

Community Inclusion and Social Determinants: From Opportunity to Health

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It is well documented that individuals with serious mental illnesses are disadvantaged in their employment, educational attainment, social relationships, family relationships, and other areas, which are all social determinants of health. They are also the focus of community inclusion initiatives that are based in legal and human rights. This column reviews the history and development of the community inclusion concept and the

health-related outcomes that are expected to result from community inclusion efforts. Incorporating fundamentals and indicators of community inclusion into mental health systems offers a paradigm for addressing social determinants and improving health as part of the larger health care agenda.

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In the 1950s, when institutionalization was standard care, parents of individuals with intellectual disabilities in Denmark were distressed by the isolation and discrimination their children faced in society. They united to demand policies and programs that enabled their children to live “normal lives” in the community. Thus was born the normalization movement, which emphasized the need for initiatives that promoted opportunities for individuals with disabilities to experience “patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society” (2). Wolfensberger (3) argued that moving in this direction was essential, because, he observed, those who do not participate in valued social roles, such as work, school, religion, or family roles, were at risk of being diminished and devalued by society, leading to abuse, neglect, isolation (e.g., institutionalization), and even death. He discussed the need for the “creation, support, and defense of valued social roles for people at risk for devaluation.” The independent living movement emerged in the 1960s to emphasize empowerment, choice, and control over resources among individuals with disabilities (4). Around the same time, the concept of disability began to be understood not simply as a result of individual impairments but instead as a poor person-environment fit that limited opportunities for full and meaningful roles for all citizens (5). This orientation is referred to as the social model of disability.

These ideas and movements converged to inspire a powerful and persuasive disability rights movement that brought about the passage of the Americans With Disabilities Act (ADA). Title II of the ADA “requires governments to give people with disabilities an equal opportunity to benefit from all programs, services, and activities (e.g., education,

employment, voting, transportation, recreation, etc.)” (6). The 1999 U.S. Supreme Court ruling known as the Olmstead decision reinforced the application of the ADA to persons with serious mental illnesses; the court concluded that “unnecessary institutionalization” is a form of discrimination prohibited by the ADA (7). The Olmstead decision clearly established a connection between the broader disability rights community and people with serious mental illnesses.

Prior to the ADA, the concept of community integration was discussed in contrast with the physical separation and social isolation inherent in institutional care. Wolfensberger (8) discussed community integration as involving “physical integration,” which is the extent to which people with disabilities are physically present in settings in the community where “nondevalued” people are present, and “social integration,” which refers to social interactions and relationships that devalued people are able to develop with nondevalued persons. The passage of the ADA offered a new rights-based orientation to the concept of community

HIGHLIGHTS

- Community inclusion is a legal and human right that addresses social determinants of health.
- The increased opportunities to live a meaningful life in the community that result from community inclusion initiatives enhance general medical, cognitive, and mental health and wellness.

integration, as the U.S. Department of Justice (DoJ) identified the goal of the “integration mandate in title II of the Americans with Disabilities Act” as providing “individuals with disabilities opportunities to live their lives like individuals without disabilities” (9).

The concept of opportunity is central to this rights-based perspective and is most consistent with the philosophy of the independent living movement, which views as essential one’s choice of and control over his or her residence, activities, and relationships. Rather than define community integration in contrast with institutional life, a rights-based orientation emphasizes a societal commitment to policies, programs, and practices that maximize opportunities for people with disabilities to choose and control their activities (and the ways and degree to which they participate in them) and their interactions and connections with nondevalued people. From this rights-based perspective, physical presence, participation, and social interactions—and their psychological consequences, which are discussed later—become outcomes of community integration initiatives rather than the definition of community integration.

The ADA, as influenced by the social model of disability, also emphasizes creating opportunities by modifying environments through physical alterations (e.g., curb cuts, ramps), accessible communications (e.g., availability of sign language interpreters, braille signage, and closed captioning), and the availability of individualized reasonable accommodations in various settings to maximize person-environment fit. From this rights-based framework, and subsequent executive branch actions (i.e., President George W. Bush’s Executive Order 13217 and DoJ enforcement of the integration mandate) and judicial acts (i.e., the Olmstead decision), the concept of community integration emerges as “the opportunity to live in the community and be valued for one’s uniquenesses and abilities, like everyone else” (10).

From Community Integration to Community Inclusion

Community inclusion is closely related to community integration but is slightly different and is more commonly used outside the United States. The Convention on the Rights of Persons with Disabilities (11), which was adopted by the United Nations General Assembly in 2006, pronounces inclusion as a human right for those with disabilities, whereby nations must “promote full and effective participation and inclusion in society, including . . . competitive employment and participation in the economic, political, social, cultural, [and] recreational activities of their communities.”

The concept of inclusion is often discussed both in contrast to institutionalization and in terms of its antonym, exclusion. Exclusion of individuals with disabilities occurs through forms of social oppression such as attitudinal, structural, and physical barriers. Wolfensberger and others raised awareness of systematic structural oppression and exclusion experienced by persons with psychiatric and other disabilities that exacerbate their exposure to social

determinants of health. From the perspective of intersectionality, it should be noted that exclusion for some individuals with serious mental illnesses is further exacerbated by discrimination based on their gender, race, ethnicity, sexuality, and other characteristics.

Indicators of inclusion practices have been described as going beyond the mere presence of people with disabilities in a particular setting, their engagement in a social role, or the availability of reasonable accommodations, all of which might satisfy community integration. Inclusion adds the requirement that environments also welcome and embrace the participation of individuals with disabilities through active outreach, efforts to alter environments to enhance person-environment fit, and clear communications about the acceptance of difference. Promoting inclusion also requires recognition that diverse communities are stronger and healthier communities, which is grounded in the economic and moral foundations of capabilities theory, a Nobel Prize-winning concept developed by Amartya Sen and expanded upon by Martha Nussbaum. Sen (12) argued that the economic development of a nation should be understood not only in terms of the income of its citizens but also in terms of the degree to which it supports the ability of each individual to do what they value or to engage in the social roles they choose (i.e., supports their capabilities). Their capabilities are advanced through various initiatives that enhance opportunities to be a part of the community. From this perspective, workplaces, educational institutions, faith communities, and other settings are expected to proactively and vigorously work to maximize the capabilities of people who have historically been excluded to fully, meaningfully, and equally participate in society.

Indicators of Community Inclusion

Indicators of community inclusion, and the enhanced opportunities for people with serious mental illnesses that result, include the presence of policies, programs, practices, and environments that provide people with disabilities maximum choice and control about what they do, how much they do it, and with whom they do it. There are many ways to assess the extent to which community inclusion is being advanced, some of which are described below.

Policies. Prioritized and adequately funded community-based supports are available that target participation in a broad range of areas (i.e., beyond housing and employment). Examples of these efforts include increasing availability, awareness, and use of accommodations and setting and achieving targets for the percentage of, for example, workers in an organization, college students at a university, or members of a faith congregation who have a disclosed disability.

Programs and practices. Specific programmatic supports are available that promote participation among individuals with serious mental illnesses in activities such as attending work

or school and dating or that assist with parenting. Furthermore, providers can encourage and support participation in valued social roles, such as those involved in employment, school, leisure, parenting, and expanded relationships with family and friends.

Environments. Mainstream settings (i.e., not behavioral or social service organizations), such as employers, faith communities, community groups and organizations, and colleges and universities, can actively reach out to individuals with mental illnesses to invite their participation; alter their requirements and expectations to meet the unique attributes of these individuals; and clearly and frequently make explicit their desire for these individuals' presence and engagement.

Outcomes of Community Inclusion

In addition to the moral and societal benefits of promoting community inclusion, including the economic benefits espoused by Sen (12), individual-level outcomes that enhance the health, wellness, and recovery of individuals with serious mental illnesses are also anticipated.

Community presence. Community inclusion should result in the increased physical presence of people with mental illnesses in the community. One indicator of increased presence may be people with mental illnesses residing in housing that is more like that of other community members rather than in institutional or congregate settings. This outcome might be assessed by counting the numbers of people with mental illnesses in state hospitals, nursing homes, and large congregate housing as well as calculating the percentage of individuals receiving services in a mental health system who live in independent apartments and homes, with or without some type of housing or independent living support.

Increased community participation. Increased opportunities to live in the community as other citizens do should also result in increased community participation in a broad range of valued social roles, such as employment; development of and involvement in intimate family and social relationships; and engagement in educational, religious, and recreational pursuits. We might also expect to see an increase in the number of participation areas that people view as important to them, extending to a reemergence of interest in areas they had not been pursuing because of exclusion (sometimes referred to as "adaptive preferences"), and increased satisfaction with their participation as they experience fewer barriers and greater opportunities and engagement.

Altered identities. Presence in the community rather than in institutions can counter "patienthood identities" that may produce learned helplessness, dependence, demoralization, and a sense of hopelessness about the future. In contrast, residing in settings that are more like those of other community members may facilitate "personhood," hope, and efforts to develop one's strengths and capabilities. Increased

presence of individuals with serious mental illnesses in the community and contact with other community members can also counter prejudice and discrimination and can generate even more welcoming and embracing environments. Increased community participation can also further enhance a person's identification with valued roles, such as employee, student, spouse, and parent.

Physical, cognitive, and mental health benefits. Community participation is clearly associated with positive health outcomes for the general population and for individuals with serious mental illnesses (1). For example, increased participation decreases sedentary behavior, can increase income and educational attainment, and expands social networks and support, all of which have general medical health benefits. Cognition is also enhanced through physical activity as well as by decreased social isolation and poverty, all of which can result from increased participation. Measures of mental health—including reduced symptoms, loneliness, and social isolation and enhanced recovery, quality of life, empowerment, self-efficacy, and sense of belonging and community—have also been shown to be associated with community participation. Additional psychological outcomes of inclusion initiatives are reductions in perceived and internalized stigma, which may also result from increased presence and participation, and the creation of more welcoming and embracing environments.

From Opportunity to Health

Community inclusion emerged from a vibrant disability rights community that fought to counter isolation and exclusion, which are at the heart of a public health orientation that understands health within the context of social determinants and socioenvironmental factors. Opportunities to work, study, play, and pray are legal and human rights that represent societal obligations to people who have historically been disenfranchised from engagement in meaningful and valued social roles and have been physically disconnected from society, literally, via placement in institutions. Individuals with serious mental illnesses do not participate in their communities to the same degree as others, and the lack of participation takes a toll on their economic stability, place in society and the community, and exposure to unsafe neighborhoods and physical environments, all of which ultimately affect health. Promotion of community inclusion and participation is consistent with the notion of addressing social determinants of health and should be considered a medical necessity. Incorporating the fundamentals and indicators of community inclusion into mental health systems offers a paradigm for creating policies, programs, and practices that benefit people with mental illnesses; increases attention to the environments in which people live; and advances a focus on social determinants as part of the larger health care agenda.

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Short Descriptions of Novel Programs Invited

Psychiatric Services invites contributions for Frontline Reports, a column featuring short descriptions of novel approaches to mental health problems or creative applications of established concepts in different settings.

Text should be 350 to 750 words. A maximum of three authors, including the contact person, can be listed; one author is preferred. References, tables, and figures are not used. Any statements about program effectiveness must be accompanied by supporting data within text.

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