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.

Defining Social Inclusion of People with Intellectual and Developmental Disabilities:
An Ecological Model of Interpersonal Relationships and Community Participation

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; Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Duggan & Linehan, 2013; Hall 2009; Overmars-Marx, Thomése, Verdonschot, & 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). Figure 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 community involvement

(Hall 2009; Power 2013). McConkey and Collins (2010a) charted a middle course by focusing on two components: social interaction and community participation (2010, p. 692).

1.1.2. Settings of Social Inclusion. Differences in the scope of social inclusion highlight the different settings in which social inclusion may take place. The interpersonal dimension of social inclusion--such as social interaction, relationships, and social networks--could take place in a private setting--such as the person's home--and researchers have thus measured the number and quality of a person's friendships (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006a). In contrast, many definitions encompass access to community facilities and community participation, which gives social inclusion a public dimension. Hence, even if someone had a high number of friendships, their level of social inclusion would be deficient if they had no access to the community. By emphasizing *community* settings, researchers underscored the value of forming relationships with nondisabled people in mainstream settings (Bates & Davis, 2004). But researchers have also argued that segregated settings may benefit people with intellectual and developmental disabilities by offering a sense of belonging, friendship, and safety (Hall 2010; Milner & Kelly, 2009).

1.1.3. Depth of Social Inclusion. This emphasis on belonging touches on the depth of the definition of social inclusion, as some researchers have focused on objective measurements (such as the number of friendships), and others have focused on subjective measurements (such as the level of satisfaction). Others aim to integrate both subjective and objective elements, similar to quality of life research (Verdugo, Schalock, Keith, & Stancliffe, 2005). For example, Cobigo et al. defined social inclusion with significant depth when they insisted that a person must (1) have a sense of belonging in a social network within which they receive and contribute support, (2) that they experience a valued social role, and (3) that they are trusted to perform that social role in the community (2012). Similarly, Walker et al.

(2011, p. 15) defined social inclusion as “societal acceptance of people with disabilities within school, work, and community settings.” This definition shifts attention to the subjective attitudes of nondisabled people toward people with disabilities.

Research on levels of satisfaction of supports and services have relied primarily on people with higher IQs and lower support needs (Copeland, Luckasson, & Shauger, 2014). This is problematic as some research has suggested that people with different levels of intellectual and developmental disabilities experience social inclusion differently. For example, people with mild and severe intellectual and developmental disabilities may be most at risk of social isolation (McConkey, 2007). People with moderate intellectual disability have reported that they prefer to form close friendships with other people with intellectual or developmental disabilities (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b). In contrast, people with severe to profound intellectual and developmental disabilities were more likely to form relationships with nondisabled family members and staff (Bogdan & Taylor 1989; Whitehouse, Chamberlain, & O’Brien, 2001).

1.2. What is not Social Inclusion?

When definitions of social inclusion multiply and diverge from one another, then the concept of social inclusion becomes interchangeable with other concepts, as represented in Figure 1, Column 2. These concepts include social interaction, social network, social capital, community participation, independent living, and a sense of belonging (Rimmerman, 2013; Duggan & Linehan, 2013; Amado et al., 2013; Cobigo et al., 2012). Conceptual ambiguity poses opportunities and challenges to researchers. On the one hand, conceptual open-endedness invites researchers to take different approaches to social inclusion that yield diverse interventions to promote it (Davis, 2008). On the other hand, the interchangeability of social inclusion with other concepts raises similar problems to its multiple definitions, such

as confusion across stakeholders, numerous and conflicting measurements, and the inability to distinguish between the definition, outcomes, and processes of social inclusion.

When researchers, policymakers, and people with intellectual and developmental disabilities define social inclusion primarily through interpersonal relationships, then social inclusion becomes interchangeable with social interaction or social networks. One of the main problems of defining social inclusion as social interaction is that social interaction is an interpersonal concept without any community dimension.

Definitions of social inclusion can also overlap with the concept of community participation, in part, due to equally expansive definitions of community participation. Take, for example Verdonchot et al., (2009) who defined community participation as involvement in “(1) domestic life, (2) interpersonal life, (3) major life areas consisting of education and employment, and (4) community, civic, and social life” (p. 304). By including domestic and interpersonal life within their definition, Verdonchot et al. dissolved the distinction between a person’s social network and their involvement in the community.

Social inclusion can also become interchangeable with social capital. This occurs when the definition of social inclusion includes benefits like increased trust, reciprocity, and personal efficacy that may result from social networks and community involvement. Social capital, like social inclusion, is a complex concept with multiple definitions (Phillips, Robison, & Kosciulek, 2014). Robert Putnam defined social capital as “features of social life--networks, norms, and trust--that enable participants to act together more effectively to pursue shared objectives” (Putnam 1995, 664-665). Elsewhere, however, Putnam defined social capital as “networks and the associated norms of reciprocity [that] have value” (2001, p. 1). Similar to strains in social inclusion, Putnam collapsed *having* interpersonal relationships/community involvement into the *effects* of these relationships/activities.

When definitions of social inclusion encompass subjective feelings of belonging, value, and acceptance, then social inclusion becomes interchangeable with a sense of belonging. Some scholars have embraced a sense of belonging over social inclusion, arguing that social inclusion without a sense of belonging misses the fact that social inclusion in mainstream settings may decrease a person's quality of life (Hall, 2010). When Power (2013) argued that belonging "does not solely involve being placed within an environment, but *fitting in* within a specified place or environments," he challenged social inclusion approaches that rely on objective and quantitative measurements (p. 69; Hall, 2010; Cobigo et al., 2012). Emphasizing the subjective component of social inclusion is important, but replacing social inclusion with a sense of belonging may tell us little about the actual level of involvement of people with disabilities in their communities or their social networks.

Finally, Duggan and Linehan (2013) argued that the concept of social inclusion has become interchangeable with independent living. Broad definitions of social inclusion include independent living within the scope of the definition (Power, 2013; Hall, 2009). Quinn and Doyle argued that independent living and social inclusion are interrelated and that the Convention on the Rights of Persons with Disabilities promotes independent living through "enhancing social connectedness" (2012, p. 15). Our review of social inclusion suggests that the concept is also interrelated with community participation, belonging, and social interaction. Thus, while narrow conceptions deemphasize the community, broad definitions of social inclusion become interchangeable with community participation, social capital, and belonging. While conflicting definitions may make it difficult to measure and implement social inclusion, it also raises questions about the purpose of social inclusion.

1.3. Social Inclusion: What is it for?

As descriptions of social inclusion have expanded, so too have its aims, as can be seen in Figure 1, column 3. Reviewing the many different purposes attributed to social inclusion

reveals the conceptual complexity embedded in the concept. This complexity arises due to the ways in which social inclusion is not only a personal issue, but also an issue of civil rights, equality, and economics. Consequently, *who* benefits from social inclusion varies across definitions. Most often, the beneficiary is the person with an intellectual and developmental disability. However, beneficiaries may also include people with intellectual and developmental disabilities as a group and to members of society more broadly.

Many have conceptualized individuals as the primary beneficiary of social inclusion. People with intellectual and developmental disabilities have identified increased opportunities for friendship and community involvement as important goals (Abbott & McConkey, 2006; Kampert & Goreczny, 2007). Researchers have argued that social inclusion promotes happiness, self-esteem, confidence, mental health (Forrester-Jones et al., 2006), well-being (Johnson, Douglas, Bigby, & Iacono, 2012), and decision-making capacity (Johnson, Douglas, Bigby, & Iacono, 2009). Essentially, social inclusion improves lives--for people with and without disabilities (Mahar, Cobigo, & Stuart, 2009; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002).

Social inclusion may also offer benefits to people with intellectual and developmental disabilities as a distinct social group. For instance, researchers have suggested that promoting social inclusion can enable people to contribute to society (Overmars-Marx et al., 2014), overcome social exclusion (Mahar et al., 2013; McConkey & Collins, 2010a), combat poverty, unemployment, and poor access to healthcare (Power, 2013), and enhance community safety and protect against abuse (Power, 2013; Quinn & Doyle, 2012). In contrast to research documenting individual outcomes of social inclusion, these broad-based outcomes are less supported by data. To accomplish these goals, it is likely insufficient if some individuals with disabilities are socially included. While these individual benefits are important, they are likely inadequate to overturn societal-wide exclusion and discrimination.

Hence, these purposes intensify the *scale* of social inclusion in order to counter the marginalization of people with intellectual and developmental disabilities as a social group.

Individual and group-based benefits from social inclusion, however, hinge upon broader changes in the attitudes and behaviours of society. Indeed, many people with intellectual and developmental disabilities have reported that negative community attitudes impede social inclusion (Abbott & McConkey, 2006). Researchers have suggested that social inclusion can decrease negative attitudes, stereotypes, stigma, and discrimination against people with intellectual and developmental disabilities (Johnson et al., 2009; Mahar et al., 2013; Power, 2013). Research seldom investigates the relationship between social inclusion and public attitudes, but because contact with people with disabilities is a consistent predictor of more positive attitudes, then increased levels of social inclusion may decrease negative attitudes (Sharma, Forlin, Loreman, & Earle, 2006). Social inclusion also fulfils the aims of national and international public policies and mandates. Thus, many authors acknowledged that social inclusion complies with the Convention on the Rights of Persons with Disabilities and national policies (Cobigo et al., 2012; Duggan & Linehan, 2013; Mahar et al., 2013; Martin et al., 2011; Overmars-Marx et al., 2014; Power 2013; Quinn & Doyle, 2012).

So, who is social inclusion for? Social inclusion is for all of us: an individual with an intellectual or developmental disability; for people with intellectual and developmental disabilities as a group; for members of society who will benefit from their inclusion; and for nation states who can benefit from the participation of people with all levels of abilities. If social inclusion is to accomplish all this, then we need a clear and accessible definition.

2. Social Inclusion Defined

Our model of social inclusion, shown in Figure 2, focuses on two domains-- interpersonal relationships and community participation. Within each domain, we define important categories that capture the structural and functional components behind social

inclusion. Interpersonal relationships and community participation recur in the social inclusion literature (McConkey & Collins 2010a; Asselt-Goverts, Embregts, & Hendriks, 2013), are central to a person's quality of life (Schalock et al., 2005), and both are necessary for social inclusion. These two domains should overlap and mutually support one another, which our model captures by the circulating arrows that course through both domains. Unlike expansive definitions of social inclusion, our model separates the definition of social inclusion from the processes that may produce social inclusion as well as the subjective feelings that may result from inclusion. Instead, we focus on specifying the components of interpersonal relationships and community participation.

2.1. Interpersonal Relationships

As shown in Figure 2, interpersonal relationships contain three kinds of characteristics: (1) category, (2) structure, and (3) function.

2.1.1. Category. Category refers to the kinds of people in the social network, including family members, staff, friends, acquaintances, and intimate partners (either with or without a disability). People with intellectual and developmental disabilities have reported valuing relationships with staff (Clarkson, Murphy, Coldwell, & Dawson, 2009) and other people with disabilities (McVilly et al., 2006b), and feeling a sense of belonging to a network when they have different people fulfilling different needs (McVilly et al., 2006a).

Research on social capital has suggested that interpersonal relationships facilitate bonding and bridging. Bonding relationships are between people who share a common bond or a common identity, and offer opportunities to build trust, reciprocity, and confidence (Cummins & Lau, 2003; Hall, 2009; Nash, 2005). Bridging relationships bring diverse people into contact and these relationships may be especially important in improving employment outcomes for people with disabilities (Phillips et al., 2014).

2.1.2. Structure. Structural components of specific interpersonal relationships include the length of the relationship, the origin of the relationship, frequency of contact, and who initiates contact (Asselts-Goverts et al., 2013). Another structural dimension is the location of social interaction, whether it occurs in the home, the community, or online.

Heaney and Israel (2008) described four additional structural characteristics: reciprocity, intensity, formality, and complexity. Reciprocity is the level of mutual support and resources, and intensity is the level of emotional closeness. Although people with intellectual and developmental disabilities reported having close relationships with staff (thus high in intensity), these relationships were seldom reciprocal as staff had more knowledge of clients (Hermesen, Embregts, Hendriks, & Frielink, 2014). Formality measures the organizational or institutional source of relationships and complexity refers to the number of functions a relationship serves (Heaney & Israel, p. 190). These structural characteristics are important, particularly in relation to relationships with staff.

The whole social network can also be measured along four important structural characteristics: size, homogeneity, geographic dispersion, and density. Homogeneity captures the similarity of network members along demographic information, such as age, race, and disability status. Geographic dispersion refers to the location of members, whereas density refers to the “extent to which network members know and interact with each other” (Heaney & Israel, p. 190). Measuring the structural components of a person’s whole social network enables us to get a broader picture of a person’s level of inclusion and exclusion.

2.1.3. Function. Relationships function to provide multiple kinds of social support and we divide support into three categories: emotional, instrumental, and informational. Emotional support includes love, care, and trust (Heaney & Israel). Instrumental support involves “tangible aid and services” and informational support includes “advice, suggestions, and

information” (Heaney & Israel, p. 190). People with disabilities have reported that they need each kind of support (Abbott & McConkey 2006; Dodevska & Vassos, 2013).

2.2. Community Participation

As shown in Figure 2, we divide Community Participation into three kinds of characteristics: (1) category, (2) structure, and (3) the degree of involvement.

2.2.1. Category. Community activities include (1) leisure activities, such as hobbies, arts, and sports, (2) political and civic activities or organizations, (3) productive activities, like employment or education; (4) consumption, or access to goods and services; and (5) religious and cultural activities and groups (McConkey, 2007; Verdonschot et al., 2009).

2.2.2. Structure. People with intellectual and developmental disabilities take part in activities in many settings, which we classify as three different structural categories: segregated, semi-segregated, and integrated settings. Parr’s analysis of mental health and his concept of “semi-institutional sites” informs our three structural categories (2000, p. 228; Hall, 2010). The concept of community most often evokes activities that take place in “mainstream” settings, as opposed to segregated settings, due in large part to the influence and value of normalization in the field of intellectual and developmental disabilities. Hall criticize this emphasis on mainstream community settings because it ignores how mainstream settings may be hostile to people with intellectual and developmental disabilities and that segregated settings may offer benefits (Hall, 2009). By offering three types of structural settings, our model of social inclusion recognizes the importance of these distinctions.

Segregated activities involve people with intellectual and developmental disabilities, paid staff, and take place in segregated facilities, such as group homes, separate classes, and sheltered workshops. Because most people with intellectual and developmental disabilities live with their families, segregated activities also refer to activities that involve a person with

an intellectual or developmental disability and members of their immediate family only. Family members have reported that they avoid activities in their communities due to perceived hostility and therefore choose activities in their own home, the homes of friends, or day centers organized by friends (Power, 2008). Time constraints and lower socio-economic status may also restrict families' engagement with their community (King, et al., 2003).

We conceptualize three forms of semi-segregated activities. The first is an activity that involves paid staff and/or family members and people with intellectual and developmental disabilities only, but which takes place in community settings, such as restaurants (Clifford, 2013), art programs (Hall, 2013), or theater groups (Perring, 2005). The second form of semi-segregated activity takes place within segregated facilities, but includes community members, such as facilitated dance groups run by volunteers and researchers (Nash, 2005). Cyber communities may be a third form of semi-segregated setting, although little research has explored this type of community activity for people with intellectual and developmental disabilities. Semi-segregated activities may offer people opportunities for developing a sense of belonging, confidence, and group identity, which may bolster a person's ability to transition to and participate in integrated settings (Hall, 2013).

Finally, we define integrated settings as mainstream settings in the community. By participating in mainstream settings, people with intellectual and developmental disabilities have the greatest opportunity to promote positive awareness about disability and inclusion. However, as integrated settings are those in which people with intellectual and developmental disabilities have been excluded, these activities may offer the most challenges.

2.2.3. Level of Involvement. People have different degrees of involvement in communities, which we conceptualize as presence, encounter, and participation. Community presence is physically being in a community with little to no contact with other people (Thorn, Pittman, Myers, & Slaughter, 2009; O'Brien & Lyle, 1987). While many approaches to social

inclusion dismiss presence as an insufficient substitute for participation (Clement & Bigby, 2009), we recognize that presence may be an important component for community activities that require minimal involvement and because presence is likely a precursor to participation.

We define community encounters as meetings between strangers in the community setting that can be fleeting or more sustained (Weisel, Bigby, & Carling-Jenkins, 2013; Bigby & Wiesel, 2011). Interactions with servers at a restaurant or people on a bus may appear unimportant, but these encounters offer a sense of belonging to people with intellectual and developmental disabilities and provide a springboard for participation (Wiesel et al., 2013). Moreover, encounter offers a way to modernize the concept of community participation, as many day-to-day interactions fall under the category of encounter (Bigby & Wiesel, 2011).

Community participation is involvement in community activities that promote the development of interpersonal relationships. Because the structural category includes segregated and semi-segregated settings, we divide participation into segregated participation, semi-segregated participation, and community participation levels. This allows us to conceptualize the different ways that people with intellectual and developmental disabilities participate across settings. Finally, while some community activities may progress from presence to participation, this progression is unnecessary for each community activity, as individual preferences will help determine the level of desired involvement.

Together, these domains--interpersonal relationships and community participation--form the main components of social inclusion and these domains interact. More community involvement should increase and strengthen a person's social network and strong interpersonal relationships should increase access to and level of involvement in the community (Petry, Maes, & Vlaskamp, 2005). Additionally, there is overlap across domains, as members in the social network are some of the same people we engage with in the community. Part of the problem for many people with intellectual and developmental

disabilities is that each domain--interpersonal and community--are so impoverished that this dynamic cycle never occurs (Duggan & Linehan, 2013).

3. Ecological Pathways to and from Social Inclusion

As shown in Figure 3, we take an ecological approach to social inclusion to capture how individual, interpersonal, organizational, community, and socio-political variables influence interpersonal relationships and community participation (Overmars-Marx et al., 2014; Verdonshot et al., 2009). An ecological model of social inclusion fits with broader trends in the developmental disabilities field that understand disability as itself a product of individual, environmental, and social factors (Luckasson & Schalock, 2013). Ecological conditions can promote or impede social inclusion, thus we conceptualize these variables as both *enabling* and *disabling* conditions. Additionally, we acknowledge the ways in which the outcomes of social inclusion may be positive or negative. Our examples of ecological conditions and outcomes are not exhaustive, but rather suggestive of the ways in which future research could use an ecological approach to social inclusion.

3.1. Individual

Individual enabling/disabling conditions include a person's level of functioning, self-motivation, confidence, knowledge of the area and of activities, and the use of goal setting (Clarkson et al., 2009; McConkey & Abbott, 2006; McConkey & Collins, 2010b). Individual outcomes of social inclusion may include increased happiness, improved self-esteem, and a sense of belonging (Cobigo et al., 2012), but social inclusion may also lead to negative feelings, such as an increased sense of loneliness (Hall, 2005).

3.2. Interpersonal

Interpersonal enabling/disabling conditions can include relationships with staff (Clarkson et al., 2009), staff attitudes (Hermsen et al., 2014; McConkey & Collins, 2010),

family attitudes (Clement & Bigby, 2009), the relationship between families and staff, and relationships across families (Power, 2008). Family members and staff members play an important role enabling people with intellectual and developmental disabilities maintain relationships and participate in their communities (Whitehouse et al., 2001). Positive interpersonal outcomes may include respect and trust between people, and increased social capital. Interpersonal relationships may include negative outcomes, such as discrimination in employment settings (Hall & Wilton, 2011) or physical abuse from intimate partners (Ward, Bosek, & Trimble, 2010), or abuse from staff, family members, or other service users (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010). Hence, some interpersonal conditions/outcomes may result in decreases in social capital and self-esteem.

3.3. Organizational

Organizational conditions exist within informal networks (like families) or formal networks (like employment settings or group homes). Organizational level conditions for families include socioeconomic status, social capital, and family culture (Chenoweth & Stehlik, 2004). Organizational level conditions within a group home may include the culture of group homes (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012); mission statements, attitudes of managers (Dodevska & Vassos, 2013); training opportunities for staff (Hutchinson et al., 2014); and access to communication services (Johnson et al., 2009). Self-advocacy organizations, where available, also have different kinds of group culture that could affect social inclusion, as these groups differ in their ability to promote self-efficacy and self-determination (Walmsley and The Central England People First History Project Team, 2014). Organizational level conditions include organizational cultures within the community, such as churches, schools, employment centers, and law enforcement. Organizational outcomes of social inclusion may include changes in organizational culture, as cultures may become more affirming of inclusion. Hostile or ambivalent organizational cultures may undercut enabling

conditions at the individual and interpersonal level, whereas positive organizational cultures may intensify the effectiveness of individual and interpersonal conditions. Hence, it is important to keep in mind how conditions interact across levels.

3.4. Community

Community level conditions include the type of living accommodation, such as size and setting (Duvdevaney & Arar, 2004; McConkey & Collins, 2010a; McConkey, 2007; Robertson et al., 2001); availability of and access to appropriate services and transportation (Power, 2008), and online communities and resources. Community conditions also encompass community attitudes, culture, geography, and discourse. While contact with people with disabilities can be predictor of more positive attitudes (Sharma et al., 2006), it does not always do so (Alghazo, Dodeen, & Algaryouti, 1999). Researchers find that the effectiveness of contact hinged on the quality of contact (McManus, Feyes, & Saucier, 2011) and that contact reinforced negative stereotypes (Siperstein, Norris, & Mohler, 2007). However, there is little research on the effects of social inclusion on public attitudes and more work is necessary to understand the role of community conditions (Amado, et al., 2013).

3.5. Socio-political

Political conditions include laws and legal enforcement (Quinn & Doyle, 2012; Vanhala, 2011), market forces (Hermsen et al., 2014), and state perspectives and histories around service delivery (Power & Kenny, 2011). Little research examines whether social inclusion affects political change, but because political change is often an outcome of groups mobilizing together--including parents, professionals, and self-advocates--increasing social inclusion could have political effects (Vanhalla, 2011). Moreover, political level conditions affect behavior, as legislative cutbacks put more pressure on families (Power, 2008) and have negatively influenced organizational cultures and staff behavior (Hermsen et al., 2014).

In optimum situations, these ecological conditions *are* enabling, but these conditions may also *constrain* inclusion, such as lack of skills (Asselt-Goverts et al., 2013), unsupportive staff (McConkey & Collins, 2010a), negative organizational cultures (Bigby, et al., 2012), societal attitudes that stereotype people with disabilities (Milner & Kelly, 2009), or lack of funding and legislative cutbacks (Asselt-Goverts, Embregts, & Hendriks, 2014). Additionally, factors at each level interact, further producing enabling or disabling conditions. For example, individual and interpersonal levels interact, as staff and/or family members may help facilitate or constrain a person's knowledge, self-motivation, and use of goal setting. Community level conditions--such as the culture of group homes and attitudes of managers--affect staff attitudes, the relationships that staff develop with clients (Bigby et al., 2012), and relationships between families and service providers (Power, 2008).

Conceptualizing interventions within an ecological model may help sustain their effectiveness, as individual behavioural change is most successful when situated in organizations, communities, and political climates that are supportive (Sallis, Owen, & Fisher, 2008). Research has shown that staff have abandoned interventions that increased social inclusion, even when participants perceived positive outcomes (Whitehouse et al., 2001). As service providers face increasing demands for showing the effectiveness of interventions (Duggan & Linehan), it is crucial that stakeholders are able to measure the relationship between social inclusion, ecological conditions, and outcomes.

4. Recommendations & Next Steps

The conceptual ambiguity of social inclusion invites both narrow and vast definitions of the concept. Narrow definitions undercut the social and political purposes of social inclusion, whereas vast definitions threaten to become too demanding, thus inviting some stakeholders to conclude that social inclusion may be for some people with disabilities, but not all. Therefore, our definition focuses on two recurring themes in the literature:

interpersonal relationships and community participation, which are also core domains of quality of life (Schalock et al., 2005). The next step is to use the ecological model of social inclusion to guide future research questions and approaches. We describe four research agendas on social inclusion that our ecological model can help move forward: (1) sustaining organizational interventions (2); the role of families; (3) people along a broader spectrum of disability; and (4) the role of communities.

4.1. Organizational Implementation

The positive results of small-scale interventions seldom promote system-wide organizational change that can sustain social inclusion within service providers (Amado et al., 2013), in part due to the confusion across stakeholders into the meaning and content of social inclusion. Additionally, research seldom looks at interventions across all five ecological levels. Our definition and model can help minimize confusion and promote a broader examination into the enabling and disabling conditions behind social inclusion.

4.2. Families

An organizational focus of research, however, should not overshadow the role of families. Indeed, most people with intellectual and developmental disabilities live with their families, yet little research examines their level of social inclusion (Amado et al., 2013). What are the ecological conditions that affect families' opportunities and obstacles for social inclusion? How do family ecological conditions--such as family culture, socioeconomic status, and social capital--affect social inclusion?

4.3. Broader Spectrum of Disability

Most research on social inclusion focuses on people with mild or moderate forms of intellectual and developmental disabilities, leaving unanswered questions about the interpersonal relationships and community involvement of people with severe and profound

forms of intellectual and developmental disabilities. How do people with severe and profound levels of impairment experience community participation? How do community attitudes on social inclusion vary according to different levels of impairment?

Similarly, there is little research on the social inclusion of adults with autism spectrum disorder (ASD). Existing literature tends to focus on adults with ASD who are high functioning and with low severity of autism symptoms (Tobin, Drager, & Richardson, 2014). How do people with ASD experience social inclusion and what are the challenges they face? Additionally, do adults with ASD without an intellectual disability have higher rates of social inclusion than adults with ASD with an intellectual disability?

4.4. Community Resources & Readiness

While these first three lines of research focus inward to the individuals, families, and service providers, our last recommendation is for researchers to look outward into the community. Communities face different challenges in fostering social inclusion depending on their characteristics, for example, rural versus urban communities, or heterogeneous versus homogenous communities. Different forms of community organizations--religious, civic, political, and employment settings--will likely have different attitudes toward people with intellectual and developmental disabilities that affect social inclusion.

5. Conclusion

Our ecological model provides a comprehensive and coherent model of social inclusion that encompasses the complex array of factors that affect social inclusion. Future research should focus on designing and promoting interventions that can increase the quantity and quality of social inclusion for people with intellectual and developmental disabilities in our communities.

Social Inclusion: Definitions, Terminology and Aims

Figure 1

Interpersonal Relationships

Community Participation

Figure 2

Ecological Pathways to and from Social Inclusion

Figure 3

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