

**What is Participation? How Mental Health Consumers Perceive Participation in their Individual Service Plans and its Impact on Services**

Erica Gosselin, M.S.

Mental Health Center of Denver

[Erica.Gosselin@MHCD.org](mailto:Erica.Gosselin@MHCD.org)

Steve Baumer, B.A.

Mental Health Center of Denver

Antonio Olmos, Ph.D.

Mental Health Center of Denver

Kristi Helvig, Ph.D.

Mental Health Center of Denver

Paper presented at the annual meeting of the American Evaluation Association, November 2006, Portland, OR.

## Introduction and Background Information

The Mental Health Center of Denver (MHCD) has received national recognition for its work in community mental health, and continues to focus on a recovery and strength-based model. The use of the focus group format serves not only as an instrument for quality improvement but can also foster empowerment among consumers with serious and persistent mental illness, which has historically been a disenfranchised group. It is believed that better consumer outcomes will occur if the treatment program is designed to fit the participants rather than expecting participants to fit the treatment providers' idea of treatment. For this reason, the definition of "treatment participation" becomes extremely relevant, and differing views on defining this process among consumers and treatment providers can impact recovery. This approach, loosely based on utilization-focused evaluation (Quinn-Patton, 1996), serves as a means to implement specific changes regarding treatment planning within a community mental health center. The current evaluation can help to inform the treatment planning process within community mental health centers in order to maximize consumer participation and improve treatment services and delivery.

This qualitative research study is an evaluation project on treatment participation of adult consumers at a large community mental health center in Denver, Colorado. It involved conducting focus groups with mental health consumers for purposes of quality improvement. The idea for this study was prompted by results from the 2005 Mental Health Statistic Improvement Program (MHSIP) Consumer Survey given by the Colorado Division of Mental Health (DMH). This survey asked mental health consumers

to rate their satisfaction in five different domains which included: perception of access, perception of quality/appropriateness, perception of outcome, participation in service/treatment planning, and overall consumer satisfaction. Out of 165 completed surveys, the percent of MHCD consumers who agreed that they participated in service/treatment planning was only 53.3%. This was much lower than the national average of 81% on this measure, as well as the Colorado average of 67%. These findings served as a catalyst to determine how consumers were defining treatment participation and how they would improve the treatment planning process.

### **Objectives**

The primary objective was to determine how adult outpatient consumers define participation in their Individual System Plan (ISP) with the aim of improving quality in the treatment planning process. Additional objectives involve examining consumer's perception of 1) current level of consumer participation in their ISP, 2) consumer's desired participation level in treatment planning, and 3) changes that consumers would like to see in terms of treatment planning. The results will be used to modify internal procedures regarding treatment planning, and the final objective would be to examine the implications of these changes and how they fit into the parameters of a strength-based and recovery-oriented mental health center.

<b>Study Design</b>
---------------------

To be able to investigate the primary objective of this study, focus groups were conducted with adult mental health consumers in the Denver metropolitan area.

Participant eligibility for the proposed study consists of inclusion criteria of being a current adult consumer at the Mental Health Center of Denver (MHCD). As the objective of the study was to examine participation in the treatment planning process, consumers who were identified as receiving medication-only services were not included in the study. Additionally, all participants were assessed for competence based on their mini-mental status examination scores prior to participating in the focus groups.

The study involved conducting 10 focus groups at different outpatient clinics through MHCD. There were 65 total subjects involved in these interviews. The different MHCD sites and number of consumers who participated in the focus groups at each site were as follows:

Stout Street Clinic	-	4
Vine Street Clinic	-	7
2 Succeed (1)	-	6
Humboldt	-	11
Arapahoe	-	5
Downing	-	9
Clermont	-	5
Monaco	-	4
Monroe	-	4
2 Succeed (2)	-	10

The focus groups were one and a half hours in length. In each focus group, members were asked the same set of standard questions regarding treatment participation and the treatment planning process. There was an introduction prior to the questions in which the

principal investigator and sub-investigator addressed several areas including: the history of the treatment plan at the Mental Health Center of Denver (MHCD), why the focus groups were being conducted, and the dictionary definition of “participation.” Consent forms were signed at the beginning of each focus group, and the competence of all participants were assessed through an individual mental status examination. All responses were audio-recorded by the primary investigator. Directly after the completion of the focus group, each consumer was given a \$5.00 gift certificate to a local fast food restaurant. The standard set of questions used in each of the focus groups is listed on page six.

## **CONSUMER PARTICIPATION FOCUS GROUP QUESTIONS**

### **INTRODUCTION**

- 1 History of the treatment plan at MHCD (include changes that have been made)**
- 2 Why we are conducting the focus groups (include MHSIP information)**
- 3 Discuss the dictionary definition of “participation.”**

### **Development of the Treatment Plan:**

- 1. How would you define participation?**
- 2. Describe your level of participation in creating/developing your treatment/service plan/ISP at MHCD?**
- 3. Does your treatment/service plan/ ISP reflect the treatment you are receiving or wish to receive at MHCD?**
- 4. Would you like to change your level of involvement in the treatment plan process? If so, what would that look like?**

### **Approachability of Staff:**

- 5. Is there anything that would make you feel more comfortable in asking your case manager/therapist questions about your treatment and medication?**
- 6. Is there anything that would make you feel more comfortable in asking your psychiatrist questions about your treatment and medication?**

### **Recovery:**

- 7. How would you define recovery?**
- 8. How has the current treatment plan helped in your recovery?**

### *Analysis*

All focus groups were audio recorded and separately coded for themes by three trained coders who will then combine the sets of themes and any notes provided from the focus groups into categories of information. Patton (2002) writes “no formula exists for transforming [qualitative data into findings]...Guidelines, procedural suggestions, and exemplars are not rules” (pp. 432–433). He explains that “content analysis is used to refer to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (p. 453). The method of content analysis was identification of recurring themes and patterns (Patton, 2002) using abridged transcripts (Krueger & Casey, 2000), a methodology well documented in the qualitative research field (Heppner, Kivlighan, & Wampold, 1992). Dr. Olmos-Gallo, Dr. Helvig, and Ms. Gosselin independently read each transcript across questions and across focus groups, reduced all statements into approximately themes, then resorted into patterns, and finally recategorized into trends. Each worked to identify emergent categories of meaning (Krueger & Casey, 2000; Ware, Tugenberg, Dickey, & McHorney, 1999) and then discuss these findings to consensus, a process called “analytical triangulation” (Patton, 2002, p. 464).

### *Results:*

#### **A. How Consumers Define Participation**

In terms of defining participation in treatment, most consumers were in agreement on the definition and gave similar responses across sites. Therefore, it did not appear that there was confusion as to how participation was defined. Many consumers described it as being

“involved” in their treatment, and as a collaboration with their case managers. Some specific samples of definitions from the sites are as follows:

- *“Getting involved”*
- *“Making a contribution to the overall group effort”*
- *“Interacting,” “Cooperating”*
- *“Involvement,” “Coming to agreement”*
- *“...participation is a two-way street”*

#### **B. Perception of Current Level of Participation in Their Treatment Plan**

There was more variability in the responses in this area which explored how much consumers felt they participated in their Individual Service Plan (ISP). Many consumers did acknowledge knowing what an ISP was, although the term “treatment plan” was more recognizable than ISP. One consumer asked “What is an ISP?” Many said that they did complete an ISP with their case managers, although the consumers at one site were slightly confused as they had two ISP’s each based on the requirements of that site. Most of the consumers recognized the ISP as an important tool for their recovery and thought its purpose was to guide their recovery. Here are some specific samples of comments by consumers about their involvement in the treatment plan:

- *“I was very much involved”*
- *“I was very involved”*
- *“I feel like I am sharing it with him (Case Manager). We are doing something”*

Although the majority of consumers acknowledged the initial completion of an ISP, not

all who completed it were given copies of their treatment plan, or remembered being given a copy of the treatment plan, which appeared to vary by site.

- *“...because I asked her for a copy and she told me I did not need one and I said I would like one.” “I had to ask for it.” “Yeah, I never got a copy of mine either...I signed them but didn’t get a copy“*
- *“Here at Bridges, I don’t think they hand anything out to us. We just sign it and they put it in our file.”*

There were also some consumers who appeared to feel confused about the ISP process and/or did not feel it was something in which they actively participated. Some commented that the initial treatment plan is often completed when they have not yet been stabilized on medications or were very sedated due to the medications; and therefore, is not conducted at a time when they feel they can adequately participate. Others felt that is was merely a formality and not necessarily something of use to their individual treatment. Some comments reflecting these views are as follows:

- *“She handed me a piece of paper with questions and I just wrote answers to it and handed it to her and I have not seen it anymore.”*
- *“I think I was just really overwhelmed with the questions. By the end of it, I don’t know, I was just really overwhelmed with the questions.”*
- *“In regards to the hour and a half of questions...I think they are computer generated. Some of it was very valid for myself and then others it was just off the wall where they came from.”*
- *“It was screaming red on her computer so it was the only reason she brought it up,*

*she had to do it.” “...it was something she had to do, it was a required thing.”*

Another important issue explored was whether the consumers felt that the ISP was actually used to guide their treatment and if it matched the treatment they received. Again this varied among consumers as well as by site, although many consumers felt it was helpful for them. One trend appeared to be that consumers further along in their recovery felt that the ISP was useful more in guiding their treatment; while consumers who had difficulties with a complex issue such as finding housing appeared more frustrated. Some comments about the ISP matching their service delivery were:

- *“Yeah, he asks me how I am doing on the job. And what my goal is to do next?...”*  
*“One if my goals is to get an ID and my case manager is helping me with this.”*
- *“My case manager reminds me of the ISP”*

The consumers who did not feel that their ISP was being used to guide treatment often cited time factors as an issue:

- *Seems like they never have time for you after they get it all done..you try to work on something and they never have time for it. They skip over it...”*
- *“With my case manager she did the ISP with me and ever since then she really doesn’t seem to have time for me...she is either going out the door or going on call. She doesn’t really talk to me about it.”*

A common factor that arose across sites that was perceived as impacting the use of the ISP to guide treatment was staff turnover. Many consumers spoke of having positive

relationships with their case managers, but felt frustration with the constant turnover.

They noted excessive turnover with both case managers and psychiatrists. It appeared that there were issues with continuity of care regarding implementation of the ISP due to this turnover. For instance, at one focus group, all of the consumers reported having had a new case manager within the past month.

- *“Nope - they don’t even go by the ISP...I have had six case managers since I have been here.”*
- *“Each time I go to the doctor, the doctor has quit.” “Everybody experiences a big turnover with doctors.” “And I have had three different psychiatrists in six months.”*

It appeared that consumers who were the most satisfied reported having a strong relationship with their case managers, and felt that they were being heard. Most consumers expressed being happy with their case managers, despite their views on the ISP.

- *“I talk to mine all the time. We talk freely.” “I feel comfortable.”*
- *“They are very good at taking care of us. Attending to our needs.”*
- *I don’t have problems with my case manager, she is always there for me. She always has a good answer, suggestions, or advice.”*

In contrast, the consumers expressed more dissatisfaction with their psychiatrists and felt that their psychiatrists did not have time for them or want to listen to what they had to say. This appeared due to time factors as well as the interactive style of some of the psychiatrists.

- *“She doesn’t let you talk. She interrupts and doesn’t let you explain...She will sidetrack and go directly to what medicine to put in.”*
- *“Sometimes we get rushed.”*
- *“No, I don’t think my doctor is listening to me.”*

However, two sites spoke very highly of their psychiatrists and it is unclear if this was due to increased time allotment or simply feeling more heard by their doctor.

- *“She is excellent.” “She is very smart.”*
- *“I can relate to her...” “We can communicate pretty good with each other.”*

### **C. Changes Consumers Would Like to See in Terms of Treatment Planning**

Many consumers felt that they were generally happy with their involvement in the treatment planning. Ones who were not as satisfied reported wanting to have more input and to have more time to prepare answers to the ISP questions. Continuity of care again arose as an issue and consumers reported that decreased turnover would help facilitate increased use of the treatment plan. Another consumer suggested that the same person who completed the initial intake should complete the ISP. Others felt that having more time with the case managers and psychiatrists would be beneficial, and would help build trust with them. Others asked for more direct help from the case managers rather than being told to accomplish an objective without understanding how to do it. Again it appeared that at certain sites, consumers desired more hands-on help and guidance than they perceived they were getting.

### **Recovery and Consumer Perception**

Consumers overall felt that they had progressed in treatment and were able to give

definitions of recovery, but did not necessarily feel that their progress was due to use of their ISP. Many clients viewed recovery in terms of their medication and substance use, rather than on other domains found in the ISP.

- *“Well, personally I have a dual diagnosis and that just means I am a recovering alcoholic and that I was addicted to pain medicine and I also have a mental illness...and part of my recovery is having my medicine given to me by the week instead of by the month...”*
- *“With my diagnosis there is no recovery from that...I am trying to but I am always going to be on meds..If I was fully recovered I wouldn’t be on meds.”*

However, other consumers, especially at one site in particular, had noticeably different definitions of recovery than the other sites, and exhibited a more positive notion that people can recover from mental illness. The differences in perception of recovery may be due to the stage of progress for each consumer which tended to vary by site. For example, consumers at 2 Succeed are often functioning at a level where they are either employed or working toward employment versus other sites where the consumers may be working on initial stabilization of their mental health symptoms.

- *“Being able to accomplish things that you didn’t think you could.”*
- *“Recovery is like similar to what she said...being stable and knowing that you can move on to the next level.”*
- *“Recovery to me...striving for that goal and it means you sincerely want to get it done that way.”*

**Areas for Follow-Up:**

This qualitative study examined the consumer's point of view in terms of participation in treatment planning and areas for desired change. A necessary follow-up piece would be to speak to the case managers and get their perspective on the ISP and their view of consumer participation in the process. Although psychiatrists do not complete the ISP with the consumers, they might also have some ideas about the ISP and its current usefulness. More user-friendly electronic charting could solve the issue of consumers not consistently getting copies of their ISP by automatically printing out two copies.

However, the larger issue is whether case managers feel that the current ISP is useful in guiding treatment and if they feel changes could be made to make it more relevant for their clients.

It would also be interesting to look at the recovery markers among the consumers who participated in these focus groups to examine any differences in consumers who have only had one case manager and psychiatrist versus multiple treatment providers.

Examining recovery markers can also assess any correlation between sites and perception of their participation in treatment. The issue of turnover is common at large community mental health centers but follow-up exploration could determine if the turnover at certain MHCD sites is higher than others, and if this correlates with the results of the focus groups.

In terms of consumers at some sites not feeling they have enough time with treatment providers, follow-up exploration could look at different caseloads among sites or

different levels of severity (or type) of symptoms. For instance, two of the sites included in this study were more specific to consumers with dual diagnosis. Due to the frustration of consumers feeling “rushed” with some psychiatrists but not others, it would be useful to determine if there were different time allotments for consumers that varied by site. If not, this would point more to dynamics within the consumer/psychiatrist relationship rather than time issues. It may be helpful to explore whether nursing staff could be used to assist the psychiatrists, who are usually extremely busy, in terms of helping answer consumer’s questions about medications and side effects. Overall, the dialogue with consumers brought up several important areas for further exploration that might make the ISP more useful in terms of perceived participation and recovery:

- Dialogue with case managers regarding usefulness of current ISP and ease of electronic-charting system
- Impact of high staff turnover with case managers and psychiatrists
- Time constraints/dynamics of relationship between consumers and treatment providers
- Level of consumer’s severity of mental health issues and differences in perception of the ISP

<b>References</b>
-------------------

Krueger, R.A., & Casey, M.A. (April 2000). *Focus Groups: A Practical Guide for Applied Research* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods* (3<sup>rd</sup> Ed). Thousand Oaks, CA: Sage Publications.

Heppner, P.P., Kivlighan, Jr., D.M., & Wampold, B.E. (1992). *Research Design in Counseling*. Pacific Grove, CA: Brooks/Cole Publishing Co.

Colorado Division of Mental Health (2005). *Mental Health Statistic Improvement Program Consumer Survey* (Report)

Ware, N.C., Tugenberg, T., Dickey, B., & McHorney, C.A. (1999). An ethnographic study of the meaning of continuity of care in mental health services. *Psychiatric Services*, 50(3), 395–400. Wierzbicki, M., & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. *Professional Psychology: Research and Practice*, 23, 190—195. Winefield, H.R., Murrell, T.G, & Clifford, J. (1995). Process and outcomes in general practice consultations: Problems in defining high quality care. *Social Science & Medicine*, 41(7), 969

United States Department of Health and Human Services(2005). *Protection of Human Subjects* (Report): United States Department of Health and Human Services, Code of Federal Regulation, section 46.406(a.) (b.).