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The Relevance and Implications of Organizational Involvement for Serious Mental Illness Populations

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Consumer involvement has gained greater prominence in serious mental illness (SMI) because of the harmonious forces of new research findings, psychiatric rehabilitation, and the recovery movement. Previously conceived subdomains of consumer involvement include physical involvement, social involvement, and psychological involvement. We posit a fourth subdomain, organizational involvement. We have operationally defined organizational involvement as the involvement of mental health consumers in activities and organizations that are relevant to the mental health aspect of their identities from an individual to a systemic level across arenas relevant to mental health. This study surveyed adults with SMI regarding their current level of organizational involvement along with their preferences and beliefs about organizational involvement. Additionally, a path model was conducted to understand the relationships between domains of consumer involvement. Although participants reported wanting to be involved in identified organizational involvement activities and believing it was important to be involved in these kinds of activities, organizational involvement was low overall. The path model indicated that psychological involvement among other factors influence organizational involvement, which informed our suggestions to improve organizational involvement among people with SMI. Successful implementation must be a thoroughly consumer-centered approach creating meaningful and accessible involvement opportunities. Our study and prior studies indicate that organizational involvement and other subdomains of consumer involvement are key to the health and wellbeing of consumers, and therefore greater priority should be given to interventions aimed at increasing these essential domains.

The past three decades have witnessed a transformation in scientific understanding, clinical treatment, and social policy regarding disabling psychiatric disorders in the schizophrenia spectrum, also known by the administrative rubric of *serious mental illness* (SMI).[1] Research has refuted the traditional downward prognosis for people with SMI, which had previously assumed that possibility of recovery was doubtful. Rather, it is becoming clear that people with SMI can benefit from treatment, and many regain most or all functional ability (e.g., Harding,

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[1] In some venues, SMI and related terms have been used to denote different groups, including those who have any *Diagnostic and Statistical Manual of Mental Disorders* diagnosis. This practice undermines consistent discussion and development of social policy regarding severe and disabling disorders in the schizophrenia spectrum. Here, we use the Charlwood, Mason, Goldacre, Cleary, and Wilkinson (1999) definition of SMI, as a mental disorder designated by a mental health professional and either (a) a score of 4 (severe/very severe problem) on at least one, or a score of 3 (moderately severe problem) on at least two of the Health of the Nation Outcome Scale items excluding #5 during the previous 6 months, or (b) there must have been a significant level of service usage over the past 5 years as shown by a total of 6 months in a psychiatric ward or day hospital, or three admissions to hospital or day hospital, or 6 months of psychiatric community care involving more than one worker or the perceived need for such care if unavailable or refused.

Brooks, Ashikaga, Strauss, & Breier, 1987a, 1987b; Harding, Zubin, & Strauss, 1992; Jobe & Harrow, 2010; Stephens, 1978; Strauss & Carpenter, 1978). *Psychiatric rehabilitation* (e.g., Anthony, Buell, et al., 1972; Liberman, 2008; Spaulding, Sullivan, & Poland, 2003) has reconfigured understanding of mental illness from a disease to be cured to a disability to be overcome, and has produced an expanding array of effective clinical tools for that purpose. Parallel emergence of the *recovery movement* (e.g., Anthony, 1993; Deegan, 1988; Jacobson & Greenley, 2001) has further elucidated new goals and challenges for treatment and rehabilitation. These goals include focusing on positive sense of self, interpersonal relationships and participation in community life (e.g., Davidson & Strauss, 1992; Davidson et al., 2001), and new agendas for clinical research and social policy (Bellack, 2006).

The imperative of *involvement* is at the center of all three of these major trends (Davidson et al., 2001; Rutter, Manley, Weaver, Crawford, & Fulop, 2004). Although involvement evolved from the developmental disabilities field, it quickly became applied to other populations who experience difficulty integrating into typical communities and social networks. Most conceptualizations of involvement across populations emphasize that although physical presence in a person's desired community is important, true involvement could only be achieved through social integration, including culturally specific acceptance by community members.

Involvement has innate utility for SMI. It has a clear relationship to the imperatives of treatment modalities including psychiatric rehabilitation and consumer-led movements including recovery. Involvement focuses on increasing functioning and activity within an autonomous and empowered context. Involvement additionally prioritizes decreasing stigma and social segregation. Researchers and associated stakeholders developed *consumer involvement*, an umbrella term encompassing aspects of involvement that are most key to stakeholders and to treatment outcomes. This construct has implications across areas of interest, from advancing scientific understanding regarding resources needed to facilitate functional improvement in SMI populations to elucidating how to structure public policies so that SMI populations have the opportunity to improve involvement.

Three major aspects of consumer involvement have been identified: *physical involvement*, *social involvement,* and *psychological involvement* (Wong & Solomon, 2002). Physical involvement chiefly focuses on involvement in activities of daily living, a key aspect of independent functioning often targeted in skills training and other evidence based practices for SMI. Social involvement focuses on one-on-one and small group social interactions, which are often deficient in SMI populations because of impaired social skills and social isolation because of stigma and difficulty integrating into typical communities. Psychological involvement focuses on the subjective experience of being involved and accepted into one's chosen community, often lacking because of unstable living arrangements, isolation, and stigma. Interventions across these domains have clear treatment implications (e.g., improving skill sets) and policy implications (e.g., decreasing instability and stigma).

An essential subdomain of involvement to consider is involvement with organizations pertinent to mental health consumers. This domain, *organizational involvement*, includes involvement across levels of organization: individual aspects of organization like treatment planning and peer services, program aspects of organization like program development and evaluation, system aspects of organization like advocacy and research, and policy aspects of organization like system-level policy planning and evaluation. The fundamental premise of this sort of involvement is to prioritize and recognize consumer worth, values, and needs at the organizational level and take congruent action with consumers in active and meaningful roles. Therefore organizational involvement adds a key element to the consumer involvement paradigm by prioritizing increases in autonomy and empowerment, and decreases in stigma at the systemic level. This encompasses many of the areas of participation particularly sought after by consumers and other stakeholders promoting the recovery movement, including client involvement in treatment planning (Deegan, 2007), consumer-run organizations and peer services (Brown, Shepherd, Merkle, Wituk, & Meissen, 2008; Schutt & Rogers, 2009).

Given calls by the recovery movement to increase empowerment, autonomy, and purpose, partially via involvement-related activities (Anthony, 1993; Brown et al., 2008), it is clear that mental health consumers value consumer involvement across domains. Despite the innate connection between recovery, community-based services, and consumer involvement, there is little research on involvement, its dimensions, or their relationships with other outcomes in SMI populations. Relevant to our article, there are no studies that we are aware of that measure practical availability or consumer awareness of involvement opportunities in the United States.

The majority of scholarly interest in consumer involvement has come from Australia and New Zealand. This appears to be partially because of increased policy focus on consumer involvement in both countries. This combination of increased policy focus and scholarly interest has led to increased interventions and other studies in this area (e.g., Happell & Roper, 2009; McCann, Baird, Clark, & Lu, 2008). These studies represent the beginnings of the implementation and study of consumer involvement and how it may impact consumers and mental health service systems. In other countries, including the United States, there are less scholarly works on consumer involvement despite increased policy focus on this area. We hope that our work can begin to expand our understandings of consumer involvement in the United States as the related regulatory processes are unfolding.

The research that does exist in the United States has generally focused on peer services, including consumer-operated services and peer support specialists (Brown et al., 2008; Corrigan, 2006). Doughty and Tse's (2011) review of peer services found that the majority of peer services are operated within a traditional mental health agency, with a minority operating independently. The review generally found that consumers benefited from working with typical treatment providers and with peers, although there was considerable variation across studies. Of course, the majority of studies used quite small sample sizes and there was appreciable heterogeneity between studies, including treatment modalities. These studies indicate that peer services are a promising area of consumer involvement, but continue to require development and study to maximize effectiveness.

Although peer services are important, they represent one aspect of one domain of consumer involvement, organizational involvement. Other key aspects of organizational involvement are rarely studied and implemented in the United States. As noted previously, Australian literature has a much wider array of literature regarding consumer involvement, including academia (Happell &

Roper, 2009), mental health administration and service planning (McCann et al., 2008), and program evaluation and quality improvement (Middleton, Stanton, & Renouf, 2004).

Across countries and areas of organizational involvement, consumers tend to report feeling positively about their organizational involvement experiences. Consumers also report positively influencing those around them, including nonconsumer staff (Middleton et al., 2004). Additionally, treatment providers often report feeling positively about organizational involvement (McCann et al., 2008), and as discussed previously, there is some evidence that organizational involvement can benefit consumers. Despite this, implementation of organizational involvement remains variable at best (Gordon, 2005; Tobin, Chen, & Leathley, 2002).

Prior studies have identified an array of barriers to successful implementation of organizational involvement. Mental health systems have been slow to adjust to new policies supporting consumer involvement, and often lack the resources needed to back these new policies. Additionally, when policies are adjusted to promote consumer involvement and increase community-based care, consumers are often not involved in making these policy decisions (Middleton et al., 2004), a process that undermines the goal of the policy. Both Tobin et al. (2002) and Middleton et al. (2004) identified the need to increase the amount of information, support, and resources available to consumers for consumer involvement policies to succeed. Although treatment providers and other stakeholders do report positive feelings about involvement, they also report not wanting consumers' responsibilities or influence to infringe on their own (McCann et al., 2008) and worrying that the "wrong" kind of consumer will be more likely to take on organizational involvement roles (Happell, 2010). Therefore, although consumer involvement has been a key component of many recent policy changes, as a result of a range of barriers, associated implementation and scholarly work is still in its infancy.

The Current Study

This study seeks to further understanding of the organizational involvement subdomain of consumer involvement. In particular, we are interested in the impact that a significant set of changes to mental health policy had on the SMI population, our target sample. The major component of these changes was downsizing the state hospital system by two thirds and transferring over 30 million dollars in state funding into community-based services (Division of Behavioral Health, 2011). A specific goal of these changes was to increase community-based services and consumer involvement through a variety of avenues. These avenues included the creation of a state-operated Office of Consumer Affairs, and a focus on consumer involvement in regional advisory boards, community agencies, and public policy (Division of Behavioral Health, 2011; Nebraska Behavioral Health Service Act, 2006). Of course, these changes did not occur in isolation. There have been movements federally (e.g., Olmstead v. LC, 1999; New Freedom Commission on Mental Health, 2003) and in other states (e.g., Kano, Willging, & Rylko-Bauer, 2009) to increase community-based services and focus on consumer involvement across domains.

The particular changes in the service area targeted created a unique opportunity to survey level of involvement in a theoretically enriched environment, as well as to understand the relationship between domains of involvement and their impact on consumers. Therefore, this study captured consumer-reported levels of current organizational involvement and other subdomains of consumer involvement among people with SMI. This sample was receiving community-based services and would otherwise be at risk for institutionalization without these policy changes intended to improve involvement.

The guiding intention of this study was to better understand the relationship between dimensions of consumer involvement in this population and to guide future policy and service development. We primarily focused on breadth of consumer involvement domains, and attempted to capture all four theoretical domains: physical involvement, social involvement, psychological involvement, and organizational involvement. We measured all four domains to understand the mechanistic relationships between these domains in this population, and how other domains impact organizational involvement given policy changes. We also considered breadth of the organizational involvement domain in particular by measuring concrete levels of involvement as well as issues like consumer awareness, interest in specific activities, and values regarding involvement.

We hypothesized that organizational involvement would be low. We hypothesized that consumers would report little involvement in activities that have been made available to them through policy change via their service providers, their community, and at the state level. We additionally hypothesized that consumers would report wanting to be involved with activities that they were not currently involved in. Lastly, we hypothesized that other types of consumer involvement, and physical involvement in particular, would be significantly associated with organizational involvement.

Method

Participants

Two hundred sixty-six consumers currently attending state-funded day programs participated in the study. Consumers must be 19 or older and meet criteria for SMI to be eligible for these services. One hundred twenty-three (46.2%) of the participants were male. The average age of the participants was 44.77 (SD = 11.478). One hundred thirteen (42.5%) of the participants lived independently, and 40 (15%) reported being in a residential rehabilitation program. Fifty-eight (22.3%) of the participants reported being employed part-time or full-time, while 47 (18.5%) reported attending school part-time or full-time. Eighty-three (38.6%) of the participants reported being involved in volunteering. A more complete description of the participants' demographics is available in Table 1.

Measures

Organizational involvement was operationally defined as active involvement by mental health consumers in organizations or other systems directly related to the advocacy, planning, regulation, evaluation, or improvement of mental health services, research, or policies, impacting a spectrum of groups (i.e., from single individual to nationwide systems or groups). Based on this definition, the research team in conjunction with an advisory group consisting of mental health consumers and mental health advocates created an

Table 1. *Selected Demographic Information for Survey Participants*

Variable	*n*	%
Living status		
Living alone	113	42.5
Living with friends or relatives	77	28.9
Living in a home with 24-hr support	50	18.8
Living alone with support	10	3.8
Government-provided housing	4	1.5
Living in a shelter	2	0.8
Services currently received		
Day rehabilitation	210	78.9
Mental health counseling	161	60.5
Community support	104	39.1
Medication management	91	34.3
Residential rehabilitation	40	15.0
Vocational rehabilitation	17	6.4
Assertive community treatment	15	5.7
Highest level of education reached		
Less than high school	55	20.7
Graduated high school	97	36.5
Some college	72	27.1
2- or 4-year college grad	31	11.7
Post college education	8	3.0

organizational involvement measure tailored to activities that consumers in our target sample would be most likely to have access to. Once the organizational involvement measure was drafted, it was pilot tested among the consumer advisory group and the consumer research assistants associated with the study. The consumer advisory group members and consumer research assistants gave feedback on the measure. Their feedback was used to refine the measure before its use in data collection.

A list of seven activities was generated: being a member of an advisory committee for service providers or state agencies; developing services; evaluating services; being a member of an independent consumer action group including but not limited to the National Alliance on Mental Illness (NAMI) and the Mental Health Association (MHA); being a peer-review team member; and being involved with the state Office of Consumer Affairs (OCA), either directly or by participating in the town hall meetings offered by the OCA. Additionally, an "other" category was offered for participants to write in additional organizational involvement activities.

For each activity, participants were asked to endorse involvement across four levels. First, participants were asked whether they were aware that involvement opportunities existed for each activity, creating an *awareness of opportunities* variable. Second, participants were asked whether they had ever been invited to become involved or otherwise given an opportunity to become involved in each activity, creating an *invited to be involved* variable. Third, participants were asked whether they were involved with each of the activities, creating an *involvement* variable. Last, participants were asked whether they would like to become involved with each activity, creating a *desire to be involved* variable.

Two questions rating the importance of organization involvement were used to parse out the difference between quantitative current involvement and the value placed on organizational involvement among the target population. First, participants were asked to rate on a 5-point Likert scale how personally important it was for them to be involved in the activities listed in the survey or other similar activities, creating a *personal importance* variable. Using the same scale, participants also rated how important they believed it was for consumers in general to be involved in these types of activities, creating a *group importance* variable.

Two additional measures were used to capture the three other subdomains of consumer involvement. Participants also completed the Community Integration Questionnaire (CIQ; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) to evaluate physical and social involvement. The CIQ was initially constructed to measure community integration following brain injury, and a study comparing longitudinal scores of participants with traumatic brain injury and those with other disabling injuries suggest that the CIQ can be generalized to other populations (Corrigan & Deming, 1995). The measure has three factors, with favorable internal consistency: Cronbach's alpha equals .76 for home integration, .73 for social integration, and .84 for productivity (Willer et al., 1993).

Lastly, participants completed the Community Integration Measure (CIM; McColl, Davies, Carlson, Johnston, & Minnes, 2001) to evaluate psychological involvement. The CIM was originally constructed to measure community integration of consumers with brain injuries after they leave inpatient settings. However, researchers have used the measure successfully with SMI populations (Lloyd, Waghorn, Best, & Gemmell, 2008; Lloyd, King, & Moore, 2010). Internal consistency of the CIM among day rehabilitation users was favorable; Cronbach's alpha = .85 (Lloyd et al., 2008).

Procedure

Consumers attending community-based day programs completed surveys at 10 sites. The majority of participants (93.4%) completed the survey at their current day program; a minority of participants (6.6%) completed the survey in public libraries. Consumers were offered an incentive of a $10 gift card. In an effort to promote organizational involvement via our study, we integrated principles of participatory action methodology (Baum, MacDougall, & Smith, 2006). Specifically, mental health consumers were hired as research assistants and invited to be on the advisory committee, and therefore were integral parts of the study process. This study received ethical approval from the Institutional Review Board at the University of Nebraska–Lincoln.

Data Analysis

To understand participants' current level of consumer involvement in the eight categories of organizational involvement activities used in the survey, first a total score of involvement was calculated for each participant for each of the four levels of involvement. Participants could have a total score ranging from 0 (if they checked "none of the above") to 8 (if they checked all of the activities) in each of the following categories: being aware of the activity (awareness of opportunities), being invited to be involved (invited to be involved), being involved in the activity (involvement), and wanting to be involved (desire to be involved). These totals were averaged across all participants. Additionally,

participants were asked how important they thought it was for them personally to be involved in these types of activities (personal importance), as well as how important it was for consumers as a whole to be involved (group importance). These totals were also averaged across all participants.

A path model using Mplus (Muthén & Muthén, 1998–2011) under robust maximum likelihood with Montecarlo integration was used to understand the mechanisms between three consumer involvement domains (psychological involvement, social involvement, and two physical involvement subdomains, productivity and home integration) and how they impact organizational involvement. This model was chosen to understand the relationships between different domains of consumer involvement, particularly in a theoretically enriched environment. Given the recent policy changes, we would expect that not only would organizational involvement increase, but other areas would as well. For instance, physical involvement should increase because of higher use of community-based services rather than inpatient services.

We hypothesized that feelings about involvement and community (e.g., psychological involvement) was a necessary precursor to involvement activities (e.g., social involvement), and therefore placed the former constructs at higher levels in the model. Additionally, we hypothesized that individual-level involvement (e.g., social involvement) was a precursor to system-level involvement (i.e., organizational involvement), and therefore again placed the former constructs at higher levels in the model.

Specifically, psychological involvement was used as a Level 1 effect to contextualize overarching beliefs about involvement, while physical involvement, social involvement, and organizational involvement beliefs were used as Level 2 effects to model daily involvement behaviors and beliefs. The four levels of organizational involvement were used as outcome variables. Robust maximum likelihood was used to account for non-normality and missing items, and Montecarlo integration was used to estimate categorical variables. The Auxiliary command was used to model a pattern of missingness using education level because some participants had difficulty during data collection caused by reading ability. The Model Constraint command was used to model the indirect effects.

Results

Reported Organizational Involvement

Overall, consumer involvement was low. The average amount of awareness of opportunities was 1.02, indicating that each participant was aware of approximately one of the eight involvement activities. The average amount of invited to be involved was 0.84, indicating that for every six participants, approximately five invitations to an involvement activity were reported. The average amount of involvement was 0.71, indicating that for every seven participants, involvement in approximately five activities was reported. The average amount of desire to be involved was 1.09, indicating that each participant wanted to be involved with about one of the eight involvement activities. Because of a lack of previous norms or other parameters, it was not possible to understand these results in greater context. Please see Figure 1 for a visual depiction of these results.

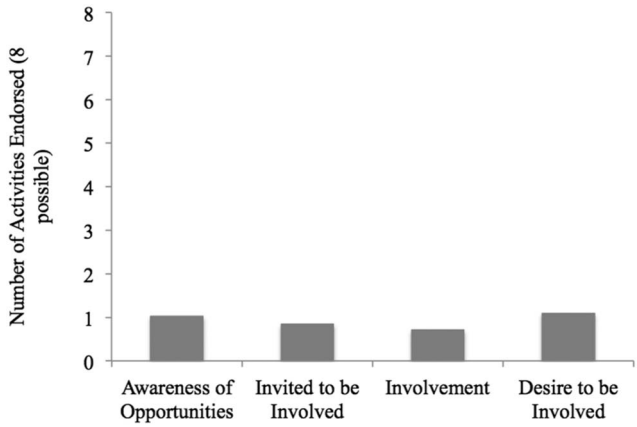

Figure 1. Visual depiction of average amount of involvement across intensities of involvement.

The amount of value participants placed on consumer involvement was high. The average amount of personal importance was 3.44 on a Likert scale from 1 (*not at all important*) to 5 (*extremely important*). The average amount of group importance was 3.84, measured on the same scale as personal importance. There was no difference between value placed on personal importance and group importance. Again, as there is no previous research in this area or using this measure, it is unclear whether these results are typical. Please see Figure 2 for a visual depiction of these results.

Comparisons Between Levels and Types of Organizational Involvement

There were no differences between types of organizational involvement. That is, participants did not report being more or less aware of opportunities than they were involved, and the same was true for all of the other possible comparisons. Table 2 is the covariance matrix between these variables. To understand these results further, each category of involvement was broken down by activity (see Table 3) and *t* test analyses were conducted to determine differences between participants' level of involvement by type of activity.

When comparing desire to be involved and involvement, more participants reported desiring to be involved in advisory committees, $t(251) = -3.042$, $p = .003$, service evaluation opportunities, $t(251) = -1.999$, $p = .047$, peer review teams, $t(251) = -3.761$, $p < .0001$, the OCA, $t(251) = -2.782$, $p = .006$, and service development opportunities, $t(251) = -4.731$, $p < .0001$ than reported being involved in those activities. Participants were more likely to want to be involved in these five activities than actually being involved in them.

When comparing desire to be involved and invited to be involved, more participants reported desiring to be involved in peer review teams, $t(251) = -2.815$, $p = .005$, the OCA, $t(251) = -3.331$, $p = .001$, and service development opportunities, $t(251) = -2.941$, $p = .004$ than reported being invited to be involved in those activities. Participants were more likely to want to be involved in these three activities than were invited to be involved with them.

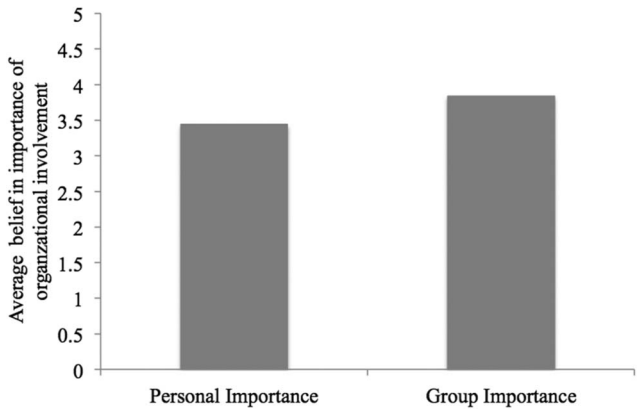

Figure 2. Visual depiction of average amount of beliefs regarding importance of organizational involvement.

When comparing desire to be involved and awareness of opportunities, more participants reported desiring to be involved in the OCA, $t(251) = -2.056$, $p = .041$ and service development opportunities, $t(251) = -2.453$, $p = .015$ than reported being aware of opportunities. Participants were more likely to want to be involved in these two activities than were previously aware that the activities existed.

When comparing involvement and invited to be involved, more participants reported being invited to be involved in advisory committees, $t(255) = 2.356$, $p = .019$, service development activities, $t(255) = 1.975$, $p = .049$, and independent consumer action groups, $t(255) = 3.768$, $p < .0001$ than reported being involved in those activities. Participants were more likely to have received an invitation to be involved in these three activities than were actually involved in them.

When comparing *involvement* and awareness of opportunities, more participants reported being *aware* of advisory committees, $t(254) = 3.529$, $p < .0001$, service evaluation activities, $t(254) = 4.364$, $p < .0001$, service development activities, $t(254) = 2.132$, $p = .034$, and independent consumer action groups, $t(254) = 3.744$, $p < .0001$ than reported being *involved* in those activities. Participants were more likely to be aware of these four activities than were actually involved in them.

When comparing invited to be involved and awareness of opportunities, more participants reported being *aware* of service evaluation activities, $t(254) = 2.748$, $p = .006$ and peer review team activities, $t(254) = 2.528$, $p = .012$ than reported being invited to be involved in those activities. Participants were more likely to be aware of these two activities than were invited to be involved in them.

There were no differences across levels of involvement for either town hall meetings or the "other" category, likely caused by the particularly low endorsement of those categories across levels.

These results showed that organizational involvement was low overall among our sample, although participants reported that organizational involvement is important to them. The results additionally showed some variability among levels and activities measured.

Path Model of Subdomains of Consumer Involvement on Current Organizational Involvement

To understand the mechanistic relationships between consumer involvement domains and how those domains impact organizational involvement, a path analysis was conducted. Figure 3 is a visual depiction of the final model.

First, analyses considering the effect of psychological involvement on Level 2 predictors found that psychological involvement significantly predicted social involvement ($\beta = .100$, $t = 3.861$, $p < .001$), home integration ($\beta = .112$, $t = 2.922$, $p = .003$), personal importance ($\beta = .627$, $t = 3.973$, $p < .001$) and group importance ($\beta = .781$, $t = 4.828$, $p < .001$).

Second, analyses considering the effect of psychological involvement on levels of organizational involvement found that psychological involvement did not directly significantly predict any level of organizational involvement, $p > .05$ for all analyses.

Third, analyses considering the effect of Level 2 predictors on levels of organizational involvement found several significant effects. Group importance ($\beta = .177$, $t = 32.280$, $p = .023$) significantly predicted awareness of opportunities. Social involvement ($\beta = .355$, $t = 1.990$, $p = .047$) and group importance ($\beta = .177$, $t = 2.642$, $p = .008$) significantly predicted invited to be involved. Personal importance ($\beta = .162$, $t = 2.350$, $p = .019$) significantly predicted involvement. Productivity ($\beta = .358$, $t = 2.008$, $p = .045$), group importance ($\beta = .271$, $t = 3.513$, $p < .001$) and personal importance ($\beta = .191$, $t = 2.469$, $p = .014$) significantly predicted desire to be involved.

Finally, analyses considering the indirect effect of *psychological involvement* on levels of organizational involvement via Level 2 effects found five significant effects. Psychological involvement had an indirect effect on levels of awareness of opportunities ($\beta = .138$, $t = 21.973$, $p = .049$), invited to be involved ($\beta = .138$, $t = 2.214$, $p = .027$), and desire to be involved ($\beta = .212$, $t = 2.669$, $p = .008$) via ***group importance.*** Additionally, psychological involvement had an indirect effect on involvement ($\beta = .102$, $t =$

Table 2. *Covariance Matrix of Levels of Involvement*

	Awareness of opportunities	Invited to be involved	Involvement	Desire to be involved
Awareness of opportunities	1.899	.921	.784	.575
Invited to be involved	.921	1.353	.878	.564
Involvement	.784	.878	1.256	.704
Desire to be involved	.575	.564	.704	2.464

Table 3. *Participants Endorsing Levels of Organizational Involvement by Activity*

Awareness	Advising committee	21.4%	Invited	Advising committee	18.4%
	Evaluation	25.2%		Evaluation	18.4%
	Peer review team	10.5%		Peer review team	7.5%
	OCA	4.5%		OCA	2.6%
	Service development	10.5%		Service development	9.6%
	Town hall meetings	5.6%		Town hall meetings	4.1%
	Independent consumer action groups	16.2%		Independent Consumer Action Groups	15.4%
	Other	3.4%		Other	2.6%
Involvement	Advising committee	13.5%	Desire	Advising committee	22.2%
	Evaluation	15.4%		Evaluation	21.8%
	Peer review team	5.6%		Peer review team	13.9%
	OCA	3.4%		OCA	8.6%
	Service development	6.4%		Service development	16.9%
	Town hall meetings	3.8%		Town hall meetings	5.3%
	Independent consumer action groups	8.6%		Independent consumer action groups	12.8%
	Other	3.4%		Other	3.8%

Note. OCA = Office of Consumer Affairs, which is state-run.

2.087, $p = .037$), and desire to be involved ($\beta = .120$, $t = 2.130$, $p = .033$) via personal importance.

Discussion

The primary hypothesis of this study was supported. We found that organizational involvement among the sample was low, despite recent state legislative changes that increased the availability and funding for consumer involvement activities.

Additionally, our second hypothesis was generally supported. The sample reported wanting to be involved with several organizational involvement activities at higher rates than they were currently involved. Additionally, they reported believing this type of involvement was important for themselves and consumers as a whole.

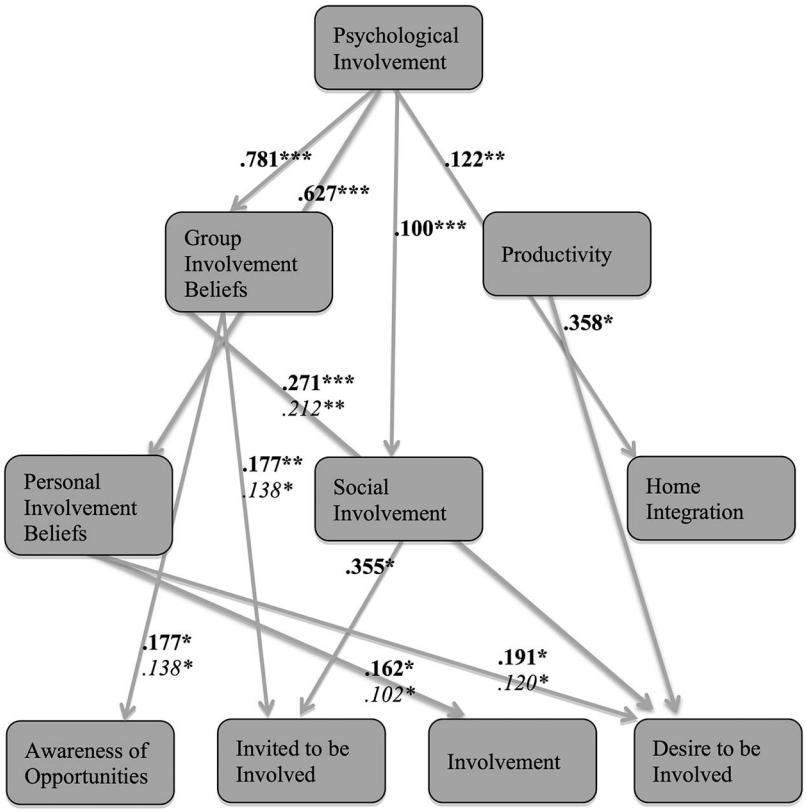

Figure 3. Diagram of path analysis modeling direct and indirect effects of consumer involvement domains and organizational involvement beliefs on levels of organizational involvement. Direct effects are bolded and indirect effects are italicized. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Lastly, our third hypothesis was not supported. Although one subdomain of physical involvement, *productivity,* did predict one subdomain of organizational involvement, desire to be involved, overall psychological involvement and beliefs about involvement were the greatest influences on levels of organizational involvement.

A major finding of this study is that there is a gap between preferred involvement and actual involvement. It is unclear whether the level of organizational involvement reported in this study is normative, because it is the first study of its kind that we are aware of in the United States. Future studies in this area will be able to collate data on this so that we can understand typical levels of organizational involvement and monitor changes as related legislation progresses. However, these results are unsurprising given documented difficulties implementing consumer involvement legislation internationally (Gordon, 2005; Kano et al., 2009). Understanding why organizational involvement is low, despite legislative initiatives and consumer desire for involvement, is central to closing this gap.

The findings of the path model and analyses conducted in this study, as well as previous findings, may hold some of the answers. Opposed to our hypothesis, we found that levels of organizational involvement were impacted most predominantly by organizational involvement beliefs, and indirectly by psychological involvement via organizational involvement beliefs. We may have been incorrect in our hypothesis, and higher order factors like psychological involvement more significantly impact organizational involvement. It is also possible that the CIQ does not measure key areas of physical involvement in for SMI populations, or that the variability in our sample was not large enough to detect effects. However, given the respectable effect sizes found in our model, the latter possibility appears unlikely.

This suggests that at present, feelings of community and belonging, and a desire to contribute to that community, are the most salient predictors of organizational involvement. It is unsurprising, then, that organizational involvement has remained low despite opportunities to become involved being set in place by the state. If psychological involvement is a critical factor to organizational involvement, then the number of significant barriers to psychological involvement in mental health service and policy sectors is likely to inhibit the impact of tangible legislative changes.

Tokenism, lack of respect for consumer involvement, and stigma have been identified as major barriers to consumer involvement (Gordon, 2005; Happell, 2010; Jacobson & Curtis, 2000; Lammers & Happell, 2003; Linhorst, Eckert, & Hamilton, 2005; Middleton et al., 2004; Tobin et al., 2002). In practice, these are overlapping mechanisms that prevent authentic opportunities for involvement. When consumer positions are created solely to adhere to a regulation, (e.g., Middleton et al., 2004) it is unlikely this position will contribute meaningfully. When consumers feel like they cannot speak up in their positions for fear of retribution (e.g., Linhorst et al., 2005), or that when they do, their opinions are dismissed (e.g., Lammers & Happell, 2003), it is likely they will contribute less and less. When administrators and providers are cynical of consumer intent (Happell, 2010), and seek to include only the "right" sorts of consumers, it is likely that representation will not be achieved and the status quo will continue.

In all of these cases there is an error in the implementation of consumer involvement. The foundation has not been laid. Consumer involvement cannot be created in a vacuum; it is not merely a position or an activity but an approach. One of the major reasons for the success noted in Happell and Roper's (2009) case study on creating a consumer academic position is the fundamentally consumer-oriented approach the team took in creating and tailoring the position. This created a position that attended to consumer preferences and was supported and integrated with the rest of the staff, and yet provided autonomy to the position, preventing tokenism.

In many cases (e.g., Middleton et al., 2004), positions and activities are created without attention to the rest of the agency. They do not attempt to fill a needed service gap or integrate with other staff. They do not grant the consumers involved significant influence. There is no reason to believe that consumers would feel like they belong in such an environment—it has not yet been made welcoming to them. Our findings suggest, intuitively, that greater community change is needed to successfully implement consumer involvement.

We cannot ignore the possible impact of concrete barriers. There was an indication of these kinds of barriers by the significant variability in organizational involvement across activities. For two of the activities, consumers reported wanting to be involved with the activity at higher rates than they reported being aware of the activity. Additionally, in some cases consumers reported being invited to become involved at higher rates than they reported being involved. For instance, although consumers were invited to become involved in developing services at higher rates than they reported currently being involved, a significant number of consumers who had not been invited reported wanting to be involved.

These findings suggest that a primary barrier to organizational involvement may be simply knowing that activities exist and how to access specific activities of interest. Accessibility may hinder involvement among those who are interested in becoming involved, and consumers who value specific consumer involvement activities may not be the consumers targeted to become involved in those activities for a variety of reasons. Although it is unknown what the cause of these gaps are in our study, past literature has also found that lack of knowledge about consumer involvement activities (Tobin et al., 2002), accessibility, and inclusive consumer targeting (Happell, 2010) inhibits involvement.

Overall, this study indicates that although some progress has been made toward implementing needed consumer involvement initiatives in the United States, there are still considerable barriers. Fortunately, there is potential to increase organizational involvement by increasing psychological involvement and beliefs about organizational involvement. Ultimately, these two latter constructs are likely to be two sides of the same coin as indicated by our path analysis. As consumers' feelings of belonging to and acceptance by the community increases, their feelings of wanting to contribute to that community will also increase. Creating the kinds of communities that encourage psychological involvement by deliberate action, increased autonomy, and use of antistigma and prorecovery movement psychoeducation is important on its own. It will also promote organizational involvement by increasing beliefs about the importance of contributing to those communities and empowering consumers to believe that their contributions are possible and beneficial. Organizational involvement initiatives must walk the consumer involvement talk, though, and create communities that

truly are inclusive to consumers and positions that enable meaningful contribution by consumers.

Limitations

This study considered aspects of consumer involvement from a perspective not yet considered in the literature. While we believe that this has yielded interesting and important results, it also necessitated the use of imperfect methodology. We used a newly created survey to measure organizational involvement because there was no scale for this aspect of involvement, and we wanted to tailor the activities to our sample as much as possible. However, this limits the replicability of our study. Additionally, as there are no known parameters to compare our finding by, it is unclear how typical these findings are. This study can at minimum set parameters for SMI populations for future research to compare to.

A minority of participants reported confusion and unfamiliarity about some of the terms we used for our activities. As we were measuring familiarity with these activities, we believe that the results are still valid, although an activity like "program evaluation" may be called different things across programs.

Additionally, we focused specifically on one population, which limits the generalizability of our study. There was low variability in some measures, particularly levels of involvement and the productivity subdomain of physical involvement. We believe that this is characteristic of this population at this time, but also limits the ability to model impacts in a wider range of involvement. We did not use objective or secondary information to confirm consumers' reports of involvement. We did not take into account the impact of factors such as symptom severity, functionality, or court or other legal involvement on the ability to be involved.

In future studies, a wider array of involvement measures would be useful to understand the impact of involvement across areas of involvement. Measures could include both locally tailored as well as generally applicable items. An interview may be a better fit for a population such as this, which includes a large percentage of illiterate or minimally literate participants.

Conclusions

Although initiatives to increase consumer involvement were implemented, thus far the implementation has been unsuccessful. Levels of involvement in organizational involvement activities associated with these initiatives are low despite the value consumers place upon them. We argue that it is not enough to merely create organizational involvement opportunities; the structure of the system must change in congruence. By simultaneously tackling the two types of barriers identified in this article, namely, inadequate approach to implementation and concrete barriers, we believe that implementation of consumer involvement can improve. Ultimately, implementation must be meaningful, holistic, and accessible.

Keywords: consumer involvement; organizational involvement; mental health policy; serious mental illness; recovery movement

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