

Background

Social inclusion, while the overarching goal of most community-based programs serving persons with intellectual disability, is a poorly defined construct, and one that is difficult to empirically assess. Employment is considered to be a primary component of life for most adults, and a vehicle for achieving social inclusion. Supported employment, wherein individuals with disabilities work in competitive settings at competitive wages using a variety of supports, is considered by many to represent success in achieving inclusive employment. But does being integrated into a workforce mean that an individual has achieved inclusion? The goal of this study was to examine the research literature relative to community based employment of persons with intellectual disabilities, and to assess the degree to which researchers have considered variables related to inclusion in their work.

Method

The primary method of this review was a scoping review of the literature, followed by qualitative analysis of the study variables to assess the aspects of social inclusion addressed in each study. Finally, the areas of focus were summed and analyzed across studies to determine the overall reach of employment-based research of the past decade, and the degree to which inclusive employment has been researched.

The search strategy included the following criteria:

- empirical research published between 2000 – 2010
- at least one study component focused on employment of persons with intellectual disability
- results for subjects with intellectual disability reported separately
- study published in English

The search included the primary research databases for publications of this nature (PubMed, Social Sciences Abstracts, PsycInfo, Eric, CINAHL), as well as Google Scholar. Search terms used to build the inquiry in each varied slightly based on the vocabulary used by the database, but included a set of terms relative to employment, and terms that identified the population of interest. For detailed information on the review strategy, please contact the authors.

A total of 245 references were initially selected based on title review. Abstract and text reviews resulted in rejection of 203 articles that did not report results on the population of persons with intellectual disabilities, or on issues related to employment, vocational development, school-to-work transition, or other topics associated with employment and productivity. The authors reviewed the remaining 42 articles and extracted information on the authorship of the studies, including geographic location, participant characteristics, dependent and independent measures, and study methodology. Based on the extracted data and detailed review of each study's tools and procedures, the authors then categorized the focus of each study in terms of components of social inclusion (see Table 1) defined in an emerging model of social inclusion (seen in Figure 1). Categorization was initially performed independently by the first two authors, and consensus was sought to reconcile disagreements.

Results

Each study measured between one and seven of the 11 elements in the model of social inclusion (mean= 2.5, median=2). The most commonly measured component was *social roles* (n=29, 69% of articles). *Environmental and personal factors* were measured by almost 40% of the studies (n=17 and n=15 respectively). Fewer than 25% of the studies addressed the remaining components. Less than 10% of studies looked at variables that could be considered measures of *community expectations, choices and needs, valorization, trust and reciprocity or sense of belonging*. Table 1 summarizes results and the indicators used within each category.

Participation – Coming to Terms with the Terms

A number of terms are used to describe conceptually related but distinct concepts related to community participation.

- *Participation* itself refers to one's relationship "to the larger whole" (Merriam Webster, 2011) and can occur at different levels. At one end of the spectrum one may be physically present in community settings with little contribution or reciprocity; at the other end, one may have valued and meaningful roles and relationships.

- *Integration* has been most frequently described in the research literature in objective terms that quantify observable characteristics or interactions (Cummins & Law, 2003) :

- ✓ the number of activities undertaken within the community
- ✓ the number or objective character of personal relationships
- ✓ the frequency of access to community resources,
- ✓ the number of leisure activities engaged in outside the home
- ✓ subjective well-being

- *Inclusion* is less well understood, and its lack of clear definition makes it difficult to measure. Persons with disabilities experience social inclusion as involving both structural, empirical elements, such as the presence of certain conditions, and more qualitative and subjective dimensions, including the lived experience (Hall, 2009):

- ✓ being accepted and recognized as an individual beyond the disability
- ✓ having personal relationships with family, friends, and acquaintances
- ✓ being involved in recreation, leisure, and other social activities
- ✓ having appropriate living accommodations
- ✓ having employment
- ✓ having appropriate formal and informal supports

- *Marginalization* is the result of inclusion gone wrong. This term describes social exclusion based on lack of power, resources, and status that afford limited opportunity to live full and engaged lives (Burton & Kagan, 2010; Hall, 2005; Jenson, 2000).

Model Component	# Studies	Sample Indicators
Social Roles	29	• types of jobs obtained (sheltered or a community-based; paid or voluntary; job retention; unemployment rates).
Environment	17	• task environment (group versus individual), physical comfort, work pressure, coworkers' cohesion, and managerial control • wages and typicalness of the hiring process, HR procedures and benefits (assets offered by the environment)
Personal Characteristics & Skills	15	• demographics; physical and mental health diagnoses; level of cognitive impairment • job skills & qualifications • self esteem and psychological well being
Tools	10	• supports received, nature of vocational training and support • impact of state policy on vocational outcomes
Personal Expectations, Choices & Needs	9	• work interests, fears and expectations about future; reasons for choosing sheltered/community employment • individual views of work, leisure, volunteerism, retirement
Mutual Satisfaction	8	• worker satisfaction with salary, job tasks, co-worker relationships, training received, or more general work satisfaction (2 studies) • employer satisfaction with punctuality, performance, social skills, etc.
Competency	5	• work related social behaviours (3 studies) • job task performance as rated by employer or co-workers (2 studies)
Community Expectations, Choices & Needs	4	• attitudes of public towards work roles for people with ID; teacher attitudes towards supported employment • co-worker attitudes/expectations
Trust & Reciprocity	4	• work relationships with co-workers; work friendships (3 studies)
Valorization	2	• occupational prestige of jobs • workers reports of feeling valued at work
Sense of Belonging	2	• sense of loneliness; subjective reports of belonging

Table 1: Representation of social inclusion model components in the research literature

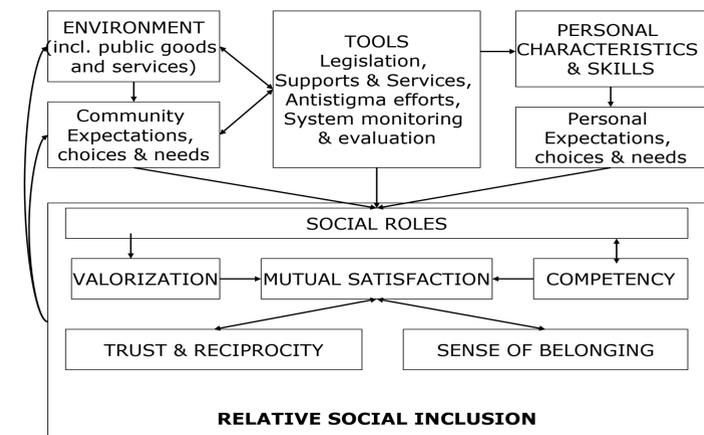


Figure 1: This model of social inclusion has been developing through an interactive and multi-stage process as part of a 3 year study designed to identify indicators of inclusion, choice and independence in Ontario, Canada. Consistent with the World Health Organization's conception of disability and health (WHO, 2001), it defines social inclusion as an interaction between environmental factors and personal characteristics that allow a person to access public goods and services and experience valued social roles that are age, gender and culture relevant and reflect individual choice. It assumes that included individuals are recognized and trusted as playing these roles in their communities and give and receive support within a social network. The process involves a dynamic interaction between 11 core elements, depicted above. The notion of relativity is based in the changing experience of inclusion across time, contexts, key players, and social demands. The model is applicable to all individuals, regardless of ability, ethnicity, culture or other characteristics, with the importance of each component differing based on the circumstances.

Reflections & Discussion

While investigators of the past decade have considered the success of employment interventions relative to various markers of inclusion, few include measures of its core features. This review is consistent with an earlier study (Cummins & Lau, 2003) that found little attention to interactional components of inclusion. We found few instances where such features as sense of belonging, valorization of work contributions, trust and reciprocity and worker satisfaction were addressed.

The cursory attention to inclusion by most researchers raises a number of points for consideration. Many studies reported community-based work participation at any level as the key measure of success, a focus that resides in the notion that community-based jobs are the ultimate goal of vocational intervention efforts and represent optimal participation. However, because no empirical link has been demonstrated between inclusion and such dimensions of work as the number of work hours or type of job and level of inclusion, job elements poorly inform our understanding of inclusive employment. Such measures are important in establishing that an individual has achieved a level of integration, but alone do not indicate if a role is valued, the worker is competent and contributing, or if reciprocity exists. They are therefore necessary but insufficient markers of inclusion. Further, social inclusion is a dynamic construct, which varies over time based on context, demands, performance, key players present, and other variables. Understanding inclusion requires multi-dimensional indicators that are sensitive to changing conditions.

As yet, research has not identified valid measures of inclusion. A clear understanding of social inclusion and the processes that help achieve it will be important to moving policy and practice towards this end (Verdonschot, de Witte, Reichrath, Buntinx & Curfs, 2009). Future studies should consider measures that address central features of inclusion, such as mutual satisfaction, valorization, trust and reciprocity, and sense of belonging. Such tools, in combination with measures of integration, may ultimately provide useful indicators of workplace inclusion.

Limitations

This review was limited to English language papers, and thus may have missed studies from non-English speaking countries based in a different focus or philosophy. Exclusion of papers that included studies of mixed populations also may have influenced findings.

The model of social inclusion that was used to evaluate the level of focus is as yet untested. It has, however, been developed and refined through a systematic and interactive process, and served as a broad and contemporary foundation upon which to conduct this review. The evaluators, having been engaged in this process, may have been subject to some biases in conducting the evaluation and interpretation of variables described in the studies reviewed.

References

- Burton M. & Kagan, C. (2010). Marginalization. In: G. Nelson & I. Prilleltensky, Eds. *Community Psychology: In Pursuit of Wellness and Liberation*. London: MacMillan/Palgrave. pp. 293 – 308.
- Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(2), 145-157.
- Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, 11, 107-115.
- Hall, S. A. (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnographic and Qualitative Research*, 3, 162-173.
- Jenson J. (2000) *Background: Thinking about Marginalization: What, Who and Why?* Ottawa: Canadian Policy Research Networks
- Merriam-Webster (2011). *Merriam-Webster Online Dictionary and Thesaurus*. Springfield, MA: Merriam-Webster Incorporated. Found at <http://www.merriam-webster.com>.
- Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Impact of environmental factors on community participation of persons with an intellectual disability: A systematic review. *Journal of Intellectual Disability Research*, 53(1), 54-64.
- World Health Organization (2001). In World Health Organization (Ed.), *International classification of impairments, disabilities and handicaps: A manual of classification relating to the consequences of disease*. Geneva, Switzerland.

The authors wish to acknowledge the Ontario Ministry of Community and Social Services for their support of this project. They also acknowledge the contributions of the MAPS researchers and co-investigators for their ongoing contributions to the Model of Social Inclusion. Visit the MAPS website at www.mapsresearch.ca.