Community Participation Can Boost Self-Determination for Individuals with Serious Mental Illness

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

People with serious mental illness have conditions like schizophrenia, depression, anxiety disorders, or bipolar disorder. People with serious mental illness may encounter stigma or discrimination which may limit their participation in their communities. However, getting involved in community activities such as work or volunteering, social groups, or preferred leisure activities can boost quality of life and foster recovery for people with serious mental illness. In a recent NIDILRR-funded study, researchers asked adults with serious mental illness, their family members, their service providers, and community leaders about the meaning of community participation for people with serious mental illness. The researchers wanted to learn about the role of community participation for people with serious mental illness, and what factors made community participation easier and more meaningful.

Researchers at the project on Enhancing the Community Living and Participation of Individuals with Psychiatric Disabilities held focus groups and interviews with four groups of people. First, they held focus groups with 11 individuals living with serious mental illness between the ages of 24 and 55. Second, they interviewed 5 family members (parents or siblings) of people with serious mental illness. Third, they held focus groups with 34 professionals serving people with serious mental illness, such as therapists and peer providers. Fourth, they interviewed 3 community leaders with an interest in enhancing the inclusion of people with serious mental illness in community activities. The participants came from both rural and urban communities. During the focus groups and interviews, the participants were asked about the meaning of community participation from their perspective.

The researchers found that the four groups of participants all described similar themes when talking about their experience of community participation and how it affected important areas of their lives. These included:

- Relatedness: Participating in the community helped people with serious mental illness connect with others. Specifically, community activities such as work, socializing, and leisure activities helped people with serious mental illness build social networks, relieve feelings of isolation, and achieve a sense of belonging. The participants with serious mental illness described how meeting others who share the experience of serious mental illness can be beneficial. At the same time, participating in “typical” activities alongside community members without serious mental illness was also beneficial as it helped them feel valued as members of society.
• Autonomy: Participating in community activities was associated with a sense of autonomy and independence. The participants with serious mental illness emphasized the importance of doing activities without relying too much on other people for support and determining for themselves when and how to ask for assistance. Achievements such as running an errand or going to the grocery store independently could foster a sense of pride and motivate further independence. Furthermore, community activities should be freely chosen by people with serious mental illness and should match their interests and goals in order to promote autonomy. The participants with serious mental illness described how internal motivation to do things they enjoyed was helpful in overcoming barriers to participation.

• Competence: Community participation supported feelings of competence by offering a sense of purpose and the opportunity to contribute to the community in ways that are valued by society. For example, activities such as holding a job, volunteering, or taking leadership in a social club could allow people with serious mental illness to hold valued roles in the community. Holding valued roles was described as helping people with serious mental illness to overcome social stigma associated with mental illness. Another beneficial aspect of community participation was the ability to overcome serious mental illness-related barriers by engaging in activities. For example, some of the participants with serious mental illness described overcoming feelings of anxiety or depression by attending local events. Overall, engaging in the community promoted self-esteem and confidence.

The authors noted that the themes emerging in this study are similar to previous studies, which have found that people with and without serious mental illness experience self-determination – defined as individual choice and control in one’s environment – when engaging in activities that fulfill the need for relatedness, autonomy, and competence. Communities can best include people with serious mental illness by encouraging the formation of social networks, by supporting people with serious mental illness to participate as independently as possible in activities that they enjoy, and by giving people with serious mental illness valued ways to contribute. When people with serious mental illness experience a sense of self-determination, they may be more able to overcome challenges and increase their community participation further. Future research may be useful to better understand factors that facilitate or impede community participation for people living with serious mental illness in different community settings.

To Learn More
The Temple University Rehabilitation Research and Training Center on Community Living and Participation for Individuals with Serious Mental Illness has many products for people with serious mental illness, family members, and community organizations to support engagement and create welcoming environments, including
• Jump-Starting Community Inclusion: A toolkit for Promoting Participation in Community Life – 66 practical first steps that community health providers can take to support their clients’ participation in community life.
• Independence Through Community Access Navigation: A Supported Leisure Intervention
• Welcoming Places in the Community: Perspectives from Individuals with Serious Mental Illness guides people with serious mental illness to identify the welcoming places in places community, and what makes those places so special.

To Learn More About this Study

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