



Mitigating Early Loss of Community Participation in Early Psychosis Services

Psychotic conditions often begin during teenage and young adult years, and can have a rapid, significant, lifelong impact on all aspects of a person's life. Approximately 100,000 new individuals each year in the United States develop psychosis.¹ Youth and young adults in the early stages of psychosis commonly withdraw socially, lose social networks, and stop participating in community activities and relationships, which can result in loneliness. These changes are partly attributable to symptoms, and partly attributable to perceived and real lack of support, negative perceptions, and discrimination from peer groups and social networks. Individuals may internalize negative cultural attitudes and beliefs, which can lead to self-stigma and reduced self-esteem, hope, self-agency, and sense of control.^{2,3}

Research and personal narratives of people in recovery from psychosis show that individuals can not only recover, but also may thrive in a supportive community.⁴ Individuals often describe a turning point at which they begin to experience hope and belief in their ability to have a positive future. This realization of personal agency allows the person to take steps in a positive direction, such as reconnecting with personally meaningful goals, activities, and relationships.³ Engagement with normal

life activities and connections, along with an awareness of the need to pay attention to vulnerabilities and stress, may help the person recover clinically, develop more confidence, and reinforce a positive sense of identity.³ Recovery is also facilitated by development of personally valued goals, proactive decision making, action toward overcoming challenges, and helping others. Recovery-related skills include self-care, focusing on existing or new talents and abilities, engaging in normal activities such as school and work, and cultivating a healthy physical environment. Skills including self-reflection, communication, and expression of thoughts and feelings are important both for recovery and for community participation.⁴

RECOVERY AND COMMUNITY PARTICIPATION IN THE EARLY STAGE OF PSYCHOSIS

Early psychosis intervention programs attempt to identify and engage with individuals as early as possible in the process of psychosis onset in order to provide rapid access to resilience-focused, evidence-based clinical care.^{1,5} In the early stage of psychosis recovery, interventions may help slow or stop the negative cycle of social and personal loss and introduce a hopeful and grounded framework that supports intentional, positive steps toward lasting community participation. By facilitating a sense of agency and competence, and

increasing community connectedness or relatedness, interventions may lay the groundwork for community participation even when the person is unable to engage fully in normal community activities.

Providing targeted psychoeducation may improve communication, offer exposure to a larger group, and support interpersonal relationships. Psychoeducation that allows the individual to incorporate their own experience while focusing on self-determination and self-management skills may increase hope, recovery, and empowerment of those with longer-term illness.⁶

Positively-oriented online materials may provide an easily accessible method to increase the person's feeling of empowerment in treatment relationships, introduce recovery, and provide grounded hope that the person can successfully pursue goals related to community participation and interests. Multiple randomized controlled studies have concluded that use of computer technology among individuals with psychosis can be highly acceptable and relevant.⁷

PEER SUPPORT AS A FACILITATOR OF EARLY RECOVERY

Early psychosis services are increasingly including peer support as a core element of care.⁸ Research suggests that peer support for individuals with psychosis may have an impact on hopefulness, empowerment, and engagement in care, as well as other clinical outcomes.⁹ Exposure to individuals who have had similar experiences or who demonstrate a sustained belief in the person's potential to recover can be an important source of hope in a positive future. With an initial awareness that there is real hope for a positive future, peer support may help facilitate early recovery by assessing the person's values, strengths, and needs; learning about the person's condition and services; supporting recovery skills; and helping the individual reconnect with others. This preparation allows individuals to face the difficult challenges of illness management, pursuing goals, and strengthening their sense of identity.¹⁰

FACILITATING COMMUNITY PARTICIPATION THROUGH PARTICIPATORY RESEARCH

Opportunities to contribute to community and society, such as leadership and participatory research, may further facilitate community participation and support well-being.⁴ Integration of youth and young adult voice into intervention development may not only improve the relevance of interventions, but also provide community participation for individuals.⁸ Community Based Participatory Research (CBPR) provides an equitable opportunity for co-researchers to have their voices heard and to meaningfully shape every phase of the project.¹¹

One example of engaging young adults in community leadership and participatory research is the Early Assessment and Support Alliance (EASA) Connections project. The EASA Young Adult Leadership Council, which is made up of graduates of Oregon's early psychosis services, recognized the challenges faced by individuals entering the program. They initiated a research project called EASA Connections, which is being carried out in collaboration with the Research and Training Center for Positive Futures (Pathways RTC) at Portland State University (<https://www.pathwaysrtc.pdx.edu/p2-easa-connections>). Young adults who have experienced psychosis work as co-researchers. To date, they have collaboratively created 1) an online resource with psycho-educational materials including themes and messages they felt would have been most helpful to them and 2) a study to try out the online resource with peers who



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are new to services. Young adult collaborators used their personal experience to engage in research and provide a potentially helpful new intervention for others. The introduction to the online resource is given by members of the Young Adult Leadership Council, and the resource contains narratives and messages based on personal experience, along with tools and information to increase self-determination, connect recovery with personal values and strengths, and engage with support networks.

As researchers and clinicians increasingly target community participation as an outcome for interventions, they will need to address both the clinical and the social aspects of recovery. There is much hope for success through early intervention, engaging young adults who are in recovery from psychosis in leadership and CBPR-driven intervention development, and combining relevant interventions such as psychoeducation, peer support, and web-based approaches. Effective treatment for individuals who have experienced psychosis will more successfully support community participation by offering interventions focused on overcoming negative attitudes and maintaining hope, agency, and social support.

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