHSIP, however, must act soon. There's no time for processing the issue, as the next generation of issues are already upon us.

The next generation of issues for consumers and family members with focus on consumer protection confidentiality, privacy, parity, and person-center outcomes, among others. MHSIP must rise to these challenges, acknowledging the national debate will increasingly influence MHSIP activities.

These exciting issues will make for a realignment of consumer goals and agenda over the coming years. In fact, it is possible consumer and family groups will find some common ground in certain areas. It is true major differences exist among these constituents - especially in the areas of coercion and involuntary treatment - but consumer protection legislation, for example, has already been introduced in several states and will likely bring these groups together in some respects.

Parity is another issue where consumers and family member interests seem to coincide. How will MHSIP respond to the trend of equality in healthcare benefits? Does MHSIP have the capability to support state and industry demands for data? How will mental health services be evaluated in an era of parity? What outcomes will be important to constituents?

Confidentiality and privacy are hallmark and divisive issues in today's healthcare system what can MHSIP contribute to this debate? How do these pivotal issues impact on constituent information needs?

The next generation of issues will also have a bearing on MHSIP's ability to respond to Consumer concerns. How will MHSIP respond? Will MHSIP, with its traditional focus on data and analysis, be equipped to deal with these dynamic issues? Will the MHSIP membership composition change to support action in these areas?

MHSIP' S current configuration and goals must be re-examined. The MHSIP construct of a committee-driven model (with all the limitations and challenges inherent in group work) will have to emerge as a conceptual framework to adapt to the state-based climate of the tiny. Finally, MHSIP will have to calibrate its orientation to a consumer driven model that coincides with present-day legislative activity and policy development of tomorrow's healthcare system.

These are but a few thoughts and questions for MHSIP to consider as it broadens its borders.