Mental Health Transformation State Incentive Grant Program

Report on Findings from Consumer/Family Member

Focus Groups Conducted in Oklahoma

September 2009

Prepared for

The Department of Health and Human Services
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services

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Introduction

This report provides information gained from focus groups conducted with consumers and family members (CFMs) in Oklahoma between June 2008 and May 2009 of the cross-site evaluation of the Center for Mental Health Services (CMHS) Mental Health Transformation State Incentive Grant (MHT SIG) program. The original intent was to conduct in-person focus groups with 15 participants during the site visit to the State. However, when the target number was not achieved on site, the remaining focus groups needed to be completed by phone subsequent to the site visit. The interview guide used for the focus groups appears in Appendix A.

Methodology

General Information

The initial focus group protocols called for interviewing at least five persons involved with the grant project, at least five persons aware of the grant but not involved, and at least five persons who were members of CFM-run organizations. When recruiting persons for the focus groups, it was difficult to identify persons who were aware of the grant but not involved. Therefore, the decision was made to have more participants who were involved in grant activities.

It is important to note that the total number of respondents in Oklahoma (15) is small and comes from a convenience sample, rather than a random or other representative sample. As a result, the focus group findings presented here cannot be generalized as applicable to all mental health CFMs in Oklahoma. Further, for many questions, responses were not provided by every participant. Accordingly, results are presented based on actual responses to particular questions. Responses are not broken out by respondent categories (adult consumer, youth consumer and family) because the number of participants is small and not representative and since persons can fall into overlapping respondent categories.

Recruitment

As has been the case for all the grantee States, the recruitment of CFMs who are knowledgeable about the grant (whether involved or not) in Oklahoma was more difficult and took longer than expected. While the original intent was to identify all candidates prior to the site visits and complete the focus group interviews during the site visits, in practice it took much longer to identify eligible candidates and complete the focus groups. As a result, this report comes much later than the site visit report for the State.

State MHT SIG project staff were asked to identify CFMs who either work for or advise the State, and the following organizations were also contacted to recruit candidates:

- Oklahoma Mental Health Consumer Council (OMHCC)
- Oklahoma Citizen Advocates for Treatment and Recovery of Addictions (OCARTA)
- National Alliance for the Mentally Ill (NAMI), Oklahoma
- NAMI, Southern Oklahoma

- NAMI, Washington County
- NAMI, Caring Families
- NAMI, OKC Metro
- NAMI, Kay County
- NAMI, Tulsa
- NAMI, Western Oklahoma
- Evolution Foundation
- Depression and Bipolar Support Alliance (DBSA), Oklahoma
- Oklahoma Federation of Families for Youth and Children's Mental Health

CFM Consultants to the cross-site evaluation project and the Consumer/Youth/Family Advisor to the MHT SIG program were also asked to help identify potential candidates. The National Coalition of Mental Health Consumer/Survivor Organizations was also invited to provide suggested candidates for all MHT SIG States. Finally, persons who expressed interest in the focus groups were invited to let others know of the opportunity to participate.

In addition to the 15 participants who completed either a focus group or individual interview, four individuals were identified who did not participate in a focus group/interview. Following are the reasons these individuals were not included:

- One person agreed to participate in the onsite focus groups but did not show up.
- One person attended a focus group as a guest of another participant but did not identify as either a consumer or family member and was therefore excluded.
- One person was interested in the onsite focus group but not selected at the time; this individual was later unreachable for a phone interview.
- One person expressed interest in participating in a phone interview but did not respond to repeated attempts to follow up.

Focus Groups

The general approach for all States was to have separate focus groups for consumers and family members and separate focus groups for youth. However, since there is overlap among these categories, complete segregation was not possible. During the Oklahoma site visit, two in-person focus groups were held in Oklahoma City on June 18 and 19, 2008, with a total of eight eligible participants. A focus group by phone was conducted May 13, 2009, with four participants. Individual phone interviews were held March 24, March 31, and May 27, 2009.

Characteristics of Participants

To protect the identity of focus group participants, youth, adult and older adult consumers have been grouped into one category, and the actual ages of participants are not

presented. All the participants were women except one, and all were over age 18. Individuals were asked to indicate their status as a current or former consumer or family member. Five participants identified themselves solely as family members of an adult consumer, and one person identified as an adult consumer only. The remaining nine individuals identified themselves as some mix of consumer, family member of a youth consumer, and family member of an adult consumer. Participants overwhelmingly had heard about grant efforts from direct involvement with the grant as a staff member, Governor's Transformation Advisory Board (GTAB) member, GTAB subcommittee member, or through their CFM organizations. One individual heard about the grant through a local community mental health center.

Involvement was slightly greater at the State level (9 of 15 participants or 60 percent) than at the local level (8 of 15 participants or 53 percent), and six persons reported both State and local involvement. Two participants said they had not been active regarding mental health transformation, and two individuals did not provide responses to these questions. Three individuals indicated they were employed by a State or local agency involved in mental health transformation.

At the State level, the most common types of involvement were with GTAB subcommittee (7), at program meetings (6), and in the Needs Assessment and Resource Inventory (NARI) and Comprehensive Mental Health Plan (CMHP) processes (6). At the local level, the most common responses were as attendees at meetings (7), on a workgroup or subcommittee (4), and being involved with the NARI or CMHP (4). Overall, 9 of 13 individuals who responded to these questions said they were involved at the State level with either the GTAB or a GTAB subcommittee or workgroup (two individuals indicated they were not involved, and two were involved at the local level only). Of those nine active at the State level, six reported local level involvement as well. The two individuals reported their only local involvement was as a CFM attendee at local meetings.

Table 1. Characteristics of Focus Group Participants

Characteristic	Distribution		
Sex and age	Males, 1, females, 14 Age: All participants were aged 18+		
Type of current or former consumer or family member	Consumer, 13; family member of youth consumer, 5; family member of adult consumer, 13		
Level of involvement	State level, 9 Local level, 8		
Member of CFM-run organization	Yes, 14 No, 0		
Employed by State or local agency involved in transformation	Yes, 3 No, 10		
Involved in mental health transformation efforts	Yes, 11 No, 2		
Involvement at State and local levels	***Type of Involvement***	***State Level***	***Local Level***
	GTAB member	5	N/A
	Work group/committee	7	4
	Consultant/advisor	3	3
	Program staff	3	2
	Attendee at meetings	6	7
	Needs Assessment or CMHP	6	4
	Assisted with grant application	4	2
	Other (grant program staff)	1	0

With regard to length of involvement, one participant indicated being involved since before the grant began, four were involved from the start of the grant, two others said early on (without being more specific), one person said recently, and four others said they were aware of the grant but had not been involved.

Findings

State Impact on Local Efforts and Local Impact on State Efforts

When asked if State efforts are having an impact on local transformation efforts, the responses were:

- Three persons indicated they were. One person cited the telemedicine initiative, the transformation Web site, positive publicity about antistigma and recovery, and flyers/brochures encouraging participation in the project. That individual also indicated effects are more like pockets of involvement locally. A second person noted there was telemedicine all over the western part of the State, so this was anticipated. The third person cited the telemedicine initiative in rural areas of the State and the recovery support specialist initiative. This individual also was aware of a children's behavioral initiative that did not exist before the grant project began.
- One person said no.

- Two other persons provided other answers. One indicated awareness only of getting technology and Webcast capability to each community mental health center. The other person felt that whatever transformation was happening was taking place elsewhere and not filtering down.

No one provided any information about whether local efforts were having an impact on State efforts.

Involvement in CFM-Run Organizations

All the participants indicated they are involved in CFM-run organizations. At a statewide level, this includes NAMI Oklahoma, the Oklahoma Federation of Families for Youth and Children's Mental Health, OMHCC, DBSA Oklahoma, and the Oklahoma Citizen Advocates for Recovery and Treatment Association. Local organizations included NAMI chapters in Oklahoma City and Kay and Washington Counties, local chapters of the OMHCC in Oklahoma City and Washington County, and one DBSA local chapter. The State organizations are involved in mental health transformation efforts, while the local organizations generally are not.

Participants are involved as members, advocates, work group participants, staff, officer/board members, trainers, facilitators, and fundraisers for their organizations. Participation is generally once or twice a month with most organizations, and daily for organizations where a person is on staff, is a board member, or is on a work group.

These organizations are working with State agencies and other organizations in the following ways:

State Organization Activities

- Coordinating with other CFM organizations to promote greater CFM involvement and have a cohesive CFM voice
- Conducting antistigma/antidiscrimination and awareness activities for the general public
- Working with the Oklahoma legislature
- Doing advocacy work
- Promoting recovery support specialists

Local Organization Activities

- Raising awareness in the community via various types of efforts; for example, mental health walks, development of articles, coordination with local organizations
- Having a speakers bureau on mental health topics
- Working with police on crisis intervention trainings
- Participating in State conferences

Reasons for Involvement in Mental Health Transformation

When asked what they are personally trying to accomplish regarding mental health transformation, respondents identified the following objectives (with more than one response shown in parentheses):

- Strengthen CFM voice (6)
    - Be a powerful voice (2)
    - Have a more meaningful voice (2)
    - Help CFMs understand their voice matters (2)
- Reduce/prevent stigma and shame (4)
- Increase service availability and access and have better funding of services (2) including more equitable funding for rural areas
- Promote peer-support services (2)
- Have therapy seen as being as important as medication for clients (2)
- Have partnering among CFM organizations
- Have a system with no wrong door
- Advocate to avoid funding cuts for mental health services
- Have parity in insurance coverage
- Have more crisis services
- Have more support service systems in our geographic area
- Have consumer-run services
- Move toward an overall recovery model
- Collaborate among mental health, substance abuse, and co-occurring clients to advocate to the Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS) and the legislature
- Get mental health awareness into elementary schools, universities, all the medical fields, vocational/technical schools, and so on, that would include the message that recovery is possible

CFM Involvement in Grant Activities

Frequency and Type of Involvement at State and Local Levels

Participants were asked to rank the frequency and type of CFM participation in State and local grant activities. Table 2 and Figure 1 show:

- State level: Three of the activities (decisions on funding, designing programs, and evaluating programs) had involvement rankings that fell midway between never and rarely (rankings of 0.6 to 0.7), while the other three activities (setting goals, making policy, and implementing programs) were ranked close to rarely (0.9 to

1.2). For type of involvement, rankings for all the activities were generally midway between no role and a minor role (0.4 to 0.7).

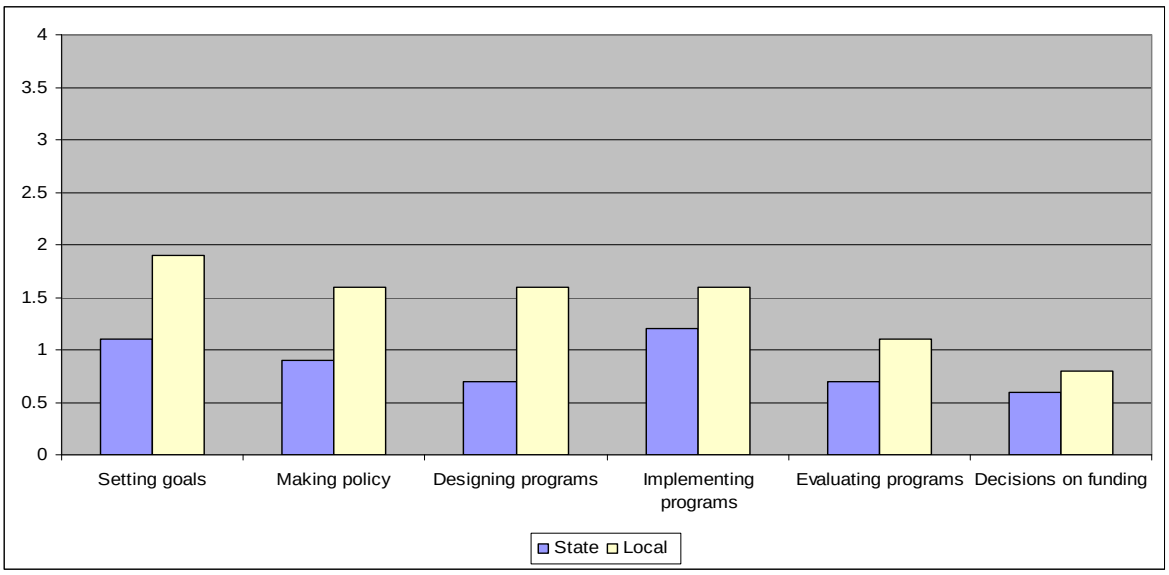
- Local level: For frequency of involvement, the highest ranking was for setting goals, which was ranked just below occasionally (1.9). Three others (making policy, designing programs, and implementing programs) fell midway between rarely and occasionally (1.6). The two lowest rankings were for decisions on funding (0.8) and evaluating programs (1.1). For type of involvement, the rankings for all but one activity were about midway between no role and a minor role (0.4 to 0.7). Participants reported having a minor role for setting policy (1.0).

Table 2. Average Rankings for Frequency of Involvement and Type of Participation of CFMs in Various Types of Activities*

Category	State Level		Local Level	
	Frequency	Type	Frequency	Type
Setting goals	**1.1** (14)	**0.7** (10)	**1.9** (14)	**1.0** (10)
Making policy	**0.9** (14)	**0.6** (10)	**1.6** (14)	**0.7** (11)
Designing programs	**0.7** (14)	**0.5** (10)	**1.6** (14)	**0.7** (10)
Implementing programs	**1.2** (14)	**0.6** (10)	**1.6** (14)	**0.7** (10)
Evaluating programs	**0.7** (14)	**0.4** (10)	**1.1** (14)	**0.5** (10)
Decisions on funding	**0.6** (14)	**0.5** (10)	**0.8** (14)	**0.4** (11)

- Number of valid responses (other than don't know or no response) is shown in parentheses. Frequency scale: Never = 0, Rarely = 1, Occasionally = 2, Frequently = 3, and Almost always = 4. Type of Involvement scale: no role = 0, minor role = 1, and major role = 2

Figure 1. Average Ranking for Frequency of CFM Involvement at State and Local Levels



Comments regarding the rankings above:

- Consumers are not allowed to design, implement, or fund State policy; input is only allowed at open meetings.
- Only certain individuals are selected, mostly Department employees with little to no experience.
- I think that people are too uninformed about the programs out there to consciously be able to participate.
- Funding decisions are low priority and political. It's very political in Oklahoma, and mental health funding is bottom of the ladder.
- I feel like consumers are not included very often and that advocacy agencies are often not included in decision meetings.
- None of the stakeholder groups I am associated with have any decisionmaking power over State policy except perhaps the Oklahoma State Planning Council.

Frequency of Involvement in Specific Types of Grant Activities

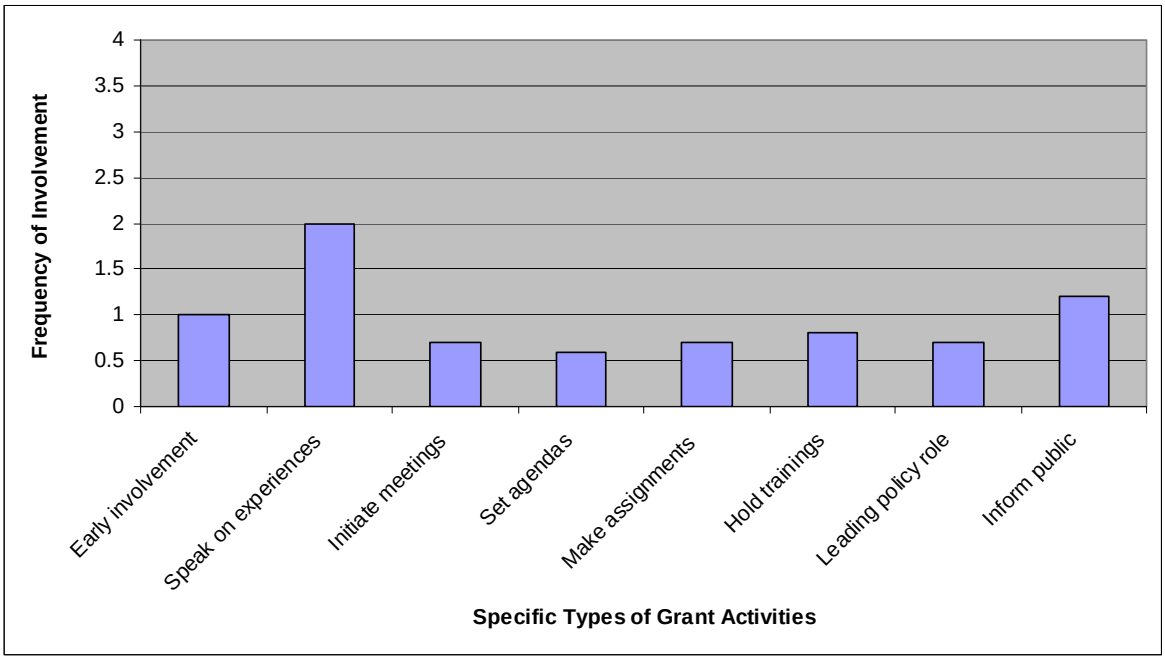
As shown in Table 3 and Figure 2, participants indicated that CFMs are occasionally involved in speaking about their own experience (ranking of 2.0). Involvement in preliminary discussions and informing the public were ranked at or just above rarely (1.0 to 1.2). For the five other activities, involvement was ranked between never and rarely (0.6 to 0.8).

Table 3. Average Rankings for Frequency of CFM Involvement by Specific Type of Grant Activity (on a five-point scale*)

Type of Activity	Average Ranking	Number of Valid Responses**
Involved in all preliminary discussions about transformation grant activities	1.0	10
Speak on their experiences during grant meetings	2.0	8
Initiate grant meetings	0.7	9
Set agendas for grant meetings	0.6	8
Make assignments to others to follow through on for grant activities	0.7	9
Hold trainings for others on the grant project	0.8	9
Have a leading role when policy research is done	0.7	9
Inform the public about grant activities	1.2	9

* Scale: Never = 0, Rarely = 1, Occasionally = 2, Frequently = 3, Almost always = 4
** Valid responses are those other than "Don't' know" or no response provided.

Figure 2. Average Ranking for Frequency of CFM Involvement by Specific Type of Grant Activity (on a five-point scale*)



The only comment related to involvement in specific activities:

- The project selects some token people.

Adequacy of Diversity

When asked whether the mental health transformation project has adequate CFM diversity in grant committees, work groups and other activities, participants indicated:

Cultural/ethnic: Five persons said no, one person said don't know, four others provided comments rather than saying yes or no, and two persons gave inconsistent answers (i.e., said yes on the interview guide form and don't know during the focus group). Comments related to cultural/ethnic diversity were:

- It has a lot to do with stigma. Oklahoma City is culturally/ethnically diverse, and the State has unique regional cultures. Sometimes because of a person's culture, he/she may not feel comfortable participating. "We try to bring people in, but they don't stick."
- We don't have enough African American, Hispanic American, or Asian participation, in part because we may not have tried, in part because of cultural factors.
- The Native American population has its own workgroup.
- There is not enough participation from African Americans.
- To engage eastern cultures, one has to speak the language. There is also ethnocentricity.

- The criminal justice workgroup was the most diverse because efforts were made to have more Native Americans, African Americans, and Asians.

Age: Three persons said no, one person said don't know, four others provided comments rather than saying yes or no, and two persons gave inconsistent answers (i.e., said yes on the interview guide form and don't know during the focus group). Comments on age diversity were:

- There have been efforts to involve youth (2). It's hard to find a time that doesn't conflict with their being in school. Meetings were scheduled at 11:00 a.m. when youth are in school.
- We need to find strategies to get better participation across the lifespan. We have gone to the aging coalition and to the Federation of Families for Youth and Children's Mental Health, but they are still not at the table.
- Youth have been represented through NAMI.
- Older adults have not been involved.
- Not many programs target older adults, and their lack of transportation limits their ability to participate.
- We've had a strong AARP presence during the grant and therefore that organization has been well represented.

Geographic: One person said no, one person said don't know, four others provided comments rather than saying yes or no, and two persons gave inconsistent answers (i.e., said yes on the interview guide form and don't know during the focus group). Comments about geographic diversity were:

- Rural areas have not been as involved (2). Transportation is an issue.
- When participating in grant subgroups, people from all over the State are there; city, rural, and frontier are all represented.
- More frontier area involvement is needed.
- Some rural areas have been involved in the consumer involvement study.
- Even though individuals live in Oklahoma City, they would not know about the grant if not on the consumer involvement study.
- Suburban and rural participation was good in criminal justice workgroups because teleconferencing was used.

General comments related to diversity were (with more than one comment shown in parentheses):

- It's a fight to get the State to adopt the consumer involvement standards (3). Reluctance is said to be related to the issue of needing funds to support CFM involvement.
- Reimbursement for participation issues (3):

    - It was a fight to get.
    - Our group did not get reimbursed.
    - We have reimbursed now that personal contact information does not need to be provided and preapproval is not required.
- Regarding hope for future diversity (3):
    - "With the new director, we can start moving and doing things, but we are having to start over again."
    - Hopefully things will improve with the new Project Director and ODMHSAS Commissioner.
    - Accountability is in place.
- How can people participate if they don't know [about the grant]?
- Teleconferencing can be used to involve more persons.
- The gay, lesbian, transgender, and bisexual population is missing, perhaps because of feeling uncomfortable about disclosing.
- There is not enough involvement by males.
- We've come a long way, but there's still a long way to go.
- We've made outstanding efforts to engage diverse population, but I don't know how successful we have been.
- Initially, we had a kaleidoscope of individuals at the table (i.e., diverse cultural/ethnic groups and age groups), but it has dwindled down to fewer persons being involved.
- The Department of Corrections is more consumer-friendly than ODMHSAS.
- The criminal justice workgroup and subgroups were mixed with regard to being consumer-driven.

Increased Involvement by CFMs

When participants were asked if the grant had led to more CFM involvement, four persons said yes, two said no, and four provided the comments below (with more than one response shown in parentheses):

- It is starting to make a difference (2).
- The grant has not made Oklahoma more consumer-friendly. Where it is more consumer-friendly, strong advocates have insisted that it be so.
- It does not look consumer-driven to me. It seems that they are trying to go that way, but really don't want to give up control. It has a "father knows best" type of feel.

When participants were asked about the kinds of differences that increased CFM involvement has made, responses were (with more than one response shown in parentheses):

- There is more effort to involve CFMs and take their comments seriously (3). However, in some meetings, one can feel like a token consumer since others are going to make the decisions and don't care what the consumer says.
- No change or not much change (2).
- Once they have realized that their voice is being heard, consumers have become more involved.
- The recovery support specialists are educating CFMs on how to better advocate for themselves, and this will help sustain grant efforts.
- Mental health, substance abuse, and co-occurring clients have come together to advocate for more for all groups. We're all going to fight for it. Hopefully, this will trickle sideways to other advocacy and community groups. Then we can take it up and down.
- Yes, there has been an impact [with no specific examples provided].
- When the statewide consumer council has conferences with consumer-run workshops, people become excited and get more involved.
- Previously, no one would have asked for a consumer's point of view.

When asked if CFMs are more hopeful because of grant efforts, six respondents said yes, one said no, two provided comments as follow:

- One hopes for the best and prepares for the worst.
- I am hopeful but don't feel comfortable saying it is related to the grant.

Barriers to Change at the State and Local Levels

The barriers to change identified by participants included (with more than one response shown in parentheses):

- Stigma (4):
    - Within ODMHSAS (2) CFMs feel patronized, treated in condescending way.
    - All across the State.
    - People would prefer to tell an employer they had committed a criminal offense than say they had been in a hospital for a mental illness.
- Reimbursement for CFMs (3):
    - CFM time is extremely less valued. There is a lack of reimbursement for many things CFMs do; this limits ability to attend meetings and participate.

    - Persons from rural areas cannot participate without support.
    - Grant will use our survey results but is not willing to pay for the time required to obtain them.
- Inadequate funding for mental health services (2) with the note that Oklahoma ranks 47th in per capita expenditures.
- Employment of consumers by ODMHSAS (2):
    - Resistance to having consumers in key roles. Implicit statement is, "This is as far as you can go" [i.e., staff roles but not leadership roles].
    - Salary levels are lower for consumers than for other comparable staff.
- Changes are giving CFMs a taste of what is possible, but many roadblocks and barriers prevent the system from being able to achieve its full potential. At times, it seems ODMHSAS is putting up the roadblocks.
- Accountability is needed and should come from outside ODMHSAS. They are trying to transform the system and need to answer to the system and individuals they are trying to change.
- Lack of independent voice for consumers; NAMI gets most of its funding from ODMHSAS and is careful about what it says.
- Long-time clients don't understand that recovery is a possibility; it's like they have been brainwashed by having received treatment under the medical model.
- Relationship barriers exist between mental health staff and clients. The building of relationships needs to go both ways.
- The thought process of clinicians doesn't seem to have changed, and therefore the structure hasn't changed.
- State grant staff and the mental health administration are not following grant regulations.
- The same consumers are being picked to participate again and again.
- The Oklahoma transformation Web site is buried in the Department's Web site.
- Funds are directed to the wrong sources [no specifics provided].
- Separate bathrooms for clients and staff at treatment programs.
- Lack of housing.
- Transportation issues.

When asked what should be happening that is not, participants said (with more than one response shown in parentheses):

- More ODMHSAS jobs are being created (2) but not filtering down to consumers or to having facilities to help people.

- A need for change in the thought process of State staff. For example, limited funding to get CFM involvement is said to be an issue, but it is not clear why they cannot use teleconferencing and videoconferencing obtained through the grant to involve CFMs from rural areas.
- The grant is not getting communication out to the rural areas.
- Changes in the Recovery Support Specialist program so it is not ODMHSAS that controls who gets the training, what the training covers, who is certified, and who gets continuing education units (CEUs); the current situation is a conflict of interest.
- More information about the grant needs to get out via NAMI.
- Housing issues should have been addressed by the grant.
- Employment/vocational services represent an important missing piece in the grant effort.

Participants were also asked about how CFMs should have been involved but have not been, and the comments related to this question were:

- CFMs should be invited to the table more often, and their opinions should be valued. There are many meetings and discussions, but no real change. It seems the Department does not want to give control to CFMs.
- Consumers who are receiving services, not just staff, from consumer-operated service agencies should be invited to participate in grant activities.
- Genuine involvement of youth and older adults.
- Advocacy groups are pushing politicians and ODMHSAS to get transformation done right. Consumers are being vocal but are not necessarily always invited [to be at the table].
- Consumers and families are not involved in all the planning.

Most Important Changes Desired

When asked about the most important changes they would like to see resulting from the State's MHT SIG project, respondents provided the following answers (with more than one response shown in parentheses):

- Changes in mental health services (7):
    - Have services be a best practices model like Comprehensive Continuous Integrated System of Care
    - Access to therapy
    - Access to affordable medications
    - Truth at the facilities [specific context is not clear]
    - Movement towards recovery first model

    - Access to employment services
    - Clients in residential facilities being taught independent living skills
- Elimination of stigma within the mental health system (6) "That we're not second-class citizens, that we deserve the right to live, not just survive, but live. That's what I want to see."
- Changes related to CFM involvement (4):
    - State staff need to listen to consumers and understand their real needs
    - More monies to NAMI to create local affiliates that will increase grassroots involvement
    - Use of telemedicine equipment to increase CFM participation
    - Change to having a consumer-led system of care
- Changes in the mental health system (4)
    - Better system with agencies working together
    - Common codes and procedures
    - Bridges between agencies and ODMHSAS
    - Change to having a recovery-oriented system of care
- Changes related to mental health treatment staff (2)
    - Address the shortage of providers
    - Have more reciprocity for licensure and credentialing
- An independent office of consumer affairs that reports directly to the ODMHSAS Director
- Education of the public to increase awareness so people will get involved and be able to access the system
- Better single access point for all State resource information; for example, SSI, legal aid, mental health center, food pantries
- Persons who graduate with a Licensed Clinical Professional Counselor (LCPC) degree from a university should know what NAMI is

Opinions About Grant Activities

Focus group participants were asked to indicate agreement or disagreement with several Likert-scale statements about various types of involvement in grant activities. Table 4 shows the average rankings. The highest level of agreement was with statements that the involvement of CFMs has made a difference, and grant staff are able to work collaboratively with CFMs. Participants had the most disagreement with the statements that there are enough CFMs involved in the grant, and they have meaningful involvement in decisions on funding of State programs.

Comments regarding the Likert-scale statements were:

- Consumers have insisted on having a part in this grant and have kept themselves informed and thereby made a great difference.
- Grant staff can but aren't allowed to work collaboratively with CFMs; the Department processes prevent efforts to promote collaboration. Disagreements are just ignored. Information about the mental health transformation grant is buried on Web sites.
- There is a lack of information/communication. Some members of our group had heard of the grant when it first came out but nothing since that time.
- I wasn't initially involved; I found out about it in August 2007. I had not been asked to participate and had difficulty getting information about what was happening with grant activities. I've not been very proactive myself the past year.
- We are making progress; sometimes we are too close to see it. I can believe the progress will continue after the grant if we continue to educate.
- I feel that consumers and their families are not included often enough in decisionmaking and policy planning and that their opinions are not considered credible.
- Some of my answers may seem contradictory, but they reflect small shades of difference in meaning in the questions.

Table 4. Average Rankings Regarding Various Aspects of CFM Participation in MHT SIG Grant Activities*

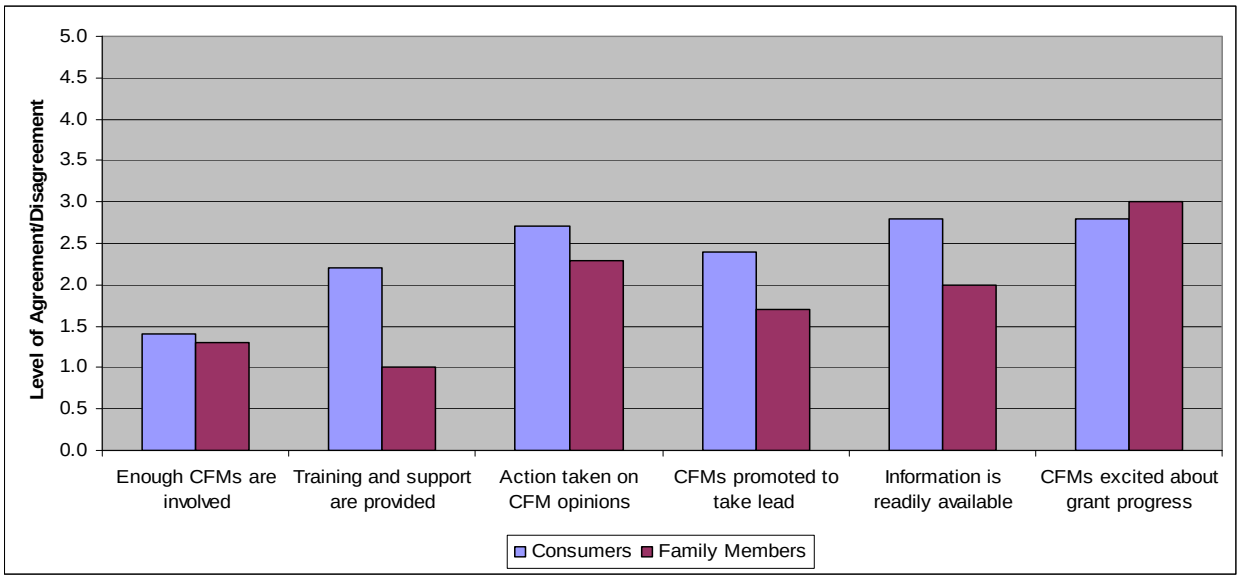
Statements	Average Rankings
1. CFMs have meaningful involvement in:	
Setting **local** goals	**2.1** (9)
Making **local** policy	**1.8** (11)
Designing **local** programs	**2.0** (11)
Implementing **local** programs	**2.2** (10)
Evaluating **local** programs	**2.0** (9)
Decisions on funding of **local** programs	**1.6** (10)
Setting **State** goals	**2.2** (12)
Making **State** policy	**1.8** (12)
Designing **State** programs	**2.0** (12)
Implementing **State** programs	**1.8** (11)
Evaluating **State** programs	**2.0** (12)
Decisions on funding of **State** programs	**1.5** (11)
2. There are enough CFMs involved in the mental health grant.	**1.4** (11)
3. Mental health service users and their family members are positively affected by this grant.	**2.9** (11)
4. CFMs are adequately compensated for their roles.	**1.8** (9)
5. Involvement of CFMs has made a difference.	**3.9** (7)
6. Grant staff are able to work collaboratively with CFM.	**3.3** (7)
7. The grant promotes collaboration among CFMs.	**3.0** (8)
8. State leaders are sensitive to cultural and linguistic issues.	**2.6** (9)
9. CFMs receive the training and support they need to participate effectively in the mental health transformation grant.	**2.0** (9)

Statements	Average Rankings
10. The grant promotes CFM understanding of the process behind developing policy.	**2.0** (10)
11. The grant promotes CFM understanding of current policy issues.	**2.3** (8)
12. The leaders of this grant make involvement by CFMs a priority.	**1.8** (10)
13. During project meetings, the opinions of CFMs are discussed.	**3.3** (8)
14. Action is taken as a result of CFM opinions.	**2.6** (9)
15. A partnership exists between CFMs and persons who are not CFMs.	**2.9** (11)
16. As a result of the grant, CFMs have the knowledge to educate the community on important issues.	**2.2** (9)
17. The grant promotes CFMs to take the lead in this transformation project.	**2.0** (11)
18. Disagreements are handled respectfully within this project.	**2.6** (8)
19. Information about the mental health transformation grant is readily available to CFMs.	**2.4** (12)
20. Professionals use language that is easily understood by nonprofessional participants.	**2.4** (9)
21. Efforts are made to evaluate CFM involvement.	**3.0** (9)
22. CFMs are excited about the progress of the grant.	**2.2** (11)
23. Persons of all cultural and ethnic origins are respected within this grant.	**2.9** (9)
24. Stigma/discrimination is not accepted at any level of this grant.	**2.4** (12)

* Scale is: Strongly disagree = 1, Disagree = 2, Neither = 3, Agree = 4, and Strongly Agree = 5. The number of valid responses (other than don't know or no response) is shown in parentheses. NA indicates not applicable.

Figure 3 shows the rankings for six selected items below by the categories of consumers and family members.

Figure 3. Average Rankings by CFMs for Selected Items



Additional Comments

In addition to responses provided to the specific questions, participants made (or reemphasized) several other points (with more than one person having a comment about the topic shown in parentheses):

- Changes associated with the change in grant leadership (5):
    - Now there is an open door policy when concerns arise about CFMs not being involved enough. The new Project Director has shown interest in the consumer involvement standards and a level of trust exists now that did not exist before.
    - The new Project Director has pushed for the consumer training academy but been turned down by the Department.
    - Now there is respect, freedom, and (equal) treatment.
    - Under the old grant leadership, qualified consumers who self-identified were not allowed to do projects on their own, were double-teamed, and had to work through a supervisor.
    - The previous grant leadership wanted to appoint people, but we fought to keep control and be consumer-driven.
- Involvement in evaluation (4):
    - There is no involvement in evaluation. "They don't want consumers doing evaluation."
    - Once an ODMHSAS staff member was known to be a consumer, life can be made difficult for them and some have considered leaving the Department.
    - Consumers decided to do an evaluation that ODMHSAS did not want to do. They were advised not to let the Department know since they might look foolish for not having participated in it.
    - We have to be careful not to step outside our bounds. If we get too big, we are a threat even though we are continuously trying to form a partnership. If we challenge them, we don't get invited to meetings and discussions.
- "When the office of consumer affairs was pushed a number of levels down in the Department, I think that I've never been more disgusted with all of the progress. It felt like all of the progress we had made went straight down the toilet because it's saying consumers are not capable of doing this job, and it's wrong.…It's State government for god's sake…[to say] that we aren't as capable as the next guy is a real slap in the face."
- Person is not sure what the goals of transformation are and what it should look like.
- Providers have problems when transferring to Oklahoma. Pay rates are so low compared to other States that this discourages people from entering the mental

health workforce here. The credentialing requirements are more stringent, but the pay is lower, creating a disincentive for certification.

- Our greatest discrimination comes from ODMHSAS.
- Tons of consumers work in ODMHSAS, but won't disclose because of fear of losing their jobs and retaliation. Persons who self-identify can feel marginalized because the Department does not want to hear what they have to say.
- Transformation needs to be done from the bottom up, not from the top down as it is now being done.
- ODMHSAS is training 50 persons a month because the turnover rate is so high. Transformation agents are leaving the agency, so there are now only 4–5 persons left out of 16 who started.
- There is a strong need to educate agency directors on consumer involvement.
- The Governor's Transformation Advisory Board has two consumers and four family members out of a total of 28 members, and participation is felt to be token.
- When developing a peer-run wellness center, Department staff designed it with no input from consumers. That's not transformative.
- The State had a huge Transformation Day where CFMs were not included. It was described as focusing on breaking down the barriers of communication and touted the Innovation Center. "Everyone was offended to the gills."
- NAMI was mentioned in one grant document as the only community partner, even though other CFM organizations are active and involved in grant activities.
- NAMI appears to be given some preferential treatment versus other organizations.
- One CFM organization that is on the ODMHSAS board did not become aware of the NARI and CMHP documents until after they had been submitted to SAMHSA.
- One of the accomplishments reported for the grant, the appointment of a consumer to the ODMHSAS board, was completed a year before the grant started.
- Funding and implementation of a consumer leadership academy has been used as a carrot for CFMs to be willing to work on other things. The budget has been reduced from $300,000 to $100,000.
- The consumer involvement study group seems different in that it is empowering. "I'm starting to feel my opinion really does matter more."
- Via involvement on the consumer involvement study, individual is aware that there are now peer leaders throughout the State.
- The Recovery Support Specialists program has been upgraded by the grant. Providers are being educated too.
- We are not hearing about the grant in rural Oklahoma. The Web site does not have anything beyond information from 2007.

- Communication from consumers statewide has narrowed over the last year and a half. It is disappointing to say that because I'm so proud of the job we were doing before that.
- ODMHSAS says they don't have the workforce to provide the services, so building the workforce is a big issue that needs to be promoted.

Summary

Overall, there are indications the MHT SIG project has resulted in more CFM involvement, but with concerns expressed about tokenism and consumers not being taken seriously because they have a mental illness. CFMs also are more hopeful because of the grant. The new Project Director is seen as having a true commitment to CFM involvement that did not exist before, and this commitment is reflected in differences occurring as a result of the grant.

The responses to frequency and participation questions indicate CFM involvement is still generally described as rarely at the State level and only somewhat higher at the local level for activities such as setting goals and designing programs. CFMs indicate their roles for these general types of activities fall about halfway between no role and a minor role. For specific activities, CFMs say they can speak about their experiences during grant meetings occasionally and have rare participation in other specific types of activities. They indicate a desire to have more CFM involved in the grant project, while recognizing that CFM involvement has made a difference.

The major barriers mentioned most often were stigma (including within ODMHSAS), reimbursement to support CFM participation, inadequate State funding for mental health services, and issues related to employment of consumers by the Department.

With regard to diversity, ethnic/racial diversity is not seen as adequate, and more youth and older adults need to be involved. Comments about geographic diversity are mixed.

The most important changes that CFMs want to see are those needed in mental health services, elimination of stigma within the mental health system, changes to promote more CFM involvement and a consumer-led system of care, and improvements in how the mental health system operates.

Appendix A: CFM Interview Guide

1. How would you describe the National/ State/ Local (Use the level of efforts that applies to the screening questions) efforts to transform mental health services? How did you first hear about it?

   Are you involved in efforts to transform your state or local mental health services?

   ☐ Yes ☐ No *(go to question #2)*

   If yes: How would you describe your roles in transformation efforts? *(Options shown below)*

State	Local	
☐		Member of State Transformation Working Group (TWG)
☐	☐	Work group/subcommittee member of TWG
☐	☐	Consultant/advisor to mental health or related program
☐	☐	Mental health program staff or evaluator
☐	☐	Consumer/family participant in meetings about mental health transformation
☐	☐	Consumer/family participant in needs assessment or State mental health plan
☐	☐	Consumer/family participant or contributor to grant application
☐	☐	Other (specify) _____

   In your own words, please describe your involvement in transformation efforts. How long you have been involved?

   Do you think State efforts are having an impact on local community efforts? Do you think local community efforts are having an impact on State efforts to transform mental health services? If yes, please provide an example?

2. Are you a member or staff of an organization run by mental health service users and their families, such as NAMI and the Federation of Families for Children's Mental Health?

   ☐Yes ☐No *(go to question # 5)*

If yes, please identify the organization(s).

Organization Name:	_____	_____	_____
State or local:	_____	_____	_____
Active in transformation (Y/N):	_____	_____	_____
Your role:	_____	_____	_____
Frequency of participation:	_____	_____	_____

For each organization: Are you involved with this organization to help transform mental health services? If yes, please describe how.

3. *For participants who are members of AYF organizations involved in transformation efforts AND for participants who are representatives of key stakeholder organizations*: Please describe how your organization works with local and State agencies and other groups to transform mental health services.

4. *For participants who identify as adults or youth who receive mental health services and/or family members:* Are you personally involved to promote mental health transformation? Are you involved with a mental health organization that advocates for mental health transformation?

   F*or participants indicating their involvement is related to State or local transformation efforts*: What are you personally trying to accomplish by being involved in mental health transformation efforts? What is your organization trying to accomplish?

5. Thinking of both mental health service users and their families, how often are they involved in the following activities? How would you describe their type of involvement?

Participation in mental health system:	**Frequency of Involvement**						**Type of Involvement**			
	Never	Rarely	Occasionally	Frequently	Almost always	Don't know	No Role	Minor Role	Major Role	Don't Know
Setting **local** goals										
Making **local** policy										
Designing **local** programs										
Implementing **local** programs										
Evaluating **local** programs										
Decisions on funding of **local** programs										
Setting **State** goals										
Making **State** policy										
Designing **State** programs										
Implementing **State** programs										
Evaluating **State** programs										
Decisions on funding of **State** programs										

Do you have any clarifications or comments: _____

_____

_____

6. Is there adequate involvement by each of the following groups?

By diverse cultural, ethnic and religious groups:
By diverse age groups:
By persons from cities, suburbs and rural/frontier areas:

Comments:

_____

_____

If answered no to a question above, what should be happening that is not?

_____

_____

7. Please indicate the frequency of involvement of both mental health service users and their families (AYF) in the following activities due to the mental health transformation grant.

Participation in particular activities:	**Frequency of Involvement**					
	Never	Rarely	Occasionally	Frequently	Almost always	Don't know
AYF are involved in all preliminary discussions about transformation grant efforts.						
AYF can speak on their experiences during grant meetings.						
AYF initiate grant meetings.						
AYF set agendas for grant meetings.						
AYF make assignments to others to follow through on for grant activities.						
AYF hold trainings for others on the grant project.						
When policy research is done for this grant, AYF have a leading role.						
AYF inform the public about transformation grant efforts.						

Comments:

_____

_____

8. Has the grant lead to more involvement by mental health service users and their families? If yes, what difference has that involvement made? Please examples of differences this participation has made.

   Are mental health service users and their families more hopeful about the future of the mental health system as a result of the grant?

9. What are the major barriers getting in the way of making changes consist with grant activities at the State and local levels? Do you see any patterns of problems? What should have happened as a result of the grant, but did not? During the grant, were there ways mental health service users and families should have been involved but were not?

10. What are the most important things that you would most like to see change as part of mental health transformation? Are the needs of mental health service users and families being addressed by this grant?

Adult, youth and family member involvement questionnaire

Interviewer instructions: Identify the perspective from which participant will be responding (if an individual falls into more than one category, s/he should reply based on the perspective most important to them). Ask each question in reference to one state and/or local transformation project, according to participant's involvement/familiarity. Items containing "A/Y/FY/FA" should be posed specifically for the perspective(s) for which the participant is responding. For example, if the participant identifies as a family member of a youth mental health service user, read item 2 as "There are enough family members of youth involved in grant activities."

Adult mental health service user (A)	Youth mental health service user (Y)	Family member/caregiver of youth mental health service user (FY)	Family member of adult mental health service user (FA)

Thinking about the *mental health transformation grant* activities that you're familiar with, please indicate how strongly you agree or disagree with each of the following statements:	Response					
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Don't Know
1. A/Y/FY/FA have meaningful participation in:						
Setting **local** goals						
Making **local** policy						
Designing **local** programs						
Implementing **local** programs						
Evaluating **local** programs						
Decisions on funding of **local** programs						
Setting **State** goals						
Making **State** policy						
Designing **State** programs						
Implementing **State** programs						
Evaluating **State** programs						
Decisions on funding of **State** programs						
2. There are enough A/Y/FY/FA involved in the mental health grant.						
3. Mental health service users and their family members are positively affected by this grant.						
4. A/Y/FY/FA are adequately compensated for their roles.						
5. Involvement of A/Y/FY/FA has made a difference.						
6. Grant staff are able to work collaboratively with A/Y/FY/FA.						
7. The grant promotes collaboration among A/Y/FY/FA.						
8. State leaders are sensitive to cultural and linguistic issues.						
9. A/Y/FY/FA receive the training and support they need to participate effectively in the mental health transformation grant.						
10. The grant promotes A/Y/FY/FA understanding of the process behind developing policy.						
11. The grant promotes A/Y/FY/FA understanding of current policy issues.						
12. The leaders of this grant make involvement by A/Y/FY/FA a priority.						

Thinking about the *mental health transformation grant* activities that you're familiar with, please indicate how strongly you agree or disagree with each of the following statements:	Response					
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	Don't Know
13. During project meetings, the opinions of A/Y/FY/FA are discussed.						
14. Action is taken as a result of A/Y/FY/FA opinions.						
15. A partnership exists between A/Y/FY/FA and persons who are not consumers/family members.						
16. As a result of the grant, A/Y/FY/FA have the knowledge to educate the community on important issues.						
17. The grant promotes A/Y/FY/FA to take the lead in this transformation project.						
18. Disagreements are handled respectfully within this project.						
19. Information about the mental health transformation grant is readily available to A/Y/FY/FA.						
20. Professionals use language that is easily understood by non-professional participants.						
21. Efforts are made to evaluate A/Y/FY/FA involvement.						
22. A/Y/FY/FA are excited about the progress of the grant.						
23. Persons of all cultural and ethnic origins are respected within this grant.						
24. Stigma/discrimination is not accepted at any level of this grant.						

Comments and clarification:

_____

_____