



Review article

Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation[☆]



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ABSTRACT

Social inclusion is an important goal for people with intellectual and developmental disabilities, families, service providers, and policymakers; however, the *concept* of social inclusion remains unclear, largely due to multiple and conflicting definitions in research and policy. We define social inclusion as the interaction between two major life domains: interpersonal relationships and community participation. We then propose an ecological model of social inclusion that includes individual, interpersonal, organizational, community, and socio-political factors. We identify four areas of research that our ecological model of social inclusion can move forward: (1) organizational implementation of social inclusion; (2) social inclusion of people with intellectual and developmental disabilities living with their families, (3) social inclusion of people along a broader spectrum of disability, and (4) the potential role of self-advocacy organizations in promoting social inclusion.

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1. Introduction

A major obstacle for achieving the goal of social inclusion for people with intellectual and developmental disabilities is that the *concept* of social inclusion remains unclear (Amado, Novak, Stancliffe, McCarren, & McCallion, 2013; Bigby, 2012a, 2012b; Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Duggan & Linehan, 2013; Hall, 2009; Overmars-Marx, Thomése, Verdonshot, & Meininger, 2014). The lack of clarity results from the numerous definitions of social inclusion, which can make the concept interchangeable with social integration, social network, community participation, and social capital. The variation between definitions impedes effective service delivery and interventions, and leads to insufficient data about its effective implementation (Duggan & Linehan, 2013; Martin & Cobigo, 2011). Moreover, the conceptual ambiguity of social inclusion hinders communication across key stakeholders – such as individuals with disabilities, family members, service providers, researchers, and policymakers – who may disagree over the meaning and purpose of social inclusion (Clement & Bigby, 2009).

Despite these issues, social inclusion remains an important element of well-being for people with intellectual and developmental disabilities (Buntinx & Schalock, 2010) and a key component of the United Nations Convention on the Rights of Persons with Disabilities (Quinn & Doyle, 2012). However, people with intellectual and developmental disabilities continue to experience high rates of social isolation (Bigby, 2008; Forrester-Jones et al., 2006; Milner & Kelly, 2009; Robertson et al., 2001), and their social networks are comprised mainly of family members and professionals (Lippold & Burns, 2009). Because enhancing social inclusion begins with a clear definition, this paper (1) conceptualizes social inclusion and (2) provides an ecological model of the many factors that promote it.

1.1. Social inclusion: What is it?

A clear definition of social inclusion can facilitate communication across service providers, policymakers, and multidisciplinary researchers (Buntinx & Schalock, 2010). In addition, a clear definition can help standardize the multiple ways that researchers measure social inclusion (Amado et al., 2013). Finally, redefining social inclusion can respond to the fact that web-based technologies have changed communities and social networks since the inception of social inclusion research in the 1970s (Clegg, 2010). Fig. 1 Column 1 lists definitions of social inclusion found in the literature in the last 10 years. Interpersonal relationships and community participation emerge as common themes, but conceptual differences emerge around the (1) scope, (2) setting, and (3) depth of social inclusion.

1.1.1. Scope of social inclusion

The scope of the definition refers to the kinds of activities, relationships, and environments that social inclusion encompasses, and definitions range from narrow to broad in scope. For example, Clement and Bigby (2009) followed a narrow definition of social inclusion when they aimed to “expand people’s social networks by facilitating relationships with people who are not staff members, relatives, or people with intellectual disabilities” (p. 266). They narrowed the scope in two ways: first, they excluded relationships with certain groups (staff, families, and people with ID), and second, they discounted community activities as a component of social inclusion, although they presumed that relationships with community members would encompass community involvement.

In contrast, broad conceptions of social inclusion can involve being accepted as an individual beyond disability, significant and reciprocal relationships, appropriate living accommodations, employment, informal and formal supports, and

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