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SOCIAL INCLUSION AND QUALITY OF LIFE FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

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Executive Summary

This paper synthesizes literature on social inclusion, quality of life and independent living for persons with Intellectual and Developmental Disabilities (IDD). Research concludes that independent living improves quality of life and social inclusion in persons with IDD (McConkey, 2007). Social inclusion is a vital domain of quality of life for individuals with IDD (Merrells, Buchanan, & Waters, 2018). The ability to live independently is one of the most important aspects of social inclusion (Abbot & McConkey, 2006). Housing type also has a significant influence on social inclusion. Studies find that individuals with independent supported living arrangements have higher levels of social inclusion (Stancliffe &Keane, 2000; McConkey, 2007). Individuals who live independently exercise autonomy and control in various aspects of their lives (Cocks et al., 2014). Independent living often needs to be offered in tandem with supports; however, persons with IDD experience success and greater independence when they contribute to the development of their own plans for person-centered, wrap around supports.

Background

This literature review was completed in partnership with the Saint John branch of the New Brunswick Association for Community Living (NBACL), which is the New Brunswick branch of the Canadian Association for Community Living. The NBACL is a provincial, non-profit organization that works with and on behalf of children and adults with intellectual and developmental disabilities (IDD) and their families (NBACL, 2019a). Since their establishment in 1957, the NBACL has worked to build inclusive communities where children and adults with IDD can live, learn, work, and play. The NCACL envisions full participation of persons with IDD in an inclusive society. Their mission is to ensure that persons with IDD live meaningful lives and participate in society as valued and contributing members. The NBACL works with the individual, their families, employers, educators, governments and communities to change lives, change communities and defend rights (NBACL, 2019b).

The values of the NBACL are equality and inclusion (NBACL, 2019b). The values inherent in the concept of equality include self-determination, autonomy, dignity, respect, inclusion, participation and independent living. The concept of inclusion focuses on the values of belonging, acceptance and citizenship. The NBACL is guided by a set of overarching principles. An important principle of the NBACL (2019b) is empowerment, as persons with disabilities require the means to maximize their independence, make their own decisions and enhance their well-being. Another principle is participation, which states that persons with IDD require full access to the social, cultural, educational, legal, economic and physical infrastructures that support our society, so they can participate fully and equally in their communities. The NBACL (2019b) follows the principle of individual focus which states that all policies and programs should be based on determining and enhancing individual strengths and capabilities. Individualized approaches seek to maximize an individual's potential and their opportunities to participate in society.

The NBACL (2019b) estimates that 22,000 New Brunswick residents have IDD and they receive over 200 requests for assistance each month. About 4.4 million Canadians, or 14.3% of the Canadian population, have a disability (Government of Canada, 2011). As an agency, the NBACL is an advocate, contributor to social policy and support service for persons with IDD and their families. They work to ensure that people with IDD can choose the supports they need to live meaningful lives and participate in their communities as valued and contributing members.

NBACL's (2019d) social inclusion program supports adults with IDD who wish to be included within communities their choice. The Social Inclusion program supports this goal by helping individuals with IDD find independent housing with the supports they require, develop strong personal relationships, and become involved in recreation, leisure and volunteer activities that match their interests and choices.

According to the NBACL (2019c), opportunities for people to live in their own home are directly linked to well-being and quality of life. Further the United Nations (2009) recognizes decent and affordable housing as a fundamental human right. Housing is also a key social determinant of health (World Health Organization, 2018). Historically, individuals with IDD have had little or no control over the most basic decisions regarding where they live and how they spend their time (Chowdhury and Benson, 2011). It is the position of the NBACL (2019c) that people have the right to choose where and with whom they live and to exercise control over their daily routines.

This literature review describes the relationship between independent living, quality of life, and social inclusion. This research can be used to provide an evidence base for NBACL programs and policies. Additionally, it can help inform future program development.

Quality of Life

From a research, practice and policy perspective, the field of intellectual disability studies is strongly influenced by the quality of life paradigm (Morisse et al., 2013). In general, quality of life may be viewed as a multidimensional concept that encompasses an individual's emotional reactions to life events, disposition, sense of satisfaction and fulfillment, and satisfaction with work and personal relationships (Theofilou, 2013). The World Health Organization defines quality of life as individuals' perceptions of their positions in life within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (Chowdhury & Benson, 2011). Quality of life contains both objective and subjective components. Objective components consist of measurable indicators, such as living arrangements, health, economic security and education (Chowdhury & Benson, 2011). Subjective components define quality of life in relation to psychological indicators, including perceptions of life experiences and opportunities (Weinberg, Seton, & Cameron, 2018).

Currently, there are over one thousand instruments designed to assess quality of life (Theofilou, 2013). Some are generic for use in the general population, while other instruments are designed for use with specific sub-populations. A study by Morisse et al. (2013), confirms the relevance of the concept of quality of life to those with IDD, and highlights eight relevant domains of quality of life. The eight domains of quality of life are personal development and self-determination, interpersonal relations, social inclusion, rights and emotional, physical and material wellbeing (Morisse et al., 2013). For individuals with intellectual disabilities, social inclusion is found to have the largest influence on quality of life (Morisse et al., 2013).

Quality of life outcomes are improved when clients are involved in their care. This happens when staff adapt interventions to the individual (Barton, 2012). However, research finds that individuals with IDD are given more choice about everyday living than about the amount and type of support they receive (Bigby, Bould, & Beadle-Brown, 2017). Models of self-directed care can provide important support to facilitate self-determination for people with IDD (Bacon et al., 2011). Self-determination leads to increased community participation and enhanced social networks (Milner et al., 2019). Community participation and social networks are critical components of social capital which is consistently linked to enhanced quality of life, mental and physical health, and economic security (Bacon et al., 2011).

As a policy, deinstitutionalization is based on the premise that relocating care and housing for persons with IDD will improve quality of life (Chowdhury & Benson, 2011). The widespread transfer of people with IDD from institutional to community living in the past four decades is of interest to many scholars who focus on the impact of residential environments on individuals' experiences and quality of life (Fahey et al., 2010). The consensus among deinstitutionalization scholars is that relocation from large traditional institutions to smaller community homes results in overall positive changes in quality of life (Chowdhury & Benson, 2011). However, these transitions must include access to appropriate and accessible supports in order to be truly successful (Chowdhury & Benson, 2011). When supports are available, the transition from residential care to community living is associated with improved emotional wellbeing, health, privacy, freedom, choice, social opportunities (Kilroy et al., 2015) and increased quality of life for individuals (Cooper & Picton, 2000).

Independent living is associated with better quality of life (Cooper & Picton, 2000). Kozma, Mansell and Beadle-Brown (2009) analyze 68 studies comparing different types of housing for individuals with an IDD. They conclude that people in community-based residences, semi-independent or supported living arrangements have a better objective quality of life than people who live in large, congregate settings. Overall, dispersed housing, which places individuals with IDD in different places across the community, improves quality of life for people with IDD (Mansell & Beadle-Brown, 2009). Like Mansell and Beadle-Brown (2009), Emerson et al. (2000) find that dispersed housing and village communities offer better quality of care and quality of life than residential campuses. In a later study Emerson (2004) determines that cluster housing, comprised of a number of residences close by or connected to each other, offers a poorer quality of life than dispersed housing and independent living. However, there is an absence of reliable data suggesting that cluster housing is harmful or detrimental to people with IDD (Cummins & Lau, 2004).

Characteristics of congregate or residential households impact quality of life. Francis, Blue-Banning, and Turnbull (2014) find that four main variables affect quality of life. These are staff characteristics, resident characteristics, household culture and household size. In congregate settings, positive staff and resident characteristics are modelled by the existence of constructive interactions between staff and residents and between fellow residents. Residences with flexible daily activities and higher levels of autonomy, which positively influences quality of life. Additionally, smaller residence size is related to quality of life, presumably because smaller residences allow a higher level of autonomy and flexibility, while also enhancing meaningful interactions with others (Francis, Blue-Banning, & Turnbull, 2014).

Rather than suggest housing options for people with IDD, researchers promote the benefits of offering multiple forms of residential accommodations to allow people with IDD to make their own informed choices (Cummins & Lau, 2004). Individuals with IDD who choose where and with whom to live experience significantly greater quality of life than those who do not have choices (Francis, Blue-Banning, & Turnbull, 2014). Individual supported living (ISL) offers people with IDD the opportunity to participate in establishing wrap around supports which are tailored to their needs. This person-centred approach is used with increased frequency and is associated with positive outcomes (Cocks et al., 2014). ISL arrangements provide more control and self-

determination, promoting positive outcomes. ISL arrangements promote financial independence, choice in employment and social relationships which are related to individual control (Shogren & Shaw, 2016). In doing so, ISL provides opportunities for individuals to exert autonomy and control over their daily lives, and as such are associated with improved quality of life for individuals with IDD (Cocks et al., 2014).

Social Inclusion

Social inclusion is a vital domain of quality of life (Merrells, Buchanan, & Waters, 2018; Morisse et al., 2013). It is essential to quality of life, but people with IDD experience barriers that limit social inclusion (Hall, 2017). NBACL (n.d.) argues that one experiences social inclusion when they have a sense of belonging and acceptance, have a valued role in the community, actively participate in the community, is involved in activities based on their own personal preferences, and has social relationships with people of their choosing.

Social inclusion is an explicit goal of policies and programs for individuals with IDD, but clear, evidence-based assertions of how to measure social inclusion are limited (Martin & Cobigo, 2011). Currently, there is no single definition of social inclusion, which makes research in the area challenging (Martin & Cobigo, 2011). Overmars-Marx et al.'s (2014) recommend that researchers attempt to measure various domains of social inclusion. Their review of literature finds five domains for social inclusion: individual characteristics, informal network, professional care, neighborhood characteristics, and government policies. They argue that social inclusion is a dynamic process with many complex interactions (Overmars-Marx et al., 2014). Merrells, Buchanan and Waters (2019) argue that it is important to understand the perspective of people with IDD and understand how they experience and perceive social inclusion within their own lives. Further research on measures of social inclusion that incorporate the perspective of people with IDD is needed.

Poverty is both a cause and a product of social exclusion (Stewart et al., 2008). Material deprivation can generate experiences of social isolation for individuals who lack the socioeconomic resources needed to fully engage in their communities (Stewart et al., 2008; 2009). These individuals often experience social exclusion and are prohibited from participating in individual, community and civic activities. Research finds that this exclusion is associated with negative health outcomes (Stewart et al., 2009). Most individuals living on low incomes report

detrimental impacts of exclusion on their social, emotional, and physical well-being (Stewart et al., 2007). A lack of financial resources often contributes to limited social inclusion for individuals with IDD (Hall, 2009). This highlights the importance of low or no cost recreational, social and community-based activities for individuals with IDD.

Individuals with intellectual disabilities have higher unemployment and underemployment rates and face significant barriers to attaining and sustaining good quality, paid employment (Petner-Arrey, Howell-Moneta, & Lysaght, 2016). Employment positively contributes to social inclusion, as important social connections can be formed in the workplace (Evans & Repper, 2000). Supported employment is intended to facilitate and promote social inclusion for individuals with IDD (Cramm et al., 2009). Supported employment involves paid work for individuals with intellectual disabilities, that allows them to work alongside non-disabled peers, with the support they require to do so (Cramm et al., 2009). From the perspective of people with IDD, supported, community-integrated employment has a positive effect on wellbeing and quality of life (Blick et Al., 2016; Cramm et al., 2009). For example, individuals involved in community-integrated employment have a greater sense of social inclusion and report more financial autonomy than those who are not engaged in community-integrated employment programs (Blick et al., 2016). As previously mentioned, financial autonomy and social connections which are built through employment are important goals, as financial insecurity, unemployment, and social isolation contribute to social exclusion.

Individuals with IDD can move from social exclusion towards inclusion with the help of appropriate supports, such as social groups, programming, and individual support arrangements (Wilson et al., 2017). People with IDD have fewer opportunities to participate in recreational programs, which enhance social inclusion (Merrells, Buchanan, & Waters, 2018). Social inclusion and participation in recreational programs increase functional independence and positive community attitudes in people with IDD (Merrells, Buchanan, & Waters, 2018). People with IDD tend to participate in social and recreational activities designed specifically for people with disabilities (Hall, 2009). Research finds that well-intentioned social support from volunteers in recreation programs designed specifically for persons with disabilities may actually limit social inclusion (Van Asselt, Buchanan, & Peterson, 2015; Hall, 2009). Programs which facilitate interactions between people with IDD reduce the time these individuals spend developing or

engaging in naturally occurring friendships (Van Asselt, Buchanan, and Peterson, 2015). Social geographers recommend that individuals with disabilities engage in social spaces of their own choice as these spaces promote genuine social inclusion and allow individuals to exercise autonomy and control over their own social interactions (Frawley and Bigby, 2015).

Individuals with IDD often have close and significant relationships with their support staff (Giesbers et al., 2019). Research finds that staff play an important role in supporting and facilitating friendships for people with IDD (Giesbers et al., 2019). Duggan and Linehan (2013) argue that people with IDD and support staff can be strong advocates of promoting social inclusion through establishing and maintaining strong social ties in communities.

The ability to live independently is one of the most important aspects of achieving social inclusion (Abbot & McConkey, 2006). Studies have determined that housing type has the most significant influence on social inclusion (McConkey, 2007). Individuals living in independent supported living arrangements have greater levels of social inclusion than those in group or residential homes (McConkey, 2007). McConkey and Collins (2010) attribute this to the increased effort by support staff to promote social inclusion in clients who live in supported independent arrangements.

Future Directions

Independent living improves quality of life and social inclusion in persons with IDD. Researchers have only recently begun to investigate independent living for persons with IDD. ISL provides people with the ability to make informed decisions and to control their own lives. Individuals with IDD who choose where and with whom to live experience significantly improved quality of life (Francis, Blue-Banning, & Turnbull, 2014), and as such more individuals and advocate groups argue for the importance of independent living.

Creative models, such as support roommate programs, which match persons with IDD with appropriate roommates, have emerged and offer new innovative, semi-independent housing options for people with IDD. Although focused on a different population, McMaster University has had success with pairing older adults with graduate student support roommates. This provides older adults with companionship and support and allows graduate students to engage in the community while living in more affordable environments. However, as research on these creative

models is limited, the authors of this report recommend that additional research on the efficacy of these programs is needed before they are broadly implemented.

and autonomy are consistently associated with quality of life outcomes (Kozma et al., 2009). Individuals with IDD living in community-based residences, semi-independent or supported living arrangements have a better objective quality of life than those living in large congregate settings (Kozma et al., 2009). Social inclusion has been identified as an especially important domain of quality of life (Morisse et al., 2013). The ability to live independently is one of the most important contributors to social inclusion (Abbot & McConkey, 2006), and housing type has the most significant influence on social inclusion (McConkey, 2007). Greater priority is given to promoting social inclusion by staff working in ISL arrangements (McConkey and Collins, 2010) and individuals living in ISL arrangements have high levels of social inclusion (McConkey, 2007). These findings illustrate the need to continue to research and develop creative, evidence-based models for ISL for persons with IDD.

Assistive technology (AT) is an umbrella term that includes "assistive, adaptive and rehabilitative devices or software" for individuals with IDD (Developmental Disabilities Association, 2019). Researchers consistently find evidence that illustrates the value of AT in enhancing social inclusion, wellbeing and independence for individuals with IDD (Owuor & Larkan, 2017). These technologies include a variety of options, which include no-tech options like visual schedules, low-tech options like screen magnifiers, or high-tech options, such as computers and tablets (Developmental Disabilities Association, 2019). As technology and independent living service innovation continues, new models of AT have become available, including Smart Home devices from microwaves that sense appropriate cooking times, reminder devices, to fully equipped homes with environmental and security controls (Berridge, Furseth, Cuthbertson, & Demello, 2014).

Currently there is a technological divide between individuals with IDD and those without; a disparity that is exacerbated by lack of access to AT in a technologically mediated world (Owuor, Larkan, & MacLachlan, 2017). AT can have a positive impact on the quality of life of individuals with IDD, and new technologies and innovations are being developed at a rapid pace. This indicates the importance of ensuring the voices of individuals with IDD are included in the technology development process, and individuals with IDD have equitable access

to technology. Equitable and accessible access to technology can assist with ISL arrangements and improve social integration.

Conclusion

A variety of factors contribute to quality of life for people with IDD, including maximized individual control, autonomy, and inclusion. As developments occur in the area of intellectual disabilities studies and practice, new, creative housing models arise, which focus on improving individual control, autonomy, and social inclusion. This literature review highlights the need for more research on independent living programs. Despite the growing popularity of ISL arrangements, there are currently too few studies that present and assess different types of independent living programs. More research is needed to understand the value of these programs and to ensure they contribute to improved quality of life and social inclusion for individuals with IDD.

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