

Mitigating Early Loss of Community Participation in Early Psychosis Services: State of the Science

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In the early stages of treatment for psychosis, community engagement and social networks are threatened through a combination of symptomology and negative messages and reactions from the environment which may result in internalized stigma, disempowerment, and prolonged isolation. While treatment programs attempt to mitigate these factors, ambivalence toward treatment and the basic concept of psychosis, along with difficulty engaging in conversation, make initial engagement more difficult. Self-determination theory and growing recovery literature point to the importance of maintaining a sense of community relatedness and connection, and developing a sense of agency and competence as important to active recovery and retention of community participation.

Emerging relevant interventions which may help foster these important underpinnings of forward movement include psychoeducation, peer-developed and delivered messaging, and easily accessible internet-based content. Interventions like EASA Connections that are designed based on this emerging research, and further include intervention recipients as co-creators in intervention development, may help increase participation in early psychosis treatment and retention of community participation over time, leading to better overall life outcomes.

The impact of early psychosis on community participation

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 (Heinssen, Goldstein, & Azrin, 2014; McGrath, Saha, Chant, & Welham, 2008). The economic and social effects of psychosis, especially Schizophrenia, are well-documented in the literature (Appleby, Cooper, Amos, & Faragher, 1999;



Palmer, Pankratz, & Bostwick, 2005; Rupp & Keith, 1993; Teplin, McClelland, Abram & Weiner, 2005; World Health Organization, 2001; Wu et al., 2005). The breadth and depth of a person's social network often deteriorates quickly at the onset of psychosis as a result of changed behavior, impaired ability for social interaction, and negative social perceptions (Angell & Test, 2002; Erickson, Beiser, Iacono, Fleming,

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& Lin, 1989). 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 care. Services include medical care and prescribing with careful attention to the impact of side effects on functioning, individualized goal setting across life domains, specialized counseling, and case management to increase resilience and encourage ongoing engagement with developmentally relevant activities and roles. Psychoeducation for the family, supporters, and the individual is also a key element, with the goals of increasing understanding, preserving functioning, and reinforcing the social network (Heinssen et al., 2014; McFarlane, 2016; McGorry, Killackey, & Yung, 2008; Melton et al., 2013). Partnership in decision making and peer support are

increasingly seen as core elements of mental health services in general, including early psychosis services (Bertolote & McGorry, 2005; Chinman et al., 2014, Corrigan et al., 2012; Du Brul et al., 2017; Jones, 2015).

Youth and young adults in the early stages of psychosis commonly experience a rapid loss of community participation. Loss of social networks, and an increase in social withdrawal and feelings of loneliness are common in the early stages of recovery from psychosis (Addington, Penn, Addington, Perkins, & Woods, 2008; Ballon, Kaur, Marks, & Cadenhead, 2007; Birchwood et al., 2006; Corcoran et al., 2011). This loss is attributable partially to symptoms that impair social interaction. Symptoms may make it difficult to plan and follow through on activities, hold a conversation, or organize a daily routine (Glahn et al., 2005). Sensory input may be overwhelming, and social withdrawal is common (Seeman, 2017). By the time individuals enter early psychosis services, their symptoms have generally progressed to the point where they are experiencing increasing detachment from the world around them (Hansen, Stige, Davidson, Moltu, & Reseth, 2017). Loneliness and level of social interaction in first-episode psychosis has been correlated with clinical outcomes (Bjornestad et al., 2017; Michalska de Rocha, Rhodes, Vasilopoulou, & Hutton, 2018). Individuals experiencing early psychosis also tend to have smaller social networks at the start of treatment, making preservation and development of supportive relationships a particularly important goal. (Bjornestad et al., 2017; Hodgekins et al., 2015; MacDonald, Hayes, & Baglioni, 2000; Thorup et al., 2006). Social disability remains common and there is need for further targeted intervention development (Fowler et al., 2018; Hodgekins et al., 2015; Rinaldi et al., 2010).

Social withdrawal and loss of community participation is also partially attributable to negative social



perceptions and discrimination, both perceived and actual. (Lim, Gleeson, Alvarez-Jimenez, & Penn., 2018; Wood, Byrne, Burke, Enache, & Morrison, 2017). Individuals in the early stages of psychosis may develop a sense of loneliness, shame, and internalization of negative cultural attitudes and incorrect beliefs related to psychosis. They may experience or perceive a lack of support and understanding from peer groups and overall social networks, and consequently lose hope, self-agency, and sense of control (Ballon et al., 2006; Birchwood et al., 2006; Lim et al., 2018; Livingston & Boyd, 2010; van Zelst, 2009; Wood et al. 2017). Negative perceptions around diagnostic terms such as Schizophrenia or psychosis can lead to self-stigma, and have negative impacts on self-esteem

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(Vass, Sitko, West, & Bentall, 2017). Self-stigma is also associated with greater anxiety and depression, and can interfere with acceptance of treatment, sense of agency, and self-esteem (Hansen et al., 2017; Pyle & Morrison, 2017).

In the early stage of treatment, the individual may not recognize the need for treatment, may be skeptical and wary of treatment providers, and may even have difficulty engaging in basic activities like holding a conversation. The same symptoms and negative attitudes that threaten loss of community participation may also cause the person to resist or be unable to participate fully in treatment and exacerbate stress in the individual’s environment (Dixon, Holoshitz & Nossel, 2016; Dunne Bishop, Avery, & Darcy, 2017; Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2017; Rickwood & Wilson, 2007; Weng Cheong Poon, Joubert, Mackinnon, & Harvey, 2017). Alienating and traumatizing experiences with hospitalization or the legal system may further reduce the person’s willingness to participate in care (Hansen et al., 2017). Early intervention to avoid unnecessary hospital and legal experiences, along with participation in strengths-oriented shared decision making may help to reduce self-stigma (Hamann, Buhner, & Rusch, 2017). While historically many mental health programs have focused primarily on treatment adherence or “compliance,” early psychosis programs generally focus on self-determination and choice within a shared decision making context. Shared decision making facilitates engagement in treatment, preserves the person’s sense of control, recognizes the value and importance of their perspective, and increases the likelihood of them following through on treatment (Corrigan et al., 2012).

Recovery from psychosis is usually gradual, and involves not only symptom reduction but also learning to manage stressors and persistent symptoms, and overcoming negative psychological and interpersonal impacts (Addington, Lambert, & Burnett, 2009; Drake & Whitley, 2014; Jordan, Pope, Lambrou, Malla, & Iyer, 2016). Early psychosis intervention works with the individual and family to increase understanding,



reduce distress and conflict, give the person and family needed time, space, and tools to recover and accomplish developmental tasks, mitigate negative pressures and experiences, and support the person to make steps toward recovery and developmental progression (Jansen, Gleeson, & Cotton, 2015; McFarlane, 2016; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015).

Community participation and recovery

A growing body of research shows that there is reason for hope. Individuals experiencing psychosis and other forms of serious mental conditions cannot only recover, but sometimes exceed, the quality of life they experienced prior to the onset of the condition (Anderson, Oades, & Caputi, 2003; Cook

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& Jonikas, 2002; Copeland, 1997; Dunkley & Bates, 2014; Gumber & Stein, 2013; Jager et al., 2015; Saks, 2013). The likelihood of recovery may be further enhanced by reducing unnecessary treatment delays (i.e., the duration of untreated psychosis or DUP)

through early intervention (Addington et al., 2015; Addington, Van Mastrigt, & Addington, 2004; Santesteban-Echarri et al., 2017). Many individuals in recovery from psychosis and other psychiatric conditions have not only written about their personal journeys, but have reached out broadly to learn from and support others in their recovery (Buekea & Caruso, 2016; Deegan et al., 2017; Jager et al. 2015; Saks, 2013; Wood & Alsawy, 2017). Central themes emerge from research about the elements of recovery: having a sense of hope, accepting that the individual has responsibility for one's own life, setting goals and gaining education to accomplish them, self-advocacy, and utilizing a support network (Anderson et al., 2003; Cook & Jonikas, 2002; Copeland, 1997; Gumber & Stein, 2013; Jager et al., 2015; Saks, 2013).

Community participation is both a result of and a contributor to the recovery process, and may look different over time. In the earliest stage of treatment, community participation may be more tenuous and difficult but no less important. Discovering a sense of control and agency in thought and action is an important starting place (Hansen et al., 2017). Individuals in recovery from psychosis often describe a turning point in 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 begin taking steps in a positive direction, such as reconnecting with personally meaningful goals, activities, and relationships (Bjornestad et al., 2017). While individuals may return to social roles from before their episode, those activities may be more difficult, and their sense of identity may be challenged. 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 (Hansen et al., 2017). Recovery is also facilitated by development of personally valued goals, proactive decision making, and 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

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school and work, and developing a healthy physical environment (Jordan et al., 2018). Skills including self-reflection, communication, and expression of thoughts and feelings are all important both for recovery and for community participation (Jordan et al., 2018). Research and personal narratives of individuals in recovery from psychosis describe the experience of greater clarity, perspective, and sense of intelligence as a result of having gone through psychosis. Individuals in recovery from psychosis may not only survive in isolation, but may thrive in a supportive community (Buekea & Caruso, 2016; Chan, Mak, Chio, & Tong, 2017; Jordan et al., 2018).

Facilitating recovery and community participation in the early stage of psychosis

The early stage of psychosis presents an important time period in which interventions may help slow or stop the negative cycle of social and personal loss, and introduce a hopeful and grounded alternative framework which supports intentional, positive steps toward lasting community participation (Addington et al., 2015; Birchwood, Connor, & Lester, 2013). Interventions must recognize the variation in individuals' capacity to interact, as well as the significant psychological and social challenges the person faces. Self-determination theory may provide a useful framework for facilitating early recovery and developmentally appropriate participation in valued roles, relationships, and activities. Self-determination is the ability to make decisions and take action for one's self with knowledge of consequences. It has been linked to involvement in activities and interests, and continuing to move forward with responsibilities (Krupa, Woodside & Pocock, 2010). Self-determination theory describes three components: a) a sense of agency; b) community connectedness or relatedness; and c) a sense of competence (Deci & Ryan, 2002). One study found self-determination theory to be a good fit over time for individuals with psychotic conditions, and helped to explain treatment outcomes including engagement in services, psychosocial functioning, and quality of life (Jochems et al., 2012, Jochems, Duivenvoorden, van Dam, van der Feltz-Cornelis, & Mulder, 2016). All of the elements of self-determination are affected in the early stage of psychosis. 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 their normal community activities.

Psychoeducation. Individual and family psychoeducation helps improve self-determination through providing targeted information and interaction, improving communication, offering exposure to a larger group, and introducing structured methods of shared decision making. Participation in evidence-based multi-family psychoeducation groups directly creates and supports interpersonal relationships (Sin et al., 2017). A meta-analysis of psychoeducation strategies showed impacts on symptoms and functioning equal to or greater than other standard treatment methods including medications, cognitive behavioral therapy, and case management (Lincoln, Wilhelm, & Nestoriuc,

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2007). Another meta-analysis concluded that psychoeducation that focuses on self-determination and self-management skills may increase hope, recovery, and empowerment of individuals with longer-term illness (Thomas, Despeaux, Drapalski, & Bennett, 2017). However, for an intervention to have an impact, the

basic messages need to be understood and accepted by the person as related to their own life as well as remembered and integrated into their everyday experience. To be effective, the individual must be supported to incorporate their own explanations of their experiences, and standardized symptom descriptions must be adjusted in recognition of differences in culture and personal experience (Dixon & Lehman, 1995; Hofer, Amering, Windhaber, Wancater, & Eberstaller, 2001; Lincoln et al., 2007; Mullen, Green, & Persinger, 1985; Myers & Ziv, 2016; Zygmont, Olfson, Boyer, & Mechanic, 2002).

Use of internet-based technology. During the early stages of psychosis treatment internet-based options may reduce isolation while providing education and encouraging positive steps to remain engaged socially (Alvarez-Jimenez et al., 2014; Dixon et al., 2016). Individuals with stigmatized conditions like Schizophrenia may be more likely than individuals with non-stigmatized health conditions to use the internet for health information (Berger, Wagner, & Baker, 2005). An individual who has difficulty with cognition and who is having difficulty leaving the house or interacting with others, may potentially benefit from targeted online materials that are available for repeated viewing whenever the person chooses. There is evidence, including multiple randomized controlled studies, that use of computer technology among individuals with psychosis can be highly acceptable and relevant (Abdel-Baki, Lal, Cjharron, Stip, & Kara, 2017; Alvarez-Jimenez et al., 2014; Hoffman et al., 2013; Lal et al., 2015). Computer-based decision aids can help individuals clarify their values and become more familiar with options, and increase their comfort level with making choices in their treatment (Stacey et al., 2011). Positively oriented online materials may 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 other areas of interest (Deegan, 2010; Drake et al., 2010; Kreyenbuhl, Nossel, & Dixon, 2009; MacDonald-Willson, Deegan, Hutchison, Parrotta, & Schuster, 2013; Ptasznik, 2011).

Opportunities to contribute to community and society such as leadership and participatory research may further facilitate community participation and support well-being.

Peer support and lived experience perspectives.

Exposure to others with lived experience is also found to be helpful in recovery and retaining community connections. A literature review of the impact of stigma on individuals diagnosed with Schizophrenia recommended a combination of psychoeducation and the “...sharing of experiences in...the context of peer support” to ameliorate internalized stigma (van Zelst, 2009, p. 295). A subjective catalyst toward hope is a key element in virtually all accounts of recovery, with that catalyst sometimes coming from within the person in reaction to negative external expectations, and sometimes coming from exposure to individuals who have had similar experiences or who demonstrate a sustained belief in the person’s potential to recover. With an initial awareness that there is real hope for a positive future, the early

recovery process is facilitated by assessing the person’s values, strengths, and needs; learning about the person’s condition and services; gaining recovery skills; and connecting with peers. This preparation allows individuals to retain hope and face the difficult challenges of illness management, pursuing goals, and strengthening the sense of identity (Andersen et al., 2003; Cook & Jonikas, 2002).

EASA Connections: 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 (Buekea & Caruso, 2016; Chan et al., 2017; Jordan et al., 2018). Integration of youth and young adult voice into intervention development may not only improve the relevance of interventions, but also create a means of community participation for individuals with early psychosis who are further along in the recovery process (Israel, Eng, Schulz, & Parker, 2005; Jones, 2015; Minkler & Wallerstein, 2003). Community based participatory research (CBPR) provides an equitable opportunity for co-researchers to have their voices heard in a meaningful fashion and to shape every phase of the project (Israel, 1998; Nicolaidis & Raymaker, 2015). CBPR has an explicitly emancipatory aim in including marginalized communities in research about them, conducting research that they feel is helpful to them, capacitating individuals and communities, and providing methods that promote greater inclusion of diverse perspectives (Israel et al., 2005; Minkler & Wallerstein, 2003). Participation in research as both study participants and as co-researchers is considered by people with disabilities to be an important and empowering aspect of community involvement (McDonald, 2012; Stack, 2013; Stack & McDonald, in press). CBPR has been used since the 1990s and grown in popularity, including



with youth and young adults, around mental health. Inclusion of young adults with psychiatric conditions increases the relevance and understandability of the research process and resultant policy recommendations (Delman, 2012, 2013; Goodyear-Smith, Corter, & Suh, 2016; Langdon et al., 2016; Vukic, Gregory, Martin-Misener, & Etowa, 2016).

One example of a CBPR effort is EASA Connections. Oregon's Early Assessment and Support Alliance (EASA) Young Adult Leadership Council includes early psychosis program graduates and supporters who want to "give back" by supporting others (Buekea & Caruso, 2016). The Council recognized the challenges faced by individuals entering the program, and their concerns led to the initiation of 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. For two years, a Design Team made up of early psychosis program graduates and participants worked with clinicians and researchers following a Community-Based Participatory Research process to create a theory of change focused on supporting community participation by individuals in the early stages of psychosis based on the elements of self-determination, and to create an online resource with educational materials including themes and messages that they felt would have been most helpful to them. The Design Team identified study materials and a protocol which included introduction of the online modules to individuals early in treatment by a "Peer Navigator" who was also a graduate of EASA. The modules were developed to supplement ongoing engagement with the EASA treatment team. Modules provide information about psychosis

and treatment, and introduce the recovery process through assessing strengths, goals, and participating in shared decision making. The modules include 36 videos designed and implemented by young adults, directly address issues of discrimination and internalized stigma, and provide step-by-step encouragement for engaging friends and family, and engaging in community activities.

The concept of community participation was extended to the experience of Design Team members who were able to use their personal experience to engage in research and provide a potentially helpful new intervention for others. The introduction to the web-based modules is provided by members of the Young Adult Leadership Council, and the modules contain narratives and messages based on personal experience, along with tools and resources the individual can use to increase self-determination and engage their support network. The Design Team developed a deeper understanding of facilitators of successful community participation, including the use of participatory decision making methods and technology within their meetings. The process of initiating, creating, and delivering EASA Connections demonstrates a potential ongoing method for extending community participation among individuals with early psychosis, by means of participatory leadership, research, and engagement in service delivery. It is hoped that the exposure of individuals new to the experience of psychosis to an empowered group of peers may mitigate distress, feelings of isolation, and loss of confidence while encouraging positive, manageable steps toward lasting recovery and community participation.



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