

Social Inclusion and Community Participation of Individuals with Intellectual/Developmental Disabilities

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Abstract

As more individuals with intellectual/developmental disabilities are physically included in community life, in schools, neighborhoods, jobs, recreation, and congregations, the challenge of going beyond physical inclusion to true social inclusion becomes more apparent. This article summarizes the status of the research about community participation and social inclusion, summarizes some debates and points of contention, notes emerging research issues, and highlights needed areas of research. It is clear that most research on these topics has been conducted with individuals who are in paid formal services, and there are great needs for understanding the community participation of individuals who live on their own or with their families, as well as researching social inclusion by focusing on the attitudes and experiences of community members themselves, not just individuals with disabilities and paid providers.

Key Words: *inclusion; community inclusion; social inclusion; integration; community membership; community living*

Introduction

The social inclusion and community participation of individuals with intellectual/developmental disabilities (IDD) have been studied since at least the first major wave of research regarding people with intellectual disabilities leaving institutions. As early as 1967 Edgerton (1967) noted that people with intellectual disabilities who left institutions wanted to “pass” as persons without disabilities, as “normal.” In the 1970s and 1980s, the de-institutionalization research that examined community participation for those individuals who left institutions was focused on physical inclusion (e.g., Hill, Lakin, Novak, & White, 1987; Hill, Lakin, Bruininks, Amado, & Anderson, 1989). For example, data were collected about the distance to and quantity of community resources and the type and frequency of weekly community activities for people in residential services; comparisons between life in the institution and in the community were based on such factors (Heal, Haney, & Novak, 1988). Even in this early de-institutionalization research, it was frequently noted that although people were in their communities, there was still a gap with people being of their

communities; this concept reflects the fact that although people might physically live in a community home or participate in community activities, they experience little sense of belonging and membership and few meaningful relationships with nondisabled community members. Over time, research shifted from focusing only on physical inclusion to also addressing social inclusion—that although people might be physically included, there were still often social barriers with ordinary community members. This distinction about social inclusion has also emerged as services and supports have become more individualized and more integrated (Stancliffe, Emerson, & Lakin, 2000). Inclusive classrooms and schools; institutional closures; the Americans with Disabilities Act; the Olmstead Supreme Court decision, which clarified the right to the most integrated environment possible; and other movements both in the United States and other countries have all contributed to the expanding vision of social inclusion and inclusive communities.

This vision has been reflected in the emergence of various other principles, theories, and practices. As the principle of normalization (Wolfensberger, 1972) developed into the concept of

Social Role Valorization (Wolfensberger, 1983), the importance of people with disabilities having valued social roles in community life emerged. The goals of community participation and community social roles have been included in measures of quality of life such as the outcome measures of the accreditation agency the Council on Quality and Leadership and in the principle they have promoted of increasing the “social capital” of individuals with disabilities (Council for Quality and Leadership, 2003). The United Nations Convention on the Rights of People with Disabilities (United Nations, 2006) includes the right to full participation and inclusion in society and community life. As these principles and practices have evolved, research has followed and contributed to greater understanding of social inclusion. This paper will summarize the established research findings in this arena of quality of life, community participation, and social inclusion and note several areas of debate or contention. While a significant amount of research has demonstrated successful inclusion in school environments (e.g., Bowe, 2005; Stainback & Stainback, 1996), the primary focus of this paper will be the community inclusion of adults with intellectual and developmental disabilities. Based on emerging research directions for this group, future directions for research will also be summarized.

What Are the Established Research Findings? What Do We Know?

The literature in this quality of life outcome area has primarily addressed four areas: (a) measurement of the degree of integration, inclusion, and participation; (b) friendship and loneliness; (c) factors that affect the degree of social inclusion; and (d) intervention studies that have identified strategies and methods that work to increase social inclusion. These four areas are summarized in this section.

Measuring the Degree of Integration, Inclusion, and Participation

Some theorists and researchers have made attempts to distinguish between integration, inclusion, participation, and belonging. Specific differences in the phenomena for which these terms are used is a point of debate as noted later in this paper, but this section will address the research about measurement for the general concept as a whole.

The degree of inclusion has been measured in many different ways, in many different types of

environments. Conroy, Fullerton, and Brown (2002) described three kinds of measures of integration, with “frequency” measures as the most often used, tested, and understood. Frequency measures reflect the actual frequency and types of community activities a person with disabilities experiences, such as their use of community resources or how frequently they see friends. For example, Harris Interactive has surveyed Americans with disabilities since 1986 (Kessler Foundation/National Organization on Disability, 2010) and compared integrative activities of citizens with and without disabilities on such measures as shopping, recreation, and going to places of worship.

The other two types of measures which Conroy et al. (2002) described are “choice” and “intensity” measures. Choice measures address such items as “if you want to go out somewhere (where everyday citizens without disabilities might go) on the spur of the moment, can you?” and “Do you have permission to go out?” Such items are frequently incorporated into instruments focused on self-determination and choice. Intensity measures reflect the degree a person is in the community versus being of that community. They balance relationships with the complexity of personal preferences. For example, some people consider one intimate friend sufficient and others are lonely despite having 10 such friends. These measures are the most difficult to develop and to validate (Conroy et al., 2002), and determining the complexities of personal preferences, satisfaction, and importance of particular relationships is certainly an emerging research issue.

The degree and nature of inclusion has been measured and described across different age groups and environments, including various school environments (e.g., Carter & Hughes, 2005; Logan & Keefe, 1997; Lohrmann & Bambara, 2006; Mu & Siegel, 2000; Rossetti, 2011; Smith, 2007), early childhood programs (e.g., Guralnick, Connor, Hammond, Gottman, & Kinnish, 1995), and post-secondary programs (e.g., Casale-Gionnola & Kamens, 2006). For adults with IDD, environments studied include community living (e.g., Cummins & Lau, 2003; Hall, 2009) and work (e.g., Chadsey, 2008; Hughes, Kim, & Hwang, 1998; McGaughey, Kiernan, McNally, Gilmore, & Keith, 1995). Specialized environments have also been studied, such as faith communities (e.g., McNair & Smith, 1998; Vogel, Polloway, & Smith, 2006), community service organizations (Amado, Boice, &

DeGrande, 2012) and community organizations such as seniors' groups (Stancliffe, Bigby, Balandin, Wilson, & Craig, 2012).

An example of this type of measurement study that used frequency measures to describe the nature of community participation and social relationships was conducted recently in the Republic of Ireland. The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) completed the first wave of data collection from a sample of 753 adults aged 40 and older randomly selected from Ireland's National Intellectual Disability Database (NIDD; McCarron et al., 2011). These individuals were living in residential or community settings, with a small number living independently or with their families. The study included questions on social networks, living situations, and community participation and roles. Some of the major findings were as follows:

1. The majority of adults had some contact with at least one family member. However, 25% reported meeting their family once a year or less. Frequency of contact declined with increasing age and was also less for those with a severe to profound intellectual disability (ID).
2. Over three quarters of respondents reported that they never wrote, texted, emailed, or used social media tools such as Facebook to contact their family or friends.
3. Older age, more severe levels of ID, and living in residential centers often meant having fewer members in one's social network.
4. Fifty percent of those self-reporting stated that they sometimes felt lonely, and one in three who reported experiencing loneliness found it difficult to make friends.
5. The majority of adults with an ID had someone to confide in; however, three quarters reported that their confidant was a key worker/support person.
6. Most adults with an ID had a hobby and engaged in eating out, attending church, shopping, and going to the hairdresser and cinema, but seldom with friends outside their home.
7. The majority of respondents did not use public transportation, were dependent upon others for transportation and assistance to access community options, and reported this to be their greatest barrier to successful community participation.
8. Overall, 14.7% of people with an ID reported receiving help from their neighbors, and 13.1%

said they helped their neighbors and reported this engagement to be a positive experience.

9. In comparison to reports for the general Irish population (Barrett, Savva, Timonen, & Kenny, 2011), adults with an ID had less involvement in retirement clubs, evening classes, or residents' associations within their communities. Special Olympics (20%) was the most frequently cited organizational engagement.

The authors concluded that society has done a better job of increasing the community presence of people with an ID than in facilitating their "living" within the community. These findings are consistent with the summary of studies in this area by Verdonchot, deWitte, Reichraft, Buntinx, and Curfs (2009b). McCarron et al. (2011) also agreed with Cummins and Lau (2003) that simple location in the community is not a sufficient measure of social connectedness, and they recommended that more work is needed to establish measures for people with severe and profound intellectual and other developmental disabilities (IDD). They also concluded that greater consideration should be given to the value of relationships with family members, people's opportunities to contribute to the benefit of their communities, and relationships with other people with IDD and with staff members that individuals consider their friends.

Friendship and Loneliness

A few recent studies have begun to examine the types of social networks that people with IDD have, as well as their reports of loneliness. Besides inclusion being an issue of values and rights, these findings provide some empirical bases for supporting the importance of inclusion.

Friendship. As above, research has found that people with IDD have few friends and mostly they name other disability service users, staff, and family members as their friends. Studies that have examined people's social networks have found that their networks are primarily made up of paid staff, family members, and others with disabilities. Examples of the use of the measure of social network size include the finding by Verdonchot et al. (2009b) of an average 3.1 people in the social networks of individuals with IDD, and that one of the 3.1 was a staff member. Another study (Horner, Stoner, & Ferguson, 1988) found 12.5 people in individuals' social networks with one or fewer nondisabled community members. Robertson et al.

(2001) examined the social networks of 500 people in residential settings and found a median of two people excluding staff. These sizes contrast with studies which have found averages of up to 125 people in the social network of individuals without disabilities (e.g., Hill & Dunbar, 2003).

Loneliness. The phenomenon of “loneliness” as reported by people with IDD has also started to be more systematically examined. The National Core Indicators instrument used by 36 U.S. states for measuring quality and progress in their service system uses personal interviews of service recipients as one method of data collection, and one of those questions is about loneliness (Stancliffe et al., 2007). Up to half of people with IDD reported feeling lonely in one study (Stancliffe et al., 2007), with one third reporting sometimes feeling lonely and one sixth reporting they often felt lonely. Stancliffe, Lakin, Taub, Chiri, and Byun (2009) found that 46% of people in intermediate care facilities and Medicaid waiver-funded homes reported feeling sometimes or often lonely. Compared to the general community, loneliness is more widespread among both children and adults with IDD (Margalit, 2004; Sheppard-Jones, Prout, Kleinert, & Taylor, 2005). McVilly, Stancliffe, Parmenter, and Burton-Smith (2006) studied the frequency of loneliness reported among people with IDD, and reported that it is often related to the absence of an intimate partner, or “girlfriend” or “boyfriend.”

Of course the simple question of whether a person experiences loneliness does not capture the complexity of this construct, such as whether one wants to be alone and whether an individual feels lonely despite having many people around. Margalit (2004) has described some of the complex aspects of loneliness in the emotional and social life of students with disabilities and such approaches could be applied to adults with IDD also.

Factors that Affect Degree of Social Inclusion

The third primary area that has been studied about social inclusion is the different factors that affect the degree of such inclusion. The factors that have been analyzed include personal characteristics such as age and degree of disability (e.g., Robertson et al., 2001) and environmental factors such as residence size (Stancliffe, Abery, & Smith, 2000). In terms of individual factors, those who are older and who have a greater degree of disability

experience less inclusion (Robertson et al., 2001). In terms of environmental factors, in general, people with IDD living in community homes have greater community participation than people living in institutions (Stancliffe et al., 2000). Although they have increased physical presence compared to institutional life, they still experience major gaps in social inclusion, relationships, and belonging (Walker, 1999). People with IDD who live in smaller community settings have more participation than people in larger more segregated settings, but their participation level is lower than nondisabled individuals and those with other types of disabilities (Verdonschot et al., 2009b).

Perry and Felce (2005) found that staff performance, which they defined as staff attention and assistance from staff, influenced social engagement and community activities. When staff paid more attention to residents, this was associated with higher frequencies of community activities and of social engagement. Verdonschot, deWitte, Reichraft, Buntinx, and Curfs (2009a) reviewed 11 studies and summarized that the following environmental factors were found to have an impact on community participation: (a) opportunities to make choices, for autonomy, and for resident involvement in policy making; (b) variety and stimulation of the facility’s environment; (c) smaller size; (d) vocational services, and (e) availability of transportation. Greater family involvement and the availability of social support were also related to increased community participation, as well as a positive staff attitude.

Interventions: Strategies and Methods that Work to Increase Social Inclusion

The fourth primary area studied has been strategies and methods that work to increase social inclusion. Many projects and initiatives have demonstrated successful methods to increase inclusion in many different types of environments. One overriding factor in success is regular contact in integrated environments, with opportunities for meaningful interaction. For example, integrated school (Smith, 2007) and work (Hughes, Kim, & Hwang, 1998) environments greatly increase inclusion. Weekly group or club activities also do so (Abery & Fahnestock, 1994; Amado et al., 2012).

Intervention projects have addressed staff efforts (e.g., Amado, 2010), congregational initiatives (Carter, 2007), inclusion in community

recreation programs (Abery & Fahnestock 1994), and community-wide efforts (Kretzmann & McKnight, 1993). An example of such an intervention study was conducted in Australia. This study was focused on older employees in sheltered employment and assisted them to begin to develop a retirement lifestyle by dropping one day per week of work and attending a local mainstream community group or volunteering opportunity that provided an inclusive opportunity to pursue personal interests (Stancliffe, Bigby, Balandin, Wilson, & Craig, 2012). The rationale was that many other Australian retirees without lifelong disability take part in community groups and volunteering. Members of the community groups volunteered as mentors and received training on how to support the person's participation in the social interactions and activities while at the group (Wilson, Stancliffe, Bigby, Balandin, & Craig, 2010). Overall 27 different community groups each accepted one individual with a disability as a long-term member with one to six mentors per participant. The diversity of groups reflected individual's preferences; for example, a man who enjoyed singing joined a community choir, a woman who loved animals volunteered at a cat shelter, and a woman with an interest in cooking attended a community kitchen.

Inclusion outcomes were very encouraging, with 86% of participants going to their community group one day per week for at least 6 months, and 72% still attending (some for as long as 2 years) when data collection ceased. Participants averaged almost 4 hours each week at their group. Compared to baseline, they significantly increased their participation in inclusive community groups, gained an average of four new social contacts (acquaintances and friends), spent much more time with these contacts, and decreased their work hours as planned. Relative to a matched comparison group who continued to work their usual hours, intervention group participants were significantly more socially satisfied post intervention; they were more likely to report having friends and people to talk to and were more likely to receive social support from others (Stancliffe et al., 2012).

A subset of these intervention studies is emerging research on the attitudes of community members and increasing their role in building inclusive communities. For example, Amado et al. (2011) surveyed community organizations about membership of individuals with disabilities in their organizations and what support the group members

needed to be successful in including members with disabilities. Studies of congregations (e.g., Vogel et al., 2006) have also assessed successful strategies for addressing barriers toward inclusion on the part of nondisabled congregation members. These studies documented the benefits that community members reported that they gained from including people with disabilities in their groups and organizations, such as increased sensitivity, caring, and friendship. Challenges reported include transportation and personal characteristics such as the individual's communication abilities. Successful strategies include mentoring, practical information, and hands-on staff support to the community members (Amado et al., 2011; Vogel et al., 2006).

What Are the Big Debates or Points of Contention?

There are four main debates or points of contention clearly identified in the literature. These are theoretical frameworks, approaches to measuring social inclusion, accounting for an individual's preferences, and whether or not staff should be considered friends. These are discussed in more detail in the following sections.

Theoretical Frameworks

There are no clear conclusions about the differences between the terms *integration*, *inclusion*, *community participation*, and *community belonging*, and the differences between the phenomena for which these terms are used. What is labeled as participation or integration can often be seen as physical integration but not social integration or inclusion. It is not clear whether these different terms reflect different experiences by the person with disabilities or community members that can be measured or described, and whether different measures reflect the differences between these concepts.

Putnam (2000, 2007) has summarized many of the broad constructs of the conceptualization and measurement of social inclusion within the general society, including the concepts of physical capital, social capital, civic participation, religious participation, workplace connections, philanthropy, and reciprocity and trust. Different and more narrow theoretical constructs regarding inclusion of persons with IDD have been proposed, including items specific to disability. Hall (2009) in his qualitative meta-analysis proposed six themes as crucial to social inclusion of persons with IDD: (a) being

accepted as an individual beyond the disability, (b) having significant and reciprocal personal relationships, (c) being involved in activities, (d) having appropriate living accommodations, (e) having employment, and (f) receiving formal and informal supports. Martin and Cobigo (2011) proposed five domains of social inclusion: (a) relationships, (b) leisure, (c) productive activities, (d) accommodations, and (e) informal supports. Minnes and colleagues (2003) compared three instruments that measured community integration but did not find any significant correlation with measures of quality of life, concluding as others have that there is a need for a clear statement in research about the definition of community integration, and including both subjective and objective indicators.

Measures and Methods of Measuring

Given the differences between possible theoretical constructs and frameworks, it is not clear what factors should be assessed to determine a person's degree of community inclusion and how these factors should be measured. In studies in which community integration is measured, there is typically little or no ability to distinguish between physical and social inclusion. For example, two typical measures used in these studies are the number of community activities an individual experiences and their access to community resources, both of which could be seen as measures of physical integration. Other types of measures often used in determining community integration are the number and nature of personal relationships and contact with family, both of which could be considered social inclusion.

Besides the variety of types of factors measured, there have also been many different sources of information used to determine an individual's degree of social inclusion, including consumer surveys (Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990) and consumer interviews (McVilly et al., 2006). Proxy sources for information have included staff surveys (Hill et al., 1989) and interviews with the person and significant others (Council for Quality and Leadership, 2003; Tichá et al., 2012). Other forms of analysis to determine the degree of inclusion have included counting community activities (Tichá et al., 2012), behavioral observations such as counting the number of interactions with community members and length of those interactions (Newton, Olson, & Horner, 1995), participant observation (e.g., Johnson, Douglas, Bigby, & Iacono, 2011), and social network

analysis (e.g., Van Asselt-Goverts, Embregts, & Hendriks, 2013), which has analyzed both amount of contact and depth of connection. "Snowball" approaches (Farmer, 2007) that determine reciprocity in relationships have also been used (e.g., if I say you are a friend, do you also say I am?) although these have primarily been used in school environments rather than in adult settings. There is no validated agreed-upon instrument or method for measuring and for clarifying what is being measured. Such instruments or measures are needed to compare lifestyles, evaluate progress, and determine the relative effectiveness of interventions. An approach using multiple sources of information would most likely provide the most accurate and comprehensive picture, and it would be worthwhile to build consensus on such an approach in the research community.

How Do We Account for Individual Preferences?

Aspects that affect both the theoretical framework and the types of instruments used include how to account for an individual's desire for integration, their satisfaction derived from it, the nature of the community into which they desire to be integrated, and the optimal level of integration for that individual. Is "more" integration better for everyone? Cummins and Lau (2003) argue that forced integration is stressful for some. While some individuals with IDD prefer the company of others with IDD at least some of the time, there is not a clear way to account for the friendships and relationships between people with IDD themselves, in determining an individual's experience of community and belonging. Research questions include whether there are differences for people with different types of disabilities, and between people with and without disabilities.

Compounding the complexity of determining an individual's preferences is how to account for a person's expressed preferences for relationships with community members when that individual has had little exposure or experience with such relationships. For example, if an individual has primarily been schooled with, lives with, and works with other people with disabilities, they may not be able to express any preference other than what is already known to them. How can we account for the self-advocacy movement and people's desires to bond with others in similar situations? If people's relationships with nondisabled community members increase, we should not assume that people with IDD

will no longer desire or value relationships with others who have IDD. As people's experiences with community members increases, as they move or change jobs, or as they age, their preferences may change, which also needs to be addressed.

Another aspect of the complexity of determining an individual's satisfaction with their social network is that frequently when individuals with IDD are asked about their relationship preferences, they respond with the importance of intimate relationships, such as girlfriends, boyfriends, and getting married (McVilly, 2012). This arena is missing in most discussions of social inclusion. For example, an individual can have many community friends but without an intimate partner, can express a great degree of loneliness.

Are Staff Friends?

There is some contention about the complex role of staff in providing friendship versus supporting greater inclusion and participation (Cummins & Lau, 2003; Marquis & Jackson, 2000; Traustodottir, 1993). While some individuals with IDD consider their direct support staff their "friends," others argue that someone in a paid role is not a friend and should not be counted as such in measures of social networks. One measure of true friendship would be if a direct support worker was only counted also as a friend if they spent nonpaid time with an individual; however, such voluntary time violates labor rules in the United States and some other countries. At a minimum, when determining whether or not to include an individual staff member in measuring a person's social network, determining the depth of the relationship on both sides might be one avenue to pursue.

What Are the Emerging and Unanswered Questions?

As services and research evolve, numerous unanswered questions about social inclusion arise. These questions emerge as the service system develops more individualized support situations, as the role of families is increasingly recognized, and as the importance of the role of community members themselves emerges. Six key areas of emerging and unanswered questions are noted in this section.

How Do We Move from Community Activities to a Person Having a Sense of Community and Belonging?

Simply having a great number of community activities in a week does not guarantee a sense of

membership and belonging. For example, one study (Saxby, Thomas, Felce, & de Kock, 1986) found that on community trips, the average time an individual with severe/profound level of disabilities spent in contact with a member of the public was 2%. Many of the successful intervention projects reflect inclusion in a specific environment, such as a work setting or community association (e.g., Stancliffe et al., 2012), but how relationships spread beyond that specific environment has not been systematically studied. While it is known in some cases that relationships do expand beyond a specific environment, whether or not there are effective ways to influence the spread from a specific integration environment to an expanded depth of relationship and contribution has not been determined.

What Happens to Relationships After Students Graduate from Integrated School Environments?

As school inclusion increases, the number of individuals experiencing such integrated environments is increasing. Frequency, choice, and intensity measures can be used to study what happens when students leave school and after those social networks that have been provided by the school environment are lost. From the perspective of understanding social inclusion for adults with IDD, longitudinal studies can be undertaken to determine the patterns of what happens to social inclusion when formerly integrated students graduate into segregated adult programs, or when adults live with their family or on their own without that "provided" social network of the school environment.

How Do We Account for Participation and Inclusion Through Social Media?

The IDS-TILDA findings (McCarron et al., 2011) and other studies suggest that there is a growing digital divide for people with IDD. While such studies compare the usage of social networking sites by persons with IDD to usage by nondisabled persons, there has been no study yet comparing the impact of social media use by individuals with IDD on their experiences of social inclusion, relationship, belonging, and loneliness, or a comparison to those effects for nondisabled individuals.

In More Integrated and/or Individualized Environments, How Do We Keep Vulnerable People Safe?

As community participation and inclusion increase, it is not clear how we can effectively support individuals with IDD in the face of prejudice, stigma, and discrimination. While there are curricula to support individuals to avoid abusive situations and exploitation, we do not understand how to do so, yet at the same time increase meaningful relationships with community members. Especially as more people receive individualized support, it would be useful to determine how they can be supported in the face of bullying and abuse and also increase their valued community roles and relationships.

There is a paucity of research concerning the social inclusion of individuals who live on their own, one of the groups most vulnerable to abuse. The nature of their social networks should be addressed, including the importance of their relationships with others who have IDD. Interview studies by trusted allies can be undertaken to determine the degree to which individuals living on their own face violence, abuse, bullying, and exploitation, and how these issues can be addressed. More research documenting the frequency of such occurrences, such as that undertaken by Sobsey (2006), needs to be undertaken in addition to intervention projects addressing the balance between managing risk while increasing inclusion and belonging.

How Should Social Inclusion Research Account for Friendships Between People With IDD, and How Can We More Effectively Support Intimate Relationships for Those Who Want Them?

Sexual relationships for individuals with disabilities are often addressed separately from the social inclusion research, without the recognition that for nondisabled people, having someone to love, with whom to be physically and social intimate, is usually a critical factor affecting a person's sense of loneliness and experience of belonging. At the same time, even if relationships between people with IDD are not sexual or physically intimate, the importance of and our understanding of the nature of social relationships between people with IDD merits more study, such as that undertaken by McVilly and his colleagues (McVilly et al., 2006; McVilly, 2012) in interviewing people about their social experiences. Understanding the complexity

of and satisfaction with social relationships can be related to the questions of how the lack of an intimate partner affects the loneliness and emotional satisfaction for an individual with IDD who has many community friends and activities, and whether or not supporting more intimate relationships affects inclusion efforts.

What Can Be Learned About Community Inclusion and Participation in Different Countries, as Service Systems Improve and Expand?

The United Nations Convention on the Rights of People with Disabilities (United Nations, 2006) declares the right of all individuals to full participation and inclusion in society and in their communities. Different cultural environments can be studied for the lessons that have been learned about community participation and social inclusion, and which lessons can be applied elsewhere. There is little understanding of how to impact community inclusion in countries where devaluation of disability is the pervasive cultural norm, and how acceptance and valuing can be systematically increased. Comparative quantitative and qualitative frameworks can be developed to compare social inclusion in different countries and to assist countries in learning more from each other.

What Are the Next Research Questions That Need to be Answered?

The current state of knowledge and emerging questions leads to numerous research priorities both for the immediate and long-term future. The four questions noted here also reflect the evolving nature of services for people with IDD.

What Are Community Members' Perspectives About Inclusion and What Works? How Can We Support an Increased Role on the Part of the Larger Community? What Are the Most Effective Intervention Approaches in the Eyes of Community Members?

Apart from nondisabled students' experience with school inclusion (e.g., Fischer, Pumpian, & Sax, 1998; Rossetti, 2011; Siperstein & Leffert, 1997; Smith, 2007) there is very little measurement of community members' attitudes toward what works to support inclusion. The studies in schools reflect

that physical inclusion and structured interactions such as paired mentorships and facilitators are very effective methods for greater inclusion. There have also been a few studies in work environments of nondisabled co-worker attitudes (e.g., Chadsey, 2008; Farris & Stancliffe, 2001; Hughes, Kim, & Hwang, 1998; Mank, Cioffi, & Yovanoff, 1999; Novak & Rogan, 2010), although these have primarily focused on co-worker attitudes in the work-place, rather than the social opportunities outside work that many typical employees enjoy. If we are to have inclusive communities, the perspectives of community members need to be assessed, including what they see to be effective or ineffective approaches. What are the benefits to social inclusion of people with disabilities in the eyes of community members, and what are the challenges? How can community members be supported when they are challenged? What are ways to understand and promote reciprocity? While some information is gained from attitudinal surveys, well-controlled intervention studies are also critical in determining what types of approaches are most effective with community members.

Past research efforts about inclusion could be seen to be restricted by historical approaches and understandings; a new “lens” is needed. A fundamental and useful redefinition would emphasize community members’ perspectives and experiences rather than focus only on the degree of inclusion of the individual with IDD. If truly inclusive communities are to exist, the role of the community itself must be emphasized. As one participant at the 2012 State of the Science Conference (SOSC) stated, “Winning the hearts and minds of the community has been under-emphasized” (SOSC, 2012). A few projects (Caitlin & Jacobson, 2011; Carlson, 2000) have been aimed at impacting the role of the larger community, and such approaches deserve to become more widespread. Carlson’s (2000) efforts to expand inclusion for people with IDD were embedded within a city’s neighborhood-based initiatives to expand community participation for all the city’s citizens. Caitlin and Jacobson (2011) described projects in several different cities in one state that were community-wide projects to enhance neighborly participation and membership, rather than focus only on persons with IDD. More community-wide interventions are called for, not only projects with people with IDD and provider

agencies. Alternative projects (such as the two mentioned here) could be developed to support community capacity building and to use generic resources to increase social connectedness; funding could go to communities to support their role in inclusivity. Measures such as those used by Putnam (2000) to measure social connectedness for all citizens, such as the numbers of and membership in community associations, could be incorporated into these research efforts.

Different communities can be studied to determine the measures for and characteristics of an inclusive community. Certain communities could be nominated as exemplary ones, and various features of those communities that reflect and promote inclusiveness could be identified. Research would need to develop measures to determine the social interpretations and perceptions of community members, as well as measures of the attitudes and resources of the community environment itself, such as generational and attitudinal characteristics or differences in resources, poverty levels, and degree of transience.

Longer-term follow-up studies would be useful. Those communities considered inclusive could be studied to determine how this capacity has been built over time. Interventions in different types of environments could be undertaken to determine what is required or desirable to effect change. Such studies could address whether there are geographic and other types of differences, and how we can leverage young people and new generational attitudes as a result of inclusive school settings.

Issues to study include which interventions work best for different types of people in different types of communities, whether a certain amount of “dosage” of social participation is needed (e.g., once a week, every day) for a sense of inclusion for different community members or individuals with IDD, and what strategies of increasing social capital for people with IDD impact service costs. While there is literature that can be drawn upon about general community organizing and development and research concerning the trends when communities have evolved to include people of different cultures and races (e.g., Alba & Nee, 2003; Putnam, 2007), this is a virtually entirely new arena for research regarding the development of communities to be more inclusive of people with IDD.

How Do We Bring “What Works” Up to Scale? How Do We Make Methods Found to Be Effective Into Ordinary Everyday Practice?

Numerous intervention studies and projects over the last 20–30 years that have used the strategies mentioned above (e.g., Abery & Fahnestock, 1994; Amado et al., 2011; Carlson, 2000; Stancliffe et al., 2012) have demonstrated that there are many effective methods to increase inclusion. These have primarily been small pilot projects, with very few and inconsistent efforts dedicated to bringing these effective strategies to an overall organizational or system-wide intervention. Since we know what to do and how to do it, it is not clear why more does not happen. Although these established and promising evidence-based practices have increased social inclusion for persons with IDD, it has not been determined how we can “scale up” what works and what needs to happen to create larger system shifts.

Systems of formal support reflect specific service arrays and reimbursement rates; our policies and systems have yet to be brought up to scale with demonstrated results. While there is a great deal of research on the impact of social relationships on health, wellness, and productivity, no study has looked at the cost/benefits of interventions in this area on such outcomes. What has been the impact of funding and regulatory structures and interventions on individual outcomes, quality of life, and satisfaction? There is a need for “translational” research and interventions that move the evidence into reimbursement and policy practices.

Our understanding of what works may also shift as the work-force becomes more diverse, since social inclusion for individuals with IDD may differ based on cultural differences among their direct support professionals. Large comparative studies could determine if differing “cultures” or differences between the socioeconomic status of people with IDD and their support staff impact inclusion.

Overall, bringing what works up to scale will require investment in developing professionals and practitioners to promote community interaction and reciprocity, and the costs to the public sector for such development and/or refocus of current investments will need to be identified. Social facilitators can develop and promote circles of support, and systematic training programs can be carried out, such as those utilized for “active

support” (Jones et al., 1999). Interventions for social inclusion can be implemented in preschool and elementary school, and social connectedness can be built into transition plans from secondary school as well as into Individual Service Plans for adults.

What is a Conceptual Framework for Understanding the Many Different Aspects of Social Inclusion and Participation? How Can We Account for the Complex Interaction of Factors Affecting Inclusion?

There are complex interactions between personal and environmental factors, including social and cultural factors, that affect relationships, inclusion, and community belonging. For example, Putnam (2000) and others have noted an increasing sense of disassociation and decreasing sense of community in the larger society. There are significant debates about whether virtual “social networking” is increasing or decreasing this sense of societal disassociation. As the importance of self-determination and choice continue to increase, how personal preferences interact with the aspects of segregation and inclusion in any given individual’s life is indeed complex.

The experiences of relatedness, community membership, and belonging are each subjective. Objective indicators such as the numbers of community activities or relationships experienced by an individual are not by themselves valid indicators of that individual’s subjective experiences. As noted in the discussion about personal preferences, there is a complex relationship between individual preferences and that person’s sense of their own well-being in terms of social integration (Cummins & Lau, 2003). Someone may have many activities and feel lonely, and someone else may have few friends and yet be perfectly happy. Reports of loneliness for those with IDD are being measured more frequently (e.g., Causton-Theoharis, Ashby, & Cosier, 2009; McVilly, 2012; McVilly et al., 2006; Stancliffe et al., 2007). However, the complex relationship between that reported experience and other individual and environmental factors is only beginning to be addressed (Stancliffe et al., 2007), although some important findings are emerging. For example, individuals who chose who they live with reported being significantly less lonely than individuals who

did not choose their living companions (Stancliffe et al., 2009).

Research is needed concerning the relationship between the subjective and objective aspects of inclusion—is there a match between the person's desire for involvement with their actual levels of involvement and with situations in which individuals with IDD apparently choose segregated environments and experiences? Such studies could address influences on these preferences such as cultural factors or an individual's previous exposure to and experiences with nondisabled community members.

As noted above, there is no systematic or agreed-upon method for measuring social inclusion, nor for determining progress in impacting such inclusion. The development of such a framework would include expanded and validated measurement methods. An operational definition and measurement of social inclusion is needed, including measures of the amount, quality, diversity, and variations, as well as the influence on quality of life. The measurement strategies would reflect the conceptual framework agreed upon or developed. The construct of social inclusion also depends on a larger framework of human rights and self-determination, as well as the environmental and economic conditions that facilitate these. In addition, a person's strengths and challenges affecting their social inclusion are different at different stages of the life span. This needed framework should also be able to compare social inclusion for people living on their own, with their families, or in residential services, and compare their experiences with social inclusion for the general population.

How Do We Address Social Inclusion for People Living With Their Families?

Most studies of social inclusion, including most intervention studies, have been focused on people in segregated and/or paid-for services. While we know that the vast majority of people with intellectual disabilities, including adults, live with their families (Larson et al., 2012), we also know that the majority of the social relationships of these individuals are mediated through their families (Amado & Lakin, 2006; Krauss, Seltzer, & Goodman, 1992). Longer-term studies of families could address how the social inclusion of an adult child with IDD changes as their parents become more elderly, the level of satisfaction for the

individual and their family member, and the relationship of the individual's social inclusion to the family's social inclusion. The effectiveness of different approaches that support individuals living with their families to increase inclusion with a wider social network for those who desire it could be compared. Recent initiatives and policies greatly encourage the use of natural supports and informal support networks, but there is little research concerning the promotion and effectiveness of approaches in these areas.

In terms of families, there is little understanding and documentation of cross-cultural expectations, desires, and requirements regarding social inclusion. There is little research that addresses the diversity of families such as interventions with families living in the inner city or with families of lower socioeconomic status, or that reflects the diversity of races and cultures. To fully understand social inclusion of people with IDD from diverse communities, it is essential to understand them in the context of their families and their families in the context of their varying communities.

Conclusion

As services and supports continue to become less physically segregated, achieving true social inclusion will continue to be challenging. This is a compelling arena for future research, with many potential directions and aspects for understanding and bringing about inclusive communities. One of the most provocative avenues is extending beyond individuals with disabilities and the services system to understanding and impacting the larger community itself, and this is an exciting frontier.

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