



January 2006

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Recommended Citation

Wong, Y. I., Metzendorf, D., & Min, S. (2006). Neighborhood Experiences and Community Integration: Perspectives from Mental Health Consumers and Providers. Retrieved from http://repository.upenn.edu/spp_papers/40

Reprinted from *Social Work in Mental Health*, Volume 4, Issue 3, 2006, pages 45-59.

Publisher URL: <http://www.haworthpress.com>

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Abstract

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Keywords

Community integration, community residential programs, focus groups, persons with psychiatric disabilities

Comments

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Neighborhood Experiences and Community Integration: Perspectives from Mental Health Consumers and Providers

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ABSTRACT. This exploratory study examines the social interactional aspect of community integration among persons with psychiatric disabilities. Six focus groups were conducted with 18 mental health consumers in three publicly sponsored community residential programs and 11 staff members providing services to these consumers. Mental health consumers reported both positive and negative experiences in their interactions with community residents. Despite perceived differences between persons with psychiatric disabilities and their neighbors, consumers considered reciprocity and mutual accommodation to be critical for building social relationships in their communities. Mental health providers suggested that

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The authors express their gratitude to Dr. Ram Cnaan for his helpful comments and suggestions.

A National Institute of Mental Health grant to the University of Pennsylvania Social Work Mental Health Research Center (R24 MH 57239) provided support for the research leading to this paper.

Social Work in Mental Health, Vol. 4(3) 2006
Available online at <http://www.haworthpress.com/web/SWMH>
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doi:10.1300/J200v04n03_03

social integration can be facilitated by developing independent living and social skills, by overcoming self-stigma and institutional and homeless mindsets, and by having a supportive community of consumers. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2006 by The Haworth Press, Inc. All rights reserved.]*

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Central to the notion of community integration is the parity between persons with psychiatric disabilities and their non-disabled neighbors as equal members of the community. The goal of community integration includes the engagement of persons with psychiatric disabilities in social interactions that take place within normative settings (Wolfensberger & Thomas, 1983) and equal access to community resources, and social and economic opportunities that are accorded to other members of society (Aubry & Myner, 1996; Prince & Prince, 2002). An integrated community is envisaged as an inclusive and accepting community, characterized by the non-discriminatory treatment of persons with psychiatric disabilities and other marginalized populations (Taylor, Biklen, & Knoll, 1987).

With the closure and downsizing of public psychiatric hospitals in the past several decades, most patients with persistent and serious psychiatric problems are living in the community on a long-term basis. In response to the deinstitutionalization movement, local communities across the United States have developed an array of community-based residential programs to meet the housing and service needs of mental health patients. These programs vary from congregate residential settings with high levels of on-site staff supervision to scattered-site apartments with outreach support services offered to mental health consumers “in vivo” and on an “as needed” basis. Regardless of the level of support provided, community integration is considered an important goal of community residential programs. It has been assumed that given adequate housing and appropriate supports suited to their mental health status and service needs, persons with psychiatric disabilities can assume roles and lifestyles as participating members in their communities.

Although community residence has become a reality for individuals with long-term mental health problems, there is insufficient evidence

regarding the relationship between increased interactions between mental health consumers and members of the general public and community integration. Research on community attitudes towards residents of congregate residential programs has suggested that while community opposition may be intense during the planning and development phase of a community residential program, adversarial attitudes toward mental health residents often change to one of acceptance and receptivity after the program is established in a neighborhood (Arens, 1993; Wahl, 1993). There is also some evidence that levels of community acceptance may vary according to the type of residential setting and individual characteristics of mental health consumers. Research has shown that living in a specialized housing program such as a group home could create barriers to community integration, whereas more community acceptance is afforded to mental health consumers who are living in apartments (Aubry, Tefft, & Currie, 1995a; Cheung, 1990; Wenocur & Belcher, 1990). The severity of psychiatric illness and the extent of behavioral disturbance exhibited by mental health residents have also been found to be strong predictors of community acceptance (Aubry, Tefft, & Currie, 1995b; Ingamells, Goodwin, & John, 1996).

While prior research has examined consumer, program, and community characteristics that are associated with community integration (Flynn & Aubry, 1999; Kruzich, 1985; Nelson, Hall, Squire, & Walsh-Bowers, 1992; Segal & Aviram, 1978; Segal, Baumohl & Moyles, 1980), there are few published, firsthand accounts of social interactions between mental health consumers and community residents and how consumers perceive such interactions (Boydell, Gladstone, Crawford, & Trainor, 1999). The body of research on community integration has focused largely on the physical presence of mental health consumers in the community—that is, on use of goods, resources and services and on participation in community activities (Wong & Solomon, 2002). Few studies to date have examined the social relationship of mental health consumers with their neighbors. Understanding the social interactional aspect of community integration (that is, social integration) requires knowledge about the contexts where interactions take place, and about the nature and quality of relationships between persons with psychiatric disabilities and their neighbors (Angell, 2003).

The exploratory study reported in this paper examines the social interactional aspect of community integration among individuals with psychiatric disabilities through the lens of mental health consumers and their providers. Drawing from narratives derived from focus groups, conducted respectively with residents and providers of community

residential programs varying in housing setting and the intensity of staff supervision, this paper intends to address the following questions: (1) What is it like for persons with psychiatric disabilities to interact with community residents? (2) What promotes or impedes social interaction between mental health residents and community residents? In exploring the views of providers in addition to those of consumers, and in using the method of focus groups, this study intends to identify factors that are critical for facilitating community membership of mental health consumers.

METHODS

Participants and Sites

This study included 18 individuals with psychiatric disabilities living in three different community residential settings in a major metropolitan area and 11 mental health staff members providing services to these individuals. The criteria for admission to community residential programs included: (1) a primary Axis I diagnosis of major mental illness (schizophrenia or major affective disorder); (2) residence in the city for six months preceding the residential placement, exclusive of any institutionalization; and (3) age 18 years or above.

Four consumers and three staff members were recruited from a semi-independent housing program with 7-day, 24-hour support from staff on-site. Consumers in this program lived with a roommate and shared household responsibilities with other program residents in the same house that accommodated 6 mental health consumers. Seven consumers and five staff members were recruited from a supported independent living (SIL) program designed to provide off-site, flexible and variable supports to allow consumers to maintain residence in their own homes. Consumers in the SIL program lived in subsidized apartments scattered in different parts of the city. Seven consumers and three providers were recruited from a transitional housing program aimed at promoting independent living and housing stability among homeless persons with major mental illness. Residents lived in scattered apartments located in a low-density rental community with program staff on-site during the daytime and some evening hours.

One-third of the consumer sample was male, and two-thirds was female. Average age was 43 years and 12 out of 18 participants were of African American descent. About 60 percent had either a high school diploma or

some college education and one-third of the sample was employed. Participants had resided in their current residence for an average of 45 months with housing tenure varying widely across three programs: 93 months for the semi-independent housing program, 50 months for the SIL program, and 12 months for the transitional housing program.

Most of the provider participants were female and were of African American descent. Providers were on average 6 years younger than consumers. Six providers had a college degree and three had some college education. Providers had worked in the residential programs for an average of 33 months, and in the mental health field for an average of 7 years.

Recruitment and Data Collection

Consumers were recruited either by direct mailing or through indirect contact via residential staff. Upon receipt of information about the focus groups, potential participants expressed their interest in the study either by calling the research team or by filling out a consent form. The research team invited residential staff to participate in the provider focus groups. All six focus groups were conducted with providers and consumers within the same program.

Methodological discussion has pointed out the desirability to have focus group members to be strangers before the discussion in order to avoid the reluctance among members to share information and opinion on embarrassing and controversial topics, and to facilitate diverse thinking (Fuller, Edwards, Vorakitphokatorn, & Sermsri, 1993; Morgan, 1988). The recruitment of all members of a given group from the same program deviates from this principle. However, protocols employed by residential programs regarding consumer rights to confidentiality and privacy make it infeasible to recruit group members from a mix of programs. It is worth noting that our discussion topics did not involve legal, moral, or taboo topics, which participants might have found reluctant to share among acquaintances.

The groups were conducted by two of the authors. All except one focus group lasted approximately one and one-half hours. The consumer group with the semi-independent housing program lasted for 45 minutes because of apparent fatigue among participants. All sessions were audiotaped and transcribed verbatim.

Data Analysis

All transcripts were reviewed independently by at least two authors and thematic codes corresponding to text units were developed. The-

matic codes and text units were then collected, distributed, and compared to come up with a common framework for analysis. The transcripts were then re-read, re-coded and re-checked by at least two authors following the key codes in the analytical framework. The text units for each of the coding categories were compiled and examined for common themes related to consumers' neighborhood experience and providers' perception of community integration.

Limitations of the Study

The exploratory nature of this study, utilization of a small and self-selected sample, and the restriction of the study to a few publicly-funded community residential programs in one geographic location limits the generalizability of this study. It is not known whether the nature and quality of social interactions with community residents would be similar for persons with psychiatric disabilities living in other housing settings, and in other communities.

RESULTS

Consumer Focus Groups: Interacting with Neighbors as Lived Experiences

Consumers participating in the focus groups gave examples about the circumstances upon which social interactions with community residents took place. Consumers waved "hello" to their neighbors when going out to work or to attend a treatment program, spoke with neighbors at bus stops and local stores, invited neighbors to their homes, attended town watch meetings, initiated a neighborhood clean-up campaign, and discussed with their neighbors about building and neighborhood issues. From the consumer focus group narratives, three themes associated with social integration emerged.

Theme I: "Good" and "Bad" Neighbors in Neighboring Acts

Consumer participants reported both positive and negative experiences in their encounters with community residents. Good neighbors were portrayed as those who showed consumers respect and who looked out for each other. One consumer noted that her neighbors were very courteous and respectful to her by clearing the street of dogs when-

ever she went out of her apartment. Neighboring acts of “looking out” for each other included collecting mails and packages when consumers were out of town, calling on each other when the smoke detector in the building went off, and exchanging phone numbers and other small favors.

Complaints about “bad” neighbors centered on noise, boundary crossing (bothersome neighbors), and the expression of hostility when resolving neighborhood issues. Consumers gave examples of bad neighbors who screamed, yelled, and stomped in the middle of the night, who asked for spring water daily for their kids’ experiments at school, and who made threatening remarks because of a creaking floor in a consumer’s apartment.

Reciprocity in social relationships was a theme reflected in consumers’ accounts of encounters with good neighbors as well as bad neighbors. In contrast to the stereotypic view of persons with psychiatric disabilities as passive and reactive, some consumers took a proactive approach in interacting with community residents, even in circumstances involving disputes and conflicts. The following two excerpts reflect consumers’ understanding of reciprocity in social relationships.

Now, in my building, when a package is delivered to me, I tell my neighbors to get them. Everybody in my building knows I get packages. They all will take my packages when they see them at the door, and when they see me come in they’ll call me that they have my package because they know when I come in, I’ll go off in the building and tell them all about their packages.

Once he (neighbor) told me my music was loud, so I told him I would turn it down, you know, being the kind of person that I am. I told him not to take my kindness for granted, and he was like, “Yeah, whatever. Don’t make me have to come down again.”

Theme II: Experience of and Response to Social Rejection and Labeling

Participants shared their experience of social rejection during focus group discussion. Not surprisingly, social rejection was reported in situations where there was high visibility of mental health consumers. The following quote illustrates the experience of rejection when a consumer attended a town watch meeting in a neighborhood with high level of clus-

tering of mental health consumers and members of other stigmatized populations.

I went to the meeting, and I got told to my face, “What are you doing at this meeting? You’re not a homeowner . . . You live in the building where those crazy people are.”

While consumers were cognizant of the devalued labels associated with individuals with psychiatric disabilities, there were differences in how they responded to such labels. Several consumers mentioned the use of “passing strategies,” including blending in, being invisible, and minding one’s own business (Boydell et al., 1999; Link, Cullen, Struening, & Shrout, 1989; Walker & Seasons, 2002). Others expressed their belief in community acceptance despite their neighbors’ knowledge of their mental health status. The following narratives illustrate two contrasting responses to social rejection.

I kind of mind my business, and keep going because . . . I remember when I didn’t have anywhere to live, so I just mind my business, and as long as it’s not bothering me directly, they’re not bothering me so I mind my own business.

People just are not going to give you an attitude because you are sick or anything. If people like you, they like you. If they are going to speak to you, they are going to speak to you.

Theme III: Being a Part of the Community—Perceiving Differences, Appreciating Diversity, and Understanding Mutual Accommodation

In spite of reported incidence of social rejection, study participants generally expressed satisfaction of living in the community amid members of the general public. They also noted differences between themselves as mental health residents and community residents. For example, one focus group member described her community as comprising both “sick” and “non-sick” people, and acknowledged that even “non-sick” people have their own share of problems. Other differences mentioned included age and family status (“She is 18 and has kids, I am 38 and don’t have kids”), nationality (“it’s like the United Nations in here”) and economic status (“they have nice cars,” “they wear nice clothes,” and “those people pay the rent”).

While recognizing these differences, consumers also expressed an appreciation of what a diverse community could offer in the process of reintegrating into society. One study participant specifically pointed out the advantage of living in a multicultural neighborhood:

And I look at the fact too, that by it being different cultures of people, it gives you a chance to see things that I ordinarily would not see if I wasn't there because you've got people from all different nationalities, and you do learn about certain cultures and what people do in their culture.

Given the differences and diversity, some participants expressed the view that being a part of the community involves mutual accommodation between mental health residents and their neighbors. As one participant pointed out, "They (community residents) have to adjust, just like we have to adjust to them." In this regard, consumers were optimistic that with time and patience, community residents would accept them. The following excerpt illustrates how acceptance and mutual accommodation evolved between a consumer in the SIL program and her housing manager.

For me, at first (housing manager) wouldn't deal with me because she thought that I couldn't tell the difference between life and death. Or, I couldn't identify what the problem was because I was too far out there. But, when she came to realize where my level was she understood, "Oh, she has it all with her. She might have a little problem, but she has it all under control. She knows what she's talking about." Now, it's like when I deal with her, she sees me on a normal level as a normal person and says, "OK, I'll take care of it, no problem."

Provider Focus Groups: Community Integration as a Process

Providers elicited different roles they played in promoting community integration of mental health residents. These roles included: escorting consumers when they were "invited into things from the community"; acting as "a kind of security blanket" so that consumers could talk about their "outside" experience; assuring consumers that they "are just as normal as the next person except for they may have to take medication or see a therapist"; and acting as mediators in resolving disputes between consumers and their neighbors.

Providers conceived community integration as a process involving building independent living and social skills, as well as overcoming various psychological barriers. They also recognized the value of developing a community of consumers as a means for facilitating community integration. In the following, we elaborate these three themes as they emerged from the focus group discussion among providers.

Theme I: Community Integration as a Process of Learning Skills in Order to Adapt to Their Neighbors

Providers perceived community integration as a process to be achieved through building skills that consumers need in order to become independent. The relationship between skills building and community integration is captured in the following excerpt:

. . . community integration is sort of a by-product of working on the skills you need to be independent and once they get comfortable, community integration sort of becomes natural; it is easier for them to do.

Providers pointed out the social skills deficits among consumers of mental health services. As one participant noted, “(Consumers’) same social skills and the way they behave and interact with each other and the people out in the public is different than what would be acceptable from normal people.” To overcome social skills deficits, providers stressed the importance of providing support to enable consumers to interact in a normalized setting. As one provider commented, “The basic etiquette is to learn how to treat your neighbor and how to live next to someone who may not be in the same situation that you are.”

The development of independent living skills and social skills is critical as mental health residents move on to an independent housing situation in which staff support is less intensive. Consistent with the findings in the consumer focus groups on diversity and difference, providers stressed the importance for mental health residents to adapt to their neighbors from different backgrounds and cultures. Providers also noted that mental health consumers and their neighbors were mutually accommodating of each other.

Theme II: Community Integration as a Process of Overcoming Self-Stigma, Institutionalized Mindset, and Homeless Mindset

Whereas consumers told about their experiences with social rejection, providers considered self-stigma the chief culprit impeding integration. As one provider expressed, “because of what traditionally has been associated as a stigma on people with disabilities that they take that on themselves, so there is some fear about going outside of what seems safe because they don’t know what to expect.”

Providers attributed consumers’ reluctance to engage in social relationships to suspicions over community residents’ knowledge about their illness and hypersensitivity toward how they were being perceived by the general public. A case in point was made regarding the internal attrition style adopted by mental health residents in response to rude receptionists. Whereas the typical response among the general public would either be ignoring the receptionists or reporting to their supervisors, consumers were more likely to perceive the rudeness as directed to them as a person, thinking that the receptionists “are rude to me because of the way I am.”

Besides self-stigma, providers identified two other psychological barriers—institutionalized mindset and homeless mindset. One provider noted that learning to be “members of the community” is a long process involving “baby steps of not functioning from an institutionalized mentality but more learning to conform more to family structure, friend structure as opposed to the institution way.”

The homeless mindset was identified as another reason for consumers’ lack of success in acclimating into the community. Characteristics of the homeless mindset included the lack of trust in and resistance to authority. As one provider illustrated when referring to mental health residents with a history of homelessness:

They have had to fend for themselves, they have been out there and it is a lack of trust. So, those are the walls and you survive by not trusting people. Those are the walls you come up against when you are working with people and trying to put things in place.

Theme III: Developing a Community of Consumers as a “Safety Net” in the Process of Integration

Segal and Aviram (1978) made a conceptual distinction between internal integration and external integration. Internal integration refers to

the extent to which a mental health consumer's life is centered around and mediated by the community residential program. External integration refers to integration with the community outside of the program. Providers in this study emphasized the importance of inculcating internal integration within the residential program to provide a safety net for supporting consumers' efforts to venture out into the community. As one provider observed:

I think it is helpful for them (mental health residents) to come back and talk about outside of the complex experiences that they can get feedback from people who are going through similar things that they do. I think it sort of works as a balance, even when they integrate out there; they need to maintain some sort of connections somewhere, some sort of support group, some sort of group of friends that has gone through what they go through.

DISCUSSION

The findings in this study suggest that the neighborhood experiences of mental health consumers were not untypical of those of the general population. Like members of the general public, mental health residents had social interactions with community residents in a variety of settings, and experienced social encounters with good as well as bad neighbors. While our study cannot be taken as providing support for a well-integrated view of consumers' community life, neither do our findings portray a picture that mental health consumers are socially isolated.

We identified a number of factors that may be critical to community membership of persons with psychiatric disabilities. From the perspective of providers, overcoming consumers' social and independent living skills deficits is a requisite step toward building normalized social relationships. Providers of the study also highlighted the importance of promoting a supportive community of consumers as a safety net for consumers in their venturing out into the community. Such community offers a platform for consumers to learn and practice their social and independent living skills and to procure support and assurance in the face of social rejection.

While community membership for mental health consumers is not devoid of social rejection and discrimination, this study does identify consumer attributes that may countervail the sense of powerlessness and self-stigma, thereby promoting integration. These include belief in

community acceptance that surpasses the labeling of mental illness, belief in mutual accommodation in spite of differences in circumstances between consumers and community residents, understanding reciprocity in social relationships, and capacity of taking a proactive role in social interactions.

It is important to note the notions of mutual accommodation, reciprocity, and proactive role in reference to society's views about mental health consumers and prior research on social integration. The idea that mental health consumers are capable of assuming a proactive role and appreciating reciprocity, for example, is not consistent with the stereotypic view of persons with psychiatric disabilities as chiefly passive and reactive in their social interactions, and that they have low expectations about their position in society. Similarly, the notion of mutual accommodation is contrary to the portrayal of mental health consumers in the research literature as accommodating "unilaterally" to the community by passively tolerating their neighbors' disruptive and bothersome behavior, and noxious elements of their neighborhood (Boydell et al., 1999, Walker & Seasons, 2002). Given the reality of social rejection and self-stigma, promoting social integration entails a process of empowering mental health consumers in believing in their right of community membership and in the possibility of mutuality and reciprocity in social interactions with their neighbors.

Finally, the notion of an institutional or homeless mindset, raised by mental health providers as an impediment to community integration, deserves some elaboration. Such notion points to the importance of identifying psychological barriers that are particularistic to the background and history of mental health consumers. An institutional or a homeless mindset can be developed as persons with psychiatric disabilities become socialized or assimilated into the institutional or street culture, and assume a sense of personal identity and lifestyle preferences that make life less physically and psychologically strenuous in these settings (Dordick, 1996; Goffman, 1963; Snow & Anderson, 1987). However adaptive the unquestioned and total compliance with rules and regulations is to the survival in an institution setting, and however adaptive the resistance to authority and distrust of other people is to the survival in a homeless setting, these practices are likely to pose formidable barriers for consumers in their endeavor to reintegrate into society. The critical question for mental health providers is how to develop effective strategies that would enable psychiatric consumers to overcome these mindsets in order to establish meaningful relationships in the community.

In conclusion, despite its exploratory nature and limited generalizability, this study offers directions for future research regarding factors that are critical for increased and positive interactions between mental health consumers and community residents. This study also shows that focus groups can be a viable method for exploring the social experiences of persons with psychiatric disabilities.

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DATE RECEIVED: 06/23/03

ACCEPTED FOR PUBLICATION: 10/29/04