# Examining Predictors of Quality of Life of Adults with Intellectual Disabilities After Deinstitutionalization

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#### Abstract

This study examined if a person's quality of life could be predicted by six relevant factors in a sample of 114 individuals with intellectual disability who had moved from institutional settings to community living settings within Ontario. Further, two aspects of self-efficacy were tested to see if they moderated the relationship between the possible predictors and the quality of life indicator. The initial multiple regression model accounted for a very small amount of the variance in the outcome ( $r^2 = .08$ ). The second analysis included decision-making as a predictor ( $r^2 = .35$ ) but did not find it to be moderator. The third analysis used opportunities for change as a predictor ( $r^2 = .28$ ), and as a moderator with two significant interaction terms, health and years in an institutional setting ( $r^2 = .35$ ). These findings support the often-theorized influence of self-efficacy on quality of life for individuals with intellectual disability.

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## Examining Predictors of Quality of Life of Adults with Intellectual Disabilities After Deinstitutionalization

In Ontario, on March 31st, 2009, the last government operated institution for people with intellectual disabilities (ID) was closed. This closure marked the final chapter of a bold initiative to close all government-operated institutions in the province of Ontario, led by the Ministry of Community and Social Services (MCSS). This movement was intended to increase the life quality of the people who were living inside of the institutions, by providing them with opportunities to live in less restrictive community settings. It was hypothesized, that moving to community settings would afford people who had lived much of their lives in institutional settings with opportunities to integrate into their community, socialize with others in their neighborhood, and possibly obtain vocational or volunteer placements. As a result, people would feel more fulfilled and satisfied with their daily lives than they were in secluded institutional settings.

The Facilities Initiative Studies, completed in Ontario in 2012, examined the processes and outcomes of deinstitutionalization in a series of studies employing multiple research methods (Griffiths, Condillac, & Owen, 2012). The data for the present study were gathered as part of the quasi-longitudinal study component (Condillac, Martin, & Frijters, 2012). That study found that participants for the most part were doing as well or better in the community setting than the institution in most areas measured. When decline was noted in some areas for small numbers of participants, it was in areas that were not unexpected given individual health status, age, diagnosis or a combination of these factors.

Typically, the move to community settings has been documented as a positive change for those who left institutional settings and settled into their new community

homes (i.e., Chowdhury & Benson, 2011). Such positive changes have been documented in critical aspects of the person's life such as: adaptive behaviour (i.e., Beadle-Brown et al., 2000; Kim, Larson, & Lakin, 2001), challenging behaviour (i.e., Lakin, Larson, & Kim, 2010), community access (i.e., Ager, Myers, Kerr, & Green, 2001; Baker, 2007), contact with family (i.e., Conroy, Spreat, Yuskauskas, & Elks, 2003), mental health (i.e., Wildrick, Bramley, & Frawley, 1997), and overall life quality (i.e., Chowdhury & Benson, 2011; Emerson & Hatton, 1996).

Some studies, however, have found unfavourable results regarding the move, such undesirable results have been found in: challenging behaviours (i.e., Nøttestad, Stromgen, & Linaker, 2000), family contact (i.e., Bigby, 2008), health and healthcare (i.e., Chowdhury & Benson, 2011), and mental health care (i.e., Nøttestad & Linaker, 1999). In spite of these few negative results, however, the move is most frequently reported to be a significant positive change for people with ID (Emerson & Hatton, 1996).

Little is known about what factors predict quality of life in individuals with ID, as demonstrated by the limited research available indicating possible predictors of life quality among this population (e.g., Miller, 2005; Harris, 1999). A subsection of research is dedicated to determining the factors that should be included when measuring quality of life (QOL), but much of this research is based on professional opinions and theoretical rationales, rather than analyses conducted to determine what might predict this construct (e.g., Schalock et al., 2002; Brown & Brown, 2009). Some research suggests that self-determination is associated with a person's QOL (i.e., Brown & Brown, 2003; Lachapelle et al., 2005). Research dedicated to determining the factors that can be used to predict life

quality in individuals with ID would be beneficial and the current study will begin to fill the void in the research base.

The current study investigated whether scores on measures of individual factors in a person's life can be used to predict a life satisfaction indicator score on a measure of QOL in a group of adults with ID following deinstitutionalization. Further analyses included the addition of decision-making and opportunities for change to the model to determine if these measures related to self-determination could predict overall life satisfaction more adequately. The factors that are hypothesized to contribute to a person's overall life quality will be overviewed, along with important aspects of QOL, and their relation to people with ID.

#### **Literature Review**

For over a century, many people with ID lived in government-operated, large scale institutions across Ontario. This trend began in 1876, when the first government-operated institution in Ontario was created, and grew over time until the 1970's (Bigby & Kristiansen, 2005). Throughout this period, over 10,000 people with ID lived in 16 different institutional settings (Martin & Ashworth, 2010). As a result of the 'normalization' principle in the 1970's, people began to change their views on people with disabilities. Nirje (1969) and Wolfensberger (1972; Wolfensberger & Nirje, 1972) who founded normalization stated that people with ID should live lives similar to people without disabilities. This included no longer living in secluded, hospital like, institutional settings, and rather, living in accessible typical houses within the community, where their necessary care was provided (Wolfensberger, 1972). A number of different initiatives in the decades that followed resulted in the closure of the majority of the institutions across the province.

Finally, in 2004, the MCSS in Ontario made a public commitment to close the remaining three government operated institutions and successfully did so by March 31st, 2009.

In more recent years the service approach for people with ID has changed significantly. The paradigm around the treatment of people with ID has changed from a deficit model of disability to a support needs model of disability (Brown, Ouellette-Kuntz, Bielska, & Elliott, 2009). Whereas the deficit model of disability focused on the limitations of the person with a disability and placed the responsibility for these challenges on the individual, the support needs model emphasizes the interaction between the person and his or her environment (Buntinx & Schalock, 2010). The support needs model attempts to promote community integration and participation, independence, inclusion, self-determination and optimizing the person's QOL (Thomspon et al., 2002). This model attempts to create person centred approaches that support the person as completely as possible (Thomspon et al., 2002), and it was under this model of disability that person centred plans were created.

The person centred plan is an individualized approach that is designed to reflect the unique life experiences and circumstances of the person, and is used to organize and plan the supports needed to optimize that person's QOL (Mansell & Beadle-Brown, 2004). These plans include the person's strengths, needs, and goals, and this plan is creating with all relevant parties included. Where possible, the person, their families, and other relevant sources of support are included and provide critical input to these plans (Mansell & Beadle-Brown, 2004). Research has indicated that the use of a person centred plan can improve life quality outcomes for participants (Robertson et al., 2007). These plans were used in the

move from institutional settings in Ontario, and continue to be used in most community placements.

#### Review of Literature on Outcomes of Deinstitutionalization

Typically, the move from institutional settings to community living settings is documented as a positive change for people with intellectual disabilities (Chowdhury & Benson, 2011; Obrien, Thesing, Tuck, & Capie, 2001; Dagnan, Ruddick, & Jones, 1998). Most commonly, researchers are interested in the changes individuals with ID experience in adaptive behaviour, challenging behaviour, community access, health, mental health, access to services, and QOL.

Adaptive behaviour. Adaptive behaviours are activities of daily living that are required to maintain a person's safety and independence. Multiple studies focused around participants leaving institutional settings and moving to community living settings have reported positive changes in adaptive behaviour post-move (Beadle-Brown et al., 2000). Kim, Larson, and Lakin (2001) reviewed 33 studies conducted in the United States from 1976 to 1988 on people who had moved from institutional settings. Kim and colleagues reported that 66% of the studies indicated that the move resulted in a statistically significant improvement in adaptive behaviours. Although this study is older, the comprehensive list of studies that were reviewed makes it important to the research base. Emerson and Hatton (1996) conducted a similar review of deinstitutionalization studies with the 46 UK research papers published between 1980 and 1994. These researchers supported the findings of Kim and colleagues and indicated that moving to community homes generally led to an increase in adaptive behaviour.

In a extensive meta-analysis by Hamelin, Frijters, Griffiths, Condillac, and Owen (2011), adaptive behaviour was found to increase after the move to community living settings, however people with more severe IDs showed smaller gains than their peers with less severe ID. This differed from Young and Ashman (2004b) who found that adaptive gains can be larger for people with more severe ID. Condillac and colleagues (2012) found that adaptive behaviour increased significantly post move to community living settings in a sample of 128 individuals with ID in Ontario. This was also true for the person's cognitive performance (Condillac et al., 2012).

In addition to the gains in adaptive behaviour frequently associated with moving out of institutional settings, Lerman, Apgar, and Jordan (2005) compared 150 'movers' to 150 'stayers' and their research indicated that not only did those who moved out of institutions demonstrate an increase in adaptive behaviours, those who remained in institutional settings experienced a decline in social and cognitive skills. Kozma, Mansell, and Beadle-Brown (2009) echo this claim in their review of 68 international studies on deinstitutionalization between 1997 and 2007.

Challenging behaviour. When compared to people who do not have disabilities, people with ID are more likely to demonstrate behaviours that are considered challenging (Gonzalez et al., 2009). Such behaviours may include a variety of actions, but the most common behaviours measured are stereotypical behaviours, aggression, destruction or self-injurious behaviours (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001).

Deinstitutionalization research in the area of challenging behaviour is mixed in its results. A policy research brief (Lakin et al., 2010) reported on 21 studies conducted in the United States (from 1982 to 2002) on deinstitutionalization and its effects on challenging

behaviour. Lakin and colleagues (2010) found that 11 studies indicated a decrease in problem behaviour, with four studies reporting statistically significant declines, whereas eight studies reported an increase in problematic behaviours after the move, with three stating that this change was statistically significant and two articles revealed no change in problematic behaviours as a result of deinstitutionalization. Differences in data collection methods, operational definitions, and sample sizes may account for the differing results.

Additionally, Nøttestad and Linaker (1999) found an increase in problem behaviour post move to community settings in 53 older adults with ID living in Norway. Eight years after living in an institution, participants demonstrated an increase in problem behaviour, with statistically significant increases in disruptive behaviours and a statistically significant decline in the number of people with no behaviour problem (Nøttestad and Linaker, 1999). It should be noted that within a sample of older adults, and a time lapse of eight years, these results might be confounded with the aging of this sample. In Kim and colleagues' (2001) review of 33 US studies from 1990 to 1999 the authors reported no significant differences in challenging behaviours after moving from institutional settings; with only three of the articles they reviewed reporting statistically significant declines.

Condillac and colleagues (2012) found no change overall in aggressive behaviour from institution to community living in an Ontario-based sample of 128 individuals with ID who had moved from institutional settings within six years of data collection. However, the individuals who had spent the longest time in institutional settings showed the most substantial decreases in aggressive behaviour post move to community living settings (Condillac et al., 2012).

Emerson and Hatton (1996) express that different data collection methods may yield dissimilar results, with direct observational methods being more likely to demonstrate statistically significant declines in challenging behaviours, and proxy respondent methods being more likely to demonstrate no change in challenging behaviour. In addition to these findings, Young and Ashman (2004a) found that participants demonstrated early declines in problematic behaviour post move, but these later leveled out to institutional frequency and severity. These findings may provide further insight to the generally variable profiles present within the post institution challenging behaviour research, as the findings may be partially dependent on the type of data collected as well as time of testing.

Community access. One of the assumed positive outcomes of deinstitutionalization was that people would have a larger amount, and more varied access to their community's resources (Bratt & Johnson, 1988). Despite the initial optimism, many researchers report that community access is still quite low among this population, with activities such as going to restaurants, shopping, playing sports, and participating in religious events not being accessed as frequently as was thought (Dagnan, Trout, Jones, & McEvoy, 1996).

Ager et al. (2001) found an increase in community activities and relationships after 58 people with ID moved from an institutional setting. The participant's home, environment, freedom, choice, and opportunities also improved post-move (Ager et al., 2001). Baker (2007) mirrored these claims, with 60 individuals who had profound ID, finding that moving to community homes led to an increase in variability and rate of community access, although this rate was still significantly lower than the more general population's usage. Baker also determined that access to the community was related to a

person's adaptive behaviour, the person's goals and where the individual lived. Verdonschot, Witte, Reichrath, Buntinx, and Curfs (2009) conducted a review of 23 quantitative studies on community access in people with ID. The researchers found that people with ID are less likely to participate in community activities when compared to people without ID, and their leisure activities are typically performed alone.

Condillac et al. (2012) found that participation in community activities increased post move to community living settings among an Ontario-based sample of 128 recent movers. On average the individuals participated in two more activities in their community living setting as compared to the institutional setting.

Health and health care. When compared to the more general population, people with ID experience more health related problems (Janicki, Davidson, & Henderson, 2002). People with ID experience many of the same health problems as their age matched peers, and experience additional health problems that may or may not be specific to their diagnosis (Janicki et al., 2002; Lunsky, Klein-Geltink, & Yates, 2013).

Health care access is typically found to be more difficult to navigate in community living settings compared to institutional settings (Loon, Knibbe, & Van Hove, 2005). When people with ID move to community living settings their care providers must find a physician who is willing to take them as a patient and who is knowledgeable in the health of people with ID (and possibly the specific diagnosis). This is in stark contrast to an institution, where a general practitioner knowledgeable about people who have ID was on staff, and available to the people who lived within the institution on a regular basis.

In a study of 128 adults with ID who had moved from institutional to community living settings, no changes in medical symptoms or pain were noted after the move

(Condillac et al., 2012). Jokinen (2003) conducted a study with 72 older individuals (40 and above) with ID living in community homes in Ontario, and found that 81% (56) of these individuals experience one or more health issue within the previous 12 month period. Of the 56 individuals who experienced one health issue, 43% (31 individuals) experienced three or more health concerns. Among the most commonly cited health concerns were medication complications (60%), visual impairments (43%) and seizures (31%). In a study conducted about morality, Janicki, Dalton and Henderson (1999) found that people with ID die of similar causes as the general population (cardiovascular, respiratory and neoplastic diseases) but they tend to die earlier.

Lunsky and colleagues (2013) conducted a large-scale study of the 66,484 adults with ID living in Ontario in 2010 and their main findings are consistent with the existing research. These researchers found that adults with ID are overall less healthy when compared to people without ID, and are more likely to be diagnosed with chronic diseases (such as: congestive heart failure, asthma, diabetes, and chronic obstructive pulmonary diseases; Lin et al., 2013). These individuals between the ages of 18 and 64 received less preventative care and were more likely to experience preventable hospitalizations. Despite these findings, these individuals saw their family care practitioner slightly more than the general population (without disabilities; Isaacs et al., 2013). Although these individuals see their primary care practitioner more frequently, they also spend more time in hospital settings. This may indicate that although these individuals are accessing primary health care, there are challenges within the system.

A lack of specifically trained physicians in the field of ID makes navigating health care particularly difficult in community living settings. In a sample of 252 physicians in

Australia, most participants reported that they felt inadequately trained to deal with the specific health needs of people with ID (Phillips, Morrison, & Davis, 2004). More specifically, physicians felt unprepared to deal with the behavioural needs of patients, sexuality issues, specific medical complications related to the disability and preventative health care needs (Phillips et al., 2004). Lennox, Diggens, and Ugoni (1997) also conducted a study in Australia regarding the difficulties in healthcare post institution with 526 physicians who had adult patients with ID. Lennox and colleagues found that there were distinct issues regarding communication with the client, and obtaining a comprehensive history for the patient. Additional challenges were found regarding examining the patient, a lack of training and experience, time constraints, compliance with the physician's recommendations, and a general difficulty determining the problem (Lennox et al., 1997).

Mental health and mental health care. People with ID are more likely to develop mental health concerns than people from the general population (Moss, Bouras, & Holt, 2000). Of 66,484 adults with ID in Ontario in 2010, 49% had a documented psychiatric diagnosis (Lin et al., 2013). This is in stark contrast to the 26% of individuals without ID who have a psychiatric diagnosis. In a different study, Cooper, Smiley, Morrison, Williamson, and Allan (2007) stated that the prevalence of mental illness within this population has been estimated to be anywhere between seven and 97%. The estimation is likely so broad because of communication barriers, a lack of awareness of typical signs among this population and diagnostic overshadowing (Moss et al., 2000).

Relating to the move from institutional settings more specifically, Wildrick et al. (1997) reported a decrease in mental illness post institution. Conversely, Nøttestad, Stromgren, and Linaker (2000) indicated no change in psychiatric symptoms among 29

adults who had moved from institutional settings in Norway, stating that their prevalence remained high. Read (2004) also found that the majority of research indicates that there is no increase in mental health issues after relocation. In growth curve analyses across four data points, two within institutional settings and two in community settings, Condillac et al. (2012) found a slight increase in depressive symptoms after the move. More specifically, these included increases in crying and negative statements. Additionally, these researchers found that anhedonia symptoms increased post move to community settings, but later showed a significant drop in community living settings.

The treatment of mental health issues is primarily done through psychotropic medications within this population (Holden & Gitlesen, 2004). The reliance on psychotropic medication makes people with ID the most highly medicated specific group (Holden & Gitlesen, 2004). Roberston et al. (2000) indicated that within institutional settings almost 60% of the individuals with ID living there were using medication to manage psychiatric symptoms whereas less than 30% of those in community living settings were using psychotropic medication. However, Conroy and colleagues (2003) found an increase in psychotropic medication use among those living in the community among 254 people with ID living in the United States. Additionally, Nøttestad and Linaker (1999) found that people within the community visit mental health professionals less than in the institutional setting in a cohort analysis of 109 individuals with ID. In an Ontario-based study of deinstitutionalization, among a sub-sample of 77 people with ID, 65% of individuals were identified as having a current mental health or behavioural concern. Eighty percent of the individuals identified as having a current mental health or behavioural concern were taking psychotropic medication and 46% of these individuals

were taking psychotropic medication in the absence of a psychiatric diagnosis (Condillac et al., 2012). The high rates of medication use reported in these studies supports the premise that individuals with ID have a higher prevalence of psychotropic medication use that exceeds the presence of formal psychiatric diagnoses. Further, variability across studies might be accounted for by inconsistent measurement of medication use across studies, and failure of many studies to consider the use of medication relative to the presence of formal psychiatric diagnoses.

#### **Quality of Life**

Quality of life can be described as the degree to which a person enjoys the important aspects of their own life (Raphael, Brown, Renwick, & Rootman, 1996). It is the philosophical measure of a person's well being (Nussbaum & Sen, 1993). A person's QOL has been discussed as a distinctly personal and unique construct that differs from person to person because of individual differences (Schalock, 1997). Life quality is a complex measure of life satisfaction that encompasses many of the factors discussed previously. The factors relating to QOL are most frequently measured separately (as demonstrated above) but some researchers indicate that this concept can also be measured as a whole, using a measure encompassing many of the above factors (Chowdhury & Benson, 2011; Dagnan et al., 1998).

Schalock et al. (2002) stated that QOL is measured for the purpose of improving people's lives and identified five principles of QOL among individuals with ID that have been identified among the literature. First, it is composed of both subjective and objective components and second, it includes the same factors as individuals without ID. Third, it is experienced when the needs and desires are met and the person is able to seek enrichment,

fourth, it is based on a person's individual needs and choices. Fifth, QOL is a multidimensional construct that encompasses personal and environmental factors such as relationships, family involvement, friendships, vocational placements, neighborhoods, physical setting, education, health and standard of living.

One of the primary goals behind closing institutional settings in Ontario was to increase the QOL of the people who lived in these settings. Chowdhury and Benson (2011) conducted a review of 15 international studies (1,238 participants total) on deinstitutionalization and found that the move was reported to have a positive impact on QOL overall. Chowdhury and Benson also noted that the positive impact on QOL was more prominent shortly after the move, and began to level off over time. Dagnan and colleagues (1998) echoed both of these claims in a smaller sample, finding an increase in the QOL of 29 older adults with ID in community living settings, and that the improvements leveled off between 41 and 53 months post move. Condillac et al., (2012) examined quality of life indicator scores in a sub-sample of 77 individuals who had been seen twice in the community following deinstitutionalization. They found mean quality of life ratings at the first community visit to fall in the "adequate" range across most areas, which is consistent with other research examining quality of life in the community for adults with ID. On a positive note, there was an increase in the QOL indicator scores between the first and second visits in the community suggesting that QOL was improving over time in the new setting (Condillac et al., 2012).

Emerson and Hatton (1996) analyzed 46 studies on deinstitutionalization conducted between 1980 and 1994. It was found that small community homes were more likely to be associated with an increase in: community access, adaptive behaviour, contact

with care providers, choice, family contact, and acceptance by people within the community. Emerson and Hatton also stated that people in small community homes generally had a better standard of living and showed a reduction in challenging behaviours. Although this is not a measure of QOL directly, it is expected that participants living in community settings had a better QOL (on average) than those in hospital like settings (Emerson & Hatton, 1996).

Little is known about the QOL changes experienced by adults with ID who have moved from institutional settings to community living settings, this is especially true for people who live in Canada. Additionally, very few studies have measured QOL in people with ID who have not undergone a move from institutional settings; even less is known about the factors that predict a person's QOL.

Factors underlying quality of life. For decades researchers have discussed the importance of measuring life quality and devising measures that capture the underlying factors contributing to life quality among this population. There is little agreement, however, as to what factors should be included when measuring QOL. Factors that have been considered include: emotional wellbeing (i.e., Schalock et al., 2002; Hanson- Baldauf, 2011), interpersonal relationships (i.e., Hanson- Baldauf, 2011), material wellbeing (i.e., Buntinx & Schalock, 2010; Chowdhury & Benson, 2011), social inclusion / community involvement (Felce & Perry, 1995; Cragg & Harrison, 1986), rights (Schalock et al., 2002; Buntinx & Schalock, 2010), personal development (i.e., Hanson- Baldauf, 2011; Chowdhury & Benson, 2011), and self-determination (i.e., Felce & Perry, 1995; Cragg & Harrison, 1986), among others.

Researchers have conceptualized QOL in different ways, and many researchers have made recommendations regarding how measures should be developed in order to encompass all of the relevant aspects of QOL according to their individual findings (i.e., Schalock et al., 2002; Buntinx & Schalock, 2004; Chowdhury & Benson, 2011). Due to this, multiple measures have been created to measure a person's QOL such as: the Quality of Life Questionnaire (QOLQ; Schalock, Keith, & Hoffman, 1990), Living in a Supervised Home: A Questionnaire on Quality of Life (Cragg & Harrison, 1986), the Quality of Life Student Questionnaire (Keith & Schalock, 1995), and the Quality of Life Other Person Questionnaire (Raphael, Brown, Renwick, & Rootman, 1996), among others. The vast amount of research regarding what factors should be included when measuring QOL, as well as the differences among the findings in the research, indicate that QOL is a very difficult construct to measure in its entirety.

More research is needed in the field of QOL and ID, but more specifically, the current research needs to be extended into which factors are important when attempting to predict QOL within this population. Additionally, determining whether QOL can be reliably measured as a whole, rather than broken down into domains, would be exceptional extensions of the existing literature. One factor, self-determination, is frequently addressed as a critical part of a person's life quality (e.g., Brown & Brown, 2003, 2009), and has been found to influence a person's QOL in research (e.g., Lachapelle et al., 2005).

Choice making and self-determination in relation to quality of life. Self-determination can be defined simply as the state of being the primary decision maker in one's own life (Lachapelle et al., 2005). Brown and Brown (2009) indicate that self-determination includes two main components, opportunities available to that person, and

the ability to make a choice. Brown and Brown also state that choice making is inherently related to a person's QOL as it is the expression of the individual's wishes and the life direction they have chosen. Also, when a person expresses their own choices, thoughts and ideas it promotes a positive self-image (Brown & Brown, 2009).

Self- determination, which encompasses choice making, has been shown to contribute to or influence a person's QOL (i.e., Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Robertson et al., 2001). In fact, self-determination is the only factor that has been identified as a predictor of a person's life quality within this population (Lachapelle et al., 2005). Lachapelle and colleagues (2005) studied 182 adults with ID living in community settings within Canada, the United States, Belgium and France. These researchers determined that having characteristics of self-determination predicted the person belonging to the 'high QOL group' and found self-determination and QOL to be significantly correlated.

Nota and colleagues (2007) researched 141 people with ID living in Italy and determined that people with more severe ID typically showed the lowest levels of choice making and self-determination. Wehmeyer and Garner (2003) also found that among 301 adults with ID those with lower IQ showed less self-determination than their higher functioning counterparts. However, Wehmeyer and Garner found this relationship to be smaller than the relationship noted by Nota and colleagues. Nota et al. also found that individuals who were a part of the lower IQ group had a lower QOL and women showed higher self-determination than the men.

Robertson and colleagues (2001) surveyed 281 adults with ID living in community based settings and found that the majority of the participants exercised little to no

decision-making over their own major life decisions. This remained true for minor life decisions. Much of the variation in exercising self-determination was accounted for by the participants' functioning level, their previous residential settings, and the rules, regulations and supports of the current residential setting (Robertson et al., 2001). In a related study, Wehmeyer and Bolding (2001) tested 31 adults with ID living in the US six months before moving from a restrictive setting to community based residential settings and six months after the move. Wehmeyer and Bolding found that self-determination and choice making increased after the move to the community setting.

Quality of life reported by proxy respondent. As some individuals with ID are non-verbal, some OOL measures have made proxy respondent options that allow another person to answer questions related to QOL on behalf of the person with an ID. The reliability of proxy respondent measures has been questioned, but multiple studies have compared answers from the individual with ID to the proxy respondent's answers and found a high correspondence rate (i.e., McVilly, Burton-Smith, & Davidson, 2000; Stancliffe, 1999). McVilly and colleagues (2000) found that proxy respondents did not significantly over or under estimate the OOL of the 24 individuals with ID whom they were reporting about. Stancliffe (1999) studied 63 pairs of respondents and persons with ID and found strong positive correlations between respondent's answers, with no statistically significant differences between responses when using the Quality of Life Questionnaire Empowerment factor. Schmidt and colleagues (2010) found similar results with a much larger sample of 874 participants across six international centres. Specifically, Schmidt and fellow researchers found significant correlations between the individual's and the proxy's answers across all five measures of QOL. Though Schmidt et al. did find that proxies

underestimated the person's QOL. In contrast, Schwartz and Rabinovitz (2003) found proxies overestimated life satisfaction in their study involving 93 triads including the person with an ID, their parent and their caregivers. Schwartz and Rabinovitz found that care provider's answers were positively correlated with the person's answers. These researchers noted that more significant differences were found between staff ratings and the client's ratings when the client was higher functioning, showed lower levels of challenging behaviour, had integrative employment or lived in an apartment with more privacy.

In a study of 41 adults with ID, using the Quality of Life Other Person Questionnaire (a proxy measure, used in the current study) and the Quality of Life Self Rating Questionnaire, the proxy measure of QOL led to slightly lower ratings of QOL when compared to the self-rated questionnaire (Raphael et al., 1996). This was true across being, belonging and becoming subscales (Raphael et al., 1996), which will be described in more detail in the measures section of this report. Among the same sample, in an analysis of decision-making and opportunities for change, individuals with ID believed that they had more choice and opportunities for change than their care providers perceived (Raphael et al., 1996). Differing results can likely be associated with the differing perspectives, biases, and control that both individual and proxy responders reported, which would likely differ across people, locations, agencies and personal beliefs.

Condillac et al. (2012) stated that in the developmental sector direct-care staff typically know the people with ID they support well, and have learned to interpret the verbal and non-verbal cues required to assist the person in their daily lives and aid in the more difficult aspects of a person's day, such as making decisions for themselves. This is

especially true for individuals with more significant challenges and limited verbal abilities. As such, the direct-care staff people who support a person with an ID on a regular basis and who have supported the individual for a long period of time are likely the best candidates to provide answers to questions for and about that person, when he or she is unable to provide answers for themselves. Thus, while proxy responding has limitations, the research evidence, practical, and clinical experience provide support for the notion that using direct-care staff as respondents to measure QOL of people they support is a viable option.

#### Rationale

Most of the research surrounding QOL in persons with ID is centred on two aspects: measurement (i.e., Buntinx & Schalock, 2010; Chowdhury & Benson, 2011; Schalock et al., 2002) and change over time (i.e., Dagnan et al., 1998; Emerson & Hatton, 1996), both of which have been reviewed previously. Researchers want to know what aspects of a person's life need to be included in a measure of QOL in order for it to be considered an effective tool, and how these aspects can be measured effectively. Additionally, researchers commonly try to measure the change in factors that are assumed to influence QOL (such as the individual factors reviewed previously) for various reasons such as transitions between settings and as intervention outcomes. A further consideration is that having a solid understanding of factors that influence QOL could assist in the development of evidence-based policy and practice, as a main outcome of support for people with ID should be enhanced QOL (Schalock, 2011).

The benefits of examining potential predictors of QOL of people with ID who have moved from institutional settings are twofold. If the factors that influence QOL within this

population are determined, this will help researchers understand which factors could be included in measures of QOL and which may influence the outcomes of measurement. Also, finding potential predictors of QOL will help practitioners to understand the factors that enhance and/or impede a person's QOL. Understanding is the first step towards action. If practitioners understand these factors, they can produce teaching strategies, prevention techniques and intervention programs in order to promote or enhance these important factors.

The purpose of this study was to determine if the factors that are typically researched in relation to deinstitutionalization with this population could be used to predict the QOL indicator. One hundred twenty individuals with ID were included in the present study. Five factors typically included when researching the outcomes of deinstitutionalization along with the number of years the person spent within the institution were included in testing three different multiple regression models to determine the most complete prediction model.

Three multiple regression analyses were proposed to determine the best avenue for predicting a person with ID's QOL indicator. First, the influence of six independent variables including number of years spent in an institutional setting, health, problem behaviour, mental health status, adaptive behaviour, and frequency of enjoyed activities on the QOL indicator score were examined. Next, to test the influence of choice making and opportunities for change, which were proposed by Brown and Brown (2009) as being critical to self-determination, two separate additional multiple regression analyses were conducted. Specifically, these two factors were examined for moderating effects in two separate analyses as they are presumed to be essential to the construct of self-

determination, and self-determination is hypothesized, and in some cases has been found to be predictive of a person's QOL (e.g., Lachapelle et al., 2005).

#### **Research Questions**

- 1. Do health, problem behaviour, mental health status, skill level, frequency of enjoyed activities, and number of years spent in an institution contribute to the individual's scores on a QOL indicator (satisfaction and importance) in the community after moving from an institutional setting? The first hypothesis was that there would be significant predictors of QOL indicator scores.
- Does the degree to which individuals have self-efficacy (decision-making / control)
  moderate the influence of the variables on the QOL indicator? The second
  hypothesis, was that self-efficacy would moderate the influence of variables on the
  QOL indicator scores.
- 3. Does the degree to which opportunities for change are available to individuals moderate the influence of the variables on the QOL indicator? The third hypothesis was that having opportunities for change would moderate the influence of variables on the QOL indicator scores.

#### Method

#### **Participants**

The sample included 67 males and 53 females (N = 120) with IDs who had recently moved from the last three institutions in Ontario (Rideau Regional Centre, Southwestern Regional Centre, and Huronia Regional Centre). These participants had moved into community-living based residences across Ontario within six years prior to the current data collection. The sample and data used in this study was part of the quasi-longitudinal

study within the Facilities Initiative Studies<sup>1</sup>. Participants ranged in age from 33 to 77 years of age, with an average age of 55 years (SD = 7.8). Participants had lived in institutional settings between 12 and 71 years, with an average of 43 years (SD = 9.6). These individuals had been living in their current setting from less than a year to six years, with an average of three years (SD = 1.2).

#### Recruitment

To recruit the current sample, the Ontario MCSS contacted former residents of the institutions and their closest family members. Contact was made through agencies supporting the individuals who had recently moved from one of the last three facilities. Consent to contact forms were distributed to these agencies directly through MCSS. When this form was returned to the Facilities Initiative team, a staff person called the potential participant's contact person. During the initial conversation, agency personnel were informed of the quasi-longitudinal section of the Facilities Initiative study more specifically and the procedure was overviewed. If there was a staff person from the agency who knew the participant well and was interested in participating, packages containing information about the study and consent forms (for the resident and support worker) were sent to the residence. During the initial contact, a visit to the home may have been booked. The staff person from the agency determined whether booking an appointment was appropriate at this time.

<sup>&</sup>lt;sup>1</sup> A team of researchers at Brock University under the principal investigators Dr. Rosemary Condillac & Dr. Dorothy Griffiths were commissioned to carry out a study examining the impact of deinstitutionalization on individuals with ID in Ontario. The Facilities Initiative Study is a multi-method study, and these data were collected as part of Quasi-Longitudinal portion of the Study.

If a visit was not booked during the initial interview, Facilities Initiative staff contacted the potential participants one to two weeks after the initial call. After the visit was scheduled and all parties were fully informed of the study's procedure and goals, consents were collected from the resident (or a substitute decision maker) and the agency staff who wished to participate. Only after consents were obtained did a Facilities Initiative staff visit the home to collect the data. Upon arrival, the research assistant on the team asked the residents approval to be in the home, and obtained assent/consent to collect information about them using a standardized script. During the visit, which on average took five hours, multiple measures were completed. These measures were designed to assess the person's QOL, including information regarding their community access, health/mental health, personalized support plans, problem behaviours, and social involvement, among others.

The research assistant encouraged the involvement of the resident, but this participation was not mandatory. As the former facility residents had a range of verbal abilities and functioning levels, the level of participation varied. When the resident was present during data collection, the research assistant was instructed to watch for signs of distress. If the person was non-verbal, the research assistant asked the agency staff member if there were any signs that would indicate such emotions or if there were any subjects that were sensitive for the former resident. If at any point the person showed signs of discomfort or distress, the research assistant would inquire if the participant or the agency staff would like to take a break or withdraw from the study. This option was echoed at multiple points throughout the study to ensure the participants were reminded they were free to withdraw at any point. One participant decided he / she did not want to be

observed during the visit, so he / she declined that aspect of the study. Additionally, one participant became tired during data collection and indicated she wanted the research assistant to leave; at this point the visit was discontinued, but permission to retain the data already collected was given. Participants were also reminded that their involvement was confidential and all of the data would be kept in a secure facility at Brock University.

#### **Measures**

The Quality of Life Instrument Package for Adults with Developmental Disabilities: Other Person Interview (Raphael, Brown, Renwick, & Rootman, 1996). The Quality of Life Other Person Interview is an Ontario made measure that is delivered in interview format to determine a participant's relative QOL. A proxy informant (in the current study, the primary support worker) answers the interview questions on behalf of the participant with ID. A proxy informant is used for people with ID who cannot or will not respond to the interview style questions regarding his or her own life quality. Within the present study, no participants were able to complete the entire questionnaire on their own behalf. The measure has 90 items, and each question is rated on a 5-point Likert scale ranging from 'not at all' to 'a lot'.

The Quality of Life Other Person Interview is divided into three domains: being, belonging and becoming. The being domain is made of three more specific domains, physical being (12 questions), psychological being (3 questions), and spiritual being (3 questions). This subsection aims to provide more information about the person's general health and life. Each of these three 'being' domains inquire about his or her daily life, psychological well-being and his or her beliefs.

The belonging domain is comprised of physical belonging, social belonging and community belonging and aims to obtain more information regarding the person's connection to their environment and community. Each of these sub domains consists of 12 questions, regarding the person's living environment, relationships and community access, respectively.

The becoming domain consists of practical becoming, leisure becoming, and growth becoming and aims to gain more information regarding the person's goals and desires.

With each domain being comprised of 12 questions regarding the person's adaptive and employment skills, leisure activities and hobbies as well as his or her ability to learn and cope with changes, respectively.

Within each of the three domains, questions are probed regarding how important specific aspects within the domain are (3 questions), how satisfied he or she is with aspects of this domain (3 questions), to what extent does he or she make decisions within this domain (3 questions) and to what extent are there opportunities for change within this domain (3 questions). The only exceptions to this are psychological being and spiritual being, as these domains only inquire about three broader questions within the domain.

Psychometric properties. The interview portion of the Quality of Life Instrument Package (Raphael, Brown, & Renwick, 1996) has robust reliability and validity and is appropriate for use with a proxy respondent within the current sample (Dr. Ivan Brown, Personal Communication, 2008). The psychometric properties of the Quality of Life Instrument package were assessed in a sample of 500 individuals with ID in Ontario (Raphael, Brown, & Renwick, 1999). The internal consistencies for the Other Person Quality of Life-Short Version are .88 and .93 for verbal and non-verbal participants,

respectively (Raphael et al., 1999). Additionally, content and construct validity have been well established (r = .98; Raphael et al., 1999).

In a sample of the care providers of 41 adults with ID, the internal consistencies of the being, belonging, and becoming score were established to be quite high, at .70, .88 and .87 respectively (Raphael et al., 1996). Additionally, the overall QOL rating was very high (.94; Raphael et al., 1996). Reliability was also assessed among 15 care providers of 15 adults with ID, finding that test-retest coefficients were robust, ranging from .75 to .81 for the person's overall QOL and .84 to .96 across subscales of importance, enjoyment, decision-making and opportunities (Raphael et al., 1996).

Within the current study, the internal consistency values were calculated and all fell within the good to excellent range. These values were rated across importance ( $\alpha$  = .86), satisfaction ( $\alpha$  = .91), decision-making ( $\alpha$  = .92), and opportunities for change ( $\alpha$  = .92). Each subscale consisted of 21 items.

Satisfaction and importance composite score. This composite score was created by dividing the importance score by three, subtracting three from the satisfaction score, and multiplying these two values. These analyses result in the scores ranging from -3.33 (very important areas have received very low enjoyment ratings) and +3.33 (very important areas have received very high enjoyment ratings). These scores were then recoded according to the guidelines specified in the manual leading to a final score ranging from one to five. Higher scores indicate a better QOL and lower scores indicate a less enjoyable life quality.

Decision-making. This composite score was created by obtaining the mean of the 21 questions regarding the person's decision-making. The questions regarding the person's

decision-making were rated on a Likert scale ranging from not at all to a lot. Scores were summed and divided by the number of questions, leading to a final score ranging from one to five.

Opportunities for change. This composite score was created by obtaining the mean of the 21 questions regarding opportunities for change in the person's life. Questions regarding if the person has opportunities to make changes in their own lives were rated on a Likert scale ranging from not at all to a lot. Scores were summed and divided by the number of questions, leading to a final score ranging from one to five.

The interRAI Intellectual Disability (interRAI ID; Hirdes et al., 2007). The interRAI ID is a broad measure that assesses multiple domains of a person's life. The interRAI ID measures the person's living environment, history, recreation and leisure activities, social supports, problem and adaptive behaviour, as well as health and mental health. This comprehensive measure is completed with a support worker who knows the person very well. The person conducting the interview requires a two-day training session as well as extensive feedback on the first few assessments completed. This training is to aid in the understanding of the multiple different scales within the interRAI ID and to educate the research assistants on the scoring procedures used. Additionally, staff people within the organization were alerted of what information would be asked of them and what supporting documents would be used. Within the current study, the research assistants received the typical two day training as well as feedback and the staff people from the organization were sent an information sheet in advance so that they could have the necessary information present when the research assistant visited.

Psychometric Properties. The reliability and validity of the interRAI ID have been established through a variety of avenues. When aspects of the interRAI ID were compared to the corresponding aspects of the Reiss Screen for Maladaptive Behavior and the Dementia Questionnaire for Persons with Mental Retardation (Burt & Aylward, 2000), scales that are widely used and have sound psychometric properties, it was found that the interRAI ID subscales were significantly correlated (Martin, Hirdes, Fries, & Smith, 2007). Additionally, each of the scales in the interRAI ID had acceptable to excellent internal consistency values (Martin et al., 2007).

Independent activities of daily living performance scale. This subscale, used within the interRAI indicates the person's ability to carry out activities of daily living such as: meal preparation, phone use, ordinary housework, shopping, managing finances, transporting to and from locations, managing medications and work placements (Hirdes et al., 2006). The scale ranges from zero to 48, with higher scores indicating a greater need for assistance.

*Medical symptoms score.* This composite score was created by summing the medical symptoms listed in the InterRAI ID (Condillac et al., 2012). More specifically, questions regarding the person's symptoms of dizziness, acid reflux, constipation, vomiting, sedation, headaches, skin conditions and seizures were summed along with information regarding pain symptoms and bowel continence, among others. This composite score can range from zero to 26, with higher scores reflecting the person presenting with more symptoms.

The Scales of Independent Behaviour- Revised (SIB-R; Bruininks, Woodcock, Weatherman & Hill, 1996). The SIB-R was designed to measure a person's functional independence on adaptive behaviours across multiple domains (such as home, community and work settings). The SIB-R measures 259 adaptive behaviours across 14 subscales.

These subscales can be grouped into larger subscales: motor skills, personal living skills, community living skills, as well as communication and social skills. The adaptive behaviours on the SIB-R are measured on a four point Likert scale, ranging from 'never or rarely' to 'does very well'. This questionnaire is norm referenced; scores on the SIB-R are compared to the normative data provided through the measure. The normative data was created from a sample of 2,182 people between the ages of three months to 90 years who lived in diverse communities across 15 states in the United States (Bruininks et al., 1996).

This measure also has a challenging behaviour scale, which measures the frequency and severity of eight challenging behaviours common in people with ID. The eight subscales of problem behaviour are rated as present or absent within the individual, and if the challenging behaviour is present frequency is rated on a scale ranging from 'never' to 'one or more times an hour' and severity is rated on a scale from 'not a problem' to 'a critical problem'. The eight subscales of problem behaviour can be grouped into three problem behaviour indexes: internalized maladaptive behaviour (hurtful to self, unusual or repetitive habits, and withdrawn or inattentive behaviour), externalized maladaptive behaviour (hurtful to others, destructive to property, and disruptive behaviour) and asocial maladaptive behaviour (socially offensive behaviour and uncooperative behaviour).

The SIB-R can be administered in two forms, in an interview or in a checklist format. In the current study the checklist format was used. The questionnaire was provided before the scheduled visit (by mail) and the primary support care worker completing the visit was to complete the survey at their leisure.

*Psychometric properties.* The psychometric properties of the SIB-R are well established (Bruininks, et al., 1996). Internal consistency ratings were found to be excellent

and test-retest reliabilities were quite high, ranging from .96 to .97 (Bruininks, et al., 1996). The reliability of the problem behaviour scales is also well established, with reliability coefficients ranging from .57 to .87 (Bruininks et al., 1996). Within the current study the general maladaptive index, including all aspects of problem behaviour within this scale yielded good internal consistency values of .80 for the severity rating and .80 for the frequency rating.

General Maladaptive Index. This subscale encompasses the eight subscales of challenging behaviour overviewed by the maladaptive behavior index on the SIB-R. The values on these scales are summed and ranged, with values ranging from -40 to 10, with lower scores indicating more problematic behaviours.

The Community Recreation and Leisure Inventory (CRLI; Condillac & White, 2010). The CRLI is an interview regarding the person's access to and variety of community services and activities. The CRLI consists of ten domains relating to community, recreation and leisure activities; the ten domains are: attractions, practical opportunities, dining / entertainment, visiting others, place of worship, passive leisure outside of the home, outdoor activities, sports / recreation, leisure at home, and hobbies. Each of the ten categories are rated on what types of activities are accessed within the domain, the persons enjoyment of the most commonly accessed activity as well as the frequency of this activity and the person's satisfaction with the frequency. Additionally, a list of possible factors that may help or hinder a person's access to this activity are rated as 'helping', 'hindering' or having no effect on the persons access. This procedure is then repeated for the activity within the domain that the person enjoys the most.

**Psychometric properties.** As the CRLI was created for the current study, psychometric information about this measure is not available. However, upon comparing this measure to other measures, the CRLI uses similar assessment methods and seems to have good face validity.

Frequency of activities "liked the most" outside of the home. This score was created by summing the frequency of the activities outside of the home that the person enjoys the most. These eight activities are rated on a Likert scale ranging from never (0) to daily (4). The overall score can range from zero to 32, with higher scores indicating higher frequencies of engagement in preferred activities.

Reiss Screen for Maladaptive Behaviour (Reiss, 1987). The Reiss Screen for Maladaptive Behavior is a generalized scale used to screen individuals with ID for possible behavioural or mental health problems. This psychopathology-screening tool has 38 items and covers multiple behaviour problems including: aggression, self-injurious behaviour, destruction, and stereotypical behaviours. Each item is rated on a three point Likert scale ranging from no problem to a major problem. There are operational definitions provided for each option. The operational definitions for scale provide detailed information regarding how often the behavior should occur, the severity, and the behavior's impact on social functioning for the score to be a valid option. The tool is recommended for use with young adults and adults with mild to profound ID who have possible mental health concerns (McIntyre, Clacher, & Baker, 2002).

**Psychometric Properties of the RSMB.** The psychometric properties of the Reiss Screen have been found to be adequate to good within the literature base. Reiss (2009) found the internal reliability coefficients of the Reiss Screen to be above .70 with few

exceptions, throughout multiple studies. Inter-rater reliability was determined to be between .39-.79 in a United States national sample (Reiss, 2009).

In a sample of sixty institutionalized adults, Sturmey, Burcham, and Perkins (1995) found the internal consistency of the entire scale to be good, with an alpha of .85. McIntyre et al. (2002) used the 26-item score and found the alpha value to be .84. Within the current study, the 26 item score yielded an excellent internal consistency of .90.

*Reiss 26 item score.* The 26-item total is recommended for use by the Reiss Manual (2009) and is a total of the 26 items on the Reiss Screen for Maladaptive Behaviour. This total value provides a score ranging from zero to 52, with higher scores indicating a higher likelihood of psychopathology.

## **Procedure**

- 1. If consent to contact forms were sent to Facilities Initiative staff, primary caregivers of potential participants were contacted by phone. The procedure and specific information regarding the present study was explained in the initial conversation. If the primary care worker for the former facility resident, or someone who knew the participant well expressed interest in participating in the study, a package containing information and consents was sent.
- 2. When consents were received from both the staff person and the resident or their substitute decision maker, a visit was organized.
- 3. Upon arrival, the research assistant confirmed that the pre-measures had been completed and both consents were read, understood and signed. Before the interview began the research assistant obtained assent from the former facility resident using a

standardized script if they had not already signed a consent (a substitute decision maker had signed instead).

4. The five hour long visit was conducted within the former facility resident's home with their support worker and a trained Facilities Initiative research assistant.

## **Results**

# **Description of the Sample**

One hundred twenty participants and their primary support providers participated in the current study. Results for six participants were excluded from the current analyses, as these participants had not completed all of the required measures. There was no discernable pattern to the missing information, some had skipped items on measures, and others had not completed the measures that were mailed in advance. To ensure that the excluded cases were not significantly different from the 114 individuals included in the analyses, additional investigation was completed. These participants did not differ from the remaining sample with respect to years in institutional setting, adaptive behaviour, community access, health, mental health, challenging behaviour or the QOL variables (importance / satisfaction, decision-making or opportunities for change; t = -.651-2.709, p > .05). The only notable difference was that these participants engaged in significantly fewer preferred activities outside of their home than the sample that was included (t = 5.496, p = .032).

The 114 remaining participants ranged from 33 to 77 years old with a mean age of 54.5 years. Sixty-two males and 52 females were included in the current sample. The participant's support needs were evaluated using the support needs measure on the SIB-R, which was completed by a staff person who knew the person well. The level of support

required by participants ranged from intermittent to pervasive, with the majority of the current sample requiring extensive support (36.8%) as shown in Figure 1.

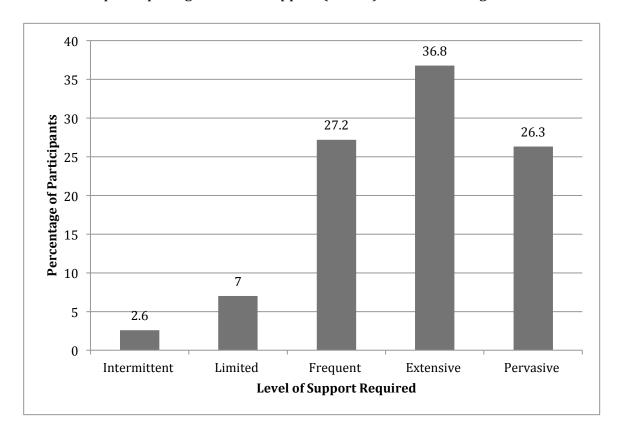


Figure 1. Level of Support Required by the Participants (n = 114)

The 114 participants had moved from the last three government-operated institutions for people with ID in Ontario, 38.6% of the participants resided in Rideau Regional Centre, 35.1% in Huronia Regional Centre and 26.3% in Southwestern Regional Centre. The participants had been living in these institutional settings between 12 and 71 years, with an average of almost 43 years (SD = 9.65). At the time the present data was collected, individuals had been living in their community homes for an average of just over three years (SD = 1.20 years, range = 0.83-6 years). A histogram of the outcome variable, QOL Importance / Satisfaction composite, is shown in Figure 2.

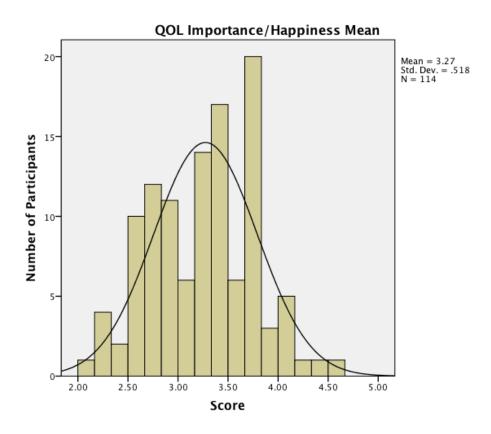


Figure 2. Histogram of QOL Importance / Satisfaction Scores

Among the current sample, 69.3% of participants were completely non-verbal, with the remaining 30.7% demonstrating some verbal abilities. The participant's ability to make themselves understood by others is outline in Table 1. Although eight participants could make themselves understood regularly, this was in the context of their basic needs, and did not necessarily correspond to the person's ability to answer questions over a five -hour period. In all cases the research assistant asked a person who knew the individual with ID well about the person's communication ability, and the visit was conducted accordingly.

Table 1.

Communication Ability (Expression)

Expression Skills	Percentage of Participants n (%)
Always Understood	8 (7)
Usually Understood	17 (14.9)
Often Understood	13 (11.4)
Sometimes Understood	58 (50.9)
Rarely or Never Understood	18 (15.8)

# **Multiple Regression Analyses**

Six possible predictor variables were included in the current analyses: number of years spent in an institutional setting, adaptive behaviour (as measured by performance in activities in daily living), participation in activities the person likes the most, a measure of health, mental health (as measured by the Reiss) and problem behaviour (as measured by the general maladaptive index on the SIB-R). These variables are displayed in Table 2.

Descriptives of Variables

Table 2.

Variable Name	Mean (M)	Standard	Range	
		Deviation (SD)		
QOL Importance/Satisfaction	2.08	.52	2.08 - 4.67	
Decision-Making	2.52	.80	1 - 4.29	
Opportunities for Change	2.99	.80	1 - 4.76	
Years Spent in Institutional Setting	42.91	9.65	12 - 71	
Performance in Activities of Daily	31.06	8.62	10 - 48	
Living				
Frequency of Activities Outside the	15.62	3.39	9 - 24	
Home the Person Likes the Most				
Health Composite Score	6.96	3.7	0 - 17	
Reiss Screen 26 Item Total	6.07	6.82	0–46	
General Maladaptive Index	-11.94	11.58	-42 - 0	

In order to fulfill the necessary criteria to conduct a multiple regression, there are five assumptions that must be fulfilled before analyses can be conducted. All of these assumptions were fulfilled in the current study. First, the variables were interval or ratio

level data. Second, model specification was fulfilled, as the correct predictors were included in the current analysis. Third, examination of the model residuals indicated that they were normally distributed. Fourth, the possible predictors' relationships with the outcome demonstrated homoscedasticity, meaning the prediction of the outcome was equal at all levels of the possible predictor variables. Lastly, the variables used in analyses were not multicollinear, meaning the independent variables, the outcomes and the hypothesized moderators are not measuring the same construct. The only correlation approaching multicollinearity was the relationship between the two possible moderators, decision-making and opportunities for change, but these measures were never included within the same analyses. Correlations between variables included in analyses are displayed in Table 3.

Table 3.

Correlations Between the Variables Included in Analyses

Variable Name	QOL Composite	Decision- Making	Opportunities Change	Years Institution	Performanc e in ADLs	Frequency Activities Like	Health	Reiss 26 Item	General Maladaptive Index
QOL Composite	1	.521**	.438**	196*	099	.149	035	086	.096
Decision- Making		1	.669**	150	034	.140	109	.206*	155
Opportunities Change			1	019	073	.106	103	.185*	082
Years in Institution				1	.052	.078	.004	075	.074
Performance ADLs					1	083	.143	.008	076
Frequency Activities						1	109	113	.025
Health Composite							1	.221*	194*
Reiss 26 Item								1	624**
General Maladaptive Index									1

Note. Decision-making and opportunities for change are not included in the same analyses. Note. \* = p < .05; \*\*p < .01; \*\*\*\*p < .001; \*\*\*\*p < .0001

Additionally, using Mahalanobis distance, one multivariate outlier was found to be concerning in the current analyses. This case was within the normal range for all of the variables but scored significantly higher than the other participants on the Reiss (a measure of mental health) and the SIB-R general maladaptive index (a measure of problem behaviour). Upon further investigation, it was found that the outlier was not influential to any of the three multiple regression models when it was removed from analyses, and therefore this case was retained in the current analyses. One additional multivariate outlier was found within the third multiple regression analysis, with opportunities for change as a moderating variable. This participant was typical on all of the variables but he or she had spent the most time in an institutional setting (71 years). No notable changes were made to the analysis when this multivariate outlier was removed, and because of this it was retained in the current analysis as well.

The Reiss 26-item score had a high kurtosis level (of 9.62). To correct for this, a square root transformation was conducted in order to increase its normality, and multiple regression analyses were conducted with the transformed variable. Transforming the variable did not result in any changes to the outcome of the multiple regressions. Therefore the original variable, with the high kurtosis level, was used for the final regression analyses. As these potentially problematic situations did not impact the results of the regression analyses, no changes were made to the data in order to fulfill all of the necessary assumptions.

Multiple regression analyses were run to determine if specific factors in a person's life could effectively predict life satisfaction in 114 individuals with ID who had recently left institutional settings. Three different models were estimated to determine the best

method for predicting an indicator of life satisfaction within this sample. Independent variables have been reviewed above, and included: number of years spent in an institutional setting, adaptive behaviour, participation in activities the person likes the most, a measure of health, mental health and problem behaviour.

Research Question 1: Do health, problem behaviour, mental health status, skill level, frequency of enjoyed activities, and number of years spent in an institution contribute to the individual's scores on a QOL indictor (satisfaction and importance) in the community after moving from an institutional setting? In order to answer the first research question, a multiple regression analysis was conducted with the six factors identified above (years in institution, adaptive behaviour, participation in preferred activities, health, mental health, and problem behaviour) to determine if these factors could predict QOL satisfaction / importance among this sample. It was found that these six independent variables predicted only eight percent of the variance in QOL importance / satisfaction, and only years spent in an institutional setting predicted this construct. The relationship was small and negative ( $\beta = -.214$ , p = .024), indicating that fewer years in an institutional setting was associated with higher OOL importance / satisfaction scores. The rest of the independent variables did not predict QOL, as demonstrated in Table 4. Therefore hypothesis one was not supported as these results indicated that only a small portion of the variance was accounted for in this model, suggesting that only the number of years in the institutional setting was a significant predictor of the indicator of QOL, and the other independent variables did not contribute significantly.

Table 4.

Index

Simple Multiple Regression Analysis Possible Predictor ß R<sup>2</sup> change *F* change sig Variable .29 .08 1.61 Years in Institutional -.21 .02 setting Performance ADLs -.07 .45 Frequency Activity .16 .10 Like the Most **Health Composite** .02 .86 .77 Reiss 26 Item total -.35 General Maladaptive .08 .48

Research Question 2: Does the degree to which individuals have self-efficacy (decision-making / control) moderate the influence of the variables on the QOL indicator? In order to test the second hypothesis, a second multiple regression analysis was conducted in the current study included decision-making as a moderator. Decision-making is a critical aspect of self-determination (Brown & Brown, 2003, 2009), and was therefore used as a moderator in the current analyses.

To determine if the factors had a unique moderating relationship with the outcome variable, interaction terms were created for each of the six independent variables with the potential moderating variable (decision making). This allowed each interaction term to be used as a moderating relationship with the six possible predictors in order to determine if this interaction term was a statistically significant moderator within the current analyses. Variables were mean-centred before construction of the interaction term to control multicollinearity in the model. To do this exploratory analysis, six two-step multiple regression analyses were conducted. The outcome remained the same (QOL importance /

satisfaction), the first step had the relevant independent variable, and the second step had the corresponding interaction term with the independent variable from step one multiplied by decision-making. One variable was determined to have a significant moderating relationship within the interaction term, general maladaptive index, a measure of problem behaviour ( $\beta$  = .283, p = .002).

The subsequent three step multiple regression analysis included the same six independent variables as possible predictors (number of years in an institution, adaptive behaviour, participation in activities the person likes the most, a measure of health, mental health and problem behaviour), with an addition of decision-making, followed by the interaction term (decision making/ problem behaviour). This third step, testing the contribution of the interaction term (decision making / problem behaviour) was removed from the final analyses because it became non-significant in the full multiple regression. Removing it in the final analyses lead to a parsimonious multiple regression model. In the final model, decision-making was included as a predictor in the second step and the model accounted for 35% of the variance in QOL importance / satisfaction (see Table 5 for additional information).

It is important to note that when decision-making was included in the model, the previously significant predictor (years in institutional setting) became non-significant ( $\mathcal{S}$  = .094, p = .092). The other five independent variables remained non-significant and decision-making was found to be a significant predictor of the QOL importance / satisfaction score (p = .000; see Table 5).

These analyses revealed that decision-making was a significant predictor of the outcome. However, as there are no moderating relationships present within this model, the

second hypothesis, that decision-making would have a moderating relationship between the independent variables tested as possible predictors and the outcome was not supported.

Table 5.

Multiple Regression Analysis with Decision-Making as a Moderator

Step in	Possible Predictor	R	R <sup>2</sup> change	F change	ß	sig
Regression	Variable					
Step 1		.29	.08	1.61		
	Years in				21	.02
	Institutional					
	setting					
	Performance ADLs				07	.45
	Frequency Activity				.16	.10
	Like the Most					0.6
	Health Composite				.02	.86
	D-: 26 It t-t-1				25	77
	Reiss 26 Item total				35	.77
	General				.08	.48
	Maladaptive Index				.00	.40
Step 2	Maiauapuve muex	.59	.27	43.53		
Step 2	Decision-Making	.57	.47	15.55	.55	.00

Research Question 3: Does the degree to which opportunities for change are available to individuals moderate the influence of the variables on the QOL

indicator? The final multiple regression analysis conducted in the current study tested the hypothesis that opportunities for change would have a moderating relationship between the independent variables previously tested and the overall QOL indicator score.

Opportunities for change in a person's life are critical to the construct of self-determination, as a person cannot be expressing their self-determination if they are not provided with opportunities for change (Brown & Brown, 2003, 2009).

To establish the factors that have unique moderating relationships with the outcome, interaction terms were created for each independent variable with the possible

moderating variable by multiplying each independent variable by opportunities for change. This allowed each of the six interaction terms to be used as a moderator with the outcome (QOL importance/satisfaction) in order to determine if each interaction term was a statistically significant moderator within the current analyses. These exploratory analyses were conducted using two-step multiple regression analyses. The QOL importance / satisfaction remained the outcome variable, the independent variable was used in step one, and the corresponding interaction term in step two. Upon this investigation, three variables were determined to be significant individual moderators: health ( $\beta$  = -.194, p = .036), adaptive behaviour ( $\beta$  = .199, p = .031), and years spent in an institutional setting ( $\beta$  = .247, p = .007).

The next multiple regression analysis included the same six independent variables as possible predictors (number of years in an institution, adaptive behaviour, participation in activities the person likes the most, a measure of health, mental health and problem behaviour), with an addition of opportunities for change in step two, followed by the three significant interaction terms in step three. Two of the interaction terms identified previously (health and years in the institution) were included in the final analysis, and one was removed as it became non-significant in the full regression model (adaptive behaviour). Removing insignificant moderators leads to a more parsimonious regression model (Thompson, 2006). When opportunities for change was included as a predictor in the current analysis, the model accounted for 28% of the variance in QOL importance / satisfaction score. When the two significant interaction terms (health and years in institutional setting) were included in the third step of the multiple regression analysis, the model accounted for 35% of the variance in the person's satisfaction with the important

aspects of their lives. The third model was the most successful at identifying potential moderating effects between opportunities for change and the independent variables, with both health and years spent in an institutional setting identified as moderating relationships in the current model.

In addition to opportunities for change ( $\beta$  = .426, p = .000) and the two interaction terms (years in institution  $\beta$  = .912, p = .005; health  $\beta$  = -.194, p = .025) being significant predictors of QOL importance / satisfaction in the current model, years in institutional setting was also a significant predictor ( $\beta$  = -1.112, p = .001), as it was in the first regression model. The remaining five independent variables did not significantly influence the scores on the QOL importance / satisfaction on their own. See Table 6 for additional information regarding the full model.

Opportunities for change was found to be a significant predictor of the QOL importance/satisfaction score, in addition to years in the institutional setting. Further, the results of these analyses provide support for the hypothesis that opportunities for change would have a moderating influence between the independent variables tested as predictors and the overall QOL indicator score. This was partially demonstrated as there were two significant interaction terms, the years in institutional setting and the health composite score, that show a moderating relationship with opportunities for change.

Table 6.

Multiple Regression Analysis with Opportunities for Change as a Moderator

Step in	Possible Predictor Variable	R	$R^2$ change	F change	ß	sig
Regression Step 1	Valiable	.29	.08	1.61		
500p 1	Years in	,		1.01	21	.02
	Institutional setting					
	Performance ADLs				07	.45
	Frequency Activity				.16	.10
	Like the Most					
	Health Composite				.02	.86
	Reiss 26 Item total				35	.77
	General Maladaptive Index				.08	.48
Step 2		.53	.20	28.96		
_	Opportunities for Change				.46	.00
Step 3	Ghange	.59	.07	5.70		
1	Interaction Term				.91	.00
	Years in Institution					
	Interaction Term				19	.03
	Health Composite					

The interaction terms included in the current analyses were analyzed through post hoc visual inspection using grouped scatterplots with the dependent variable, the independent variable and the moderator split by its median (into 'low' and 'high' opportunities for change). The visual analysis for years in institutional setting, QOL importance / satisfaction and median split opportunities for change revealed a unique relationship. The trend indicated that there was a negative relationship between years in institution and QOL importance / satisfaction ( $r^2 = -.12$ ). For example, the context of low opportunities for change and a long stay in an institutional setting was associated with the lowest QOL scores. However, if the person has more opportunities for change, then the number of years a person spent in an institutional setting would not influence their scores

on QOL importance / satisfaction ( $r^2$  = .00). See Figure 3 for a visual depiction of this relationship.

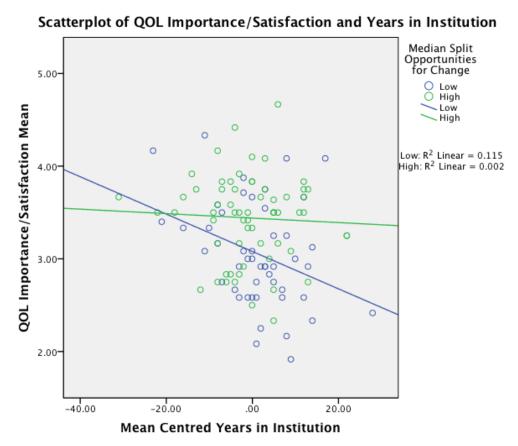


Figure 3. Grouped Scatterplot of Years in Institution by QOL Importance / Satisfaction Split by Low and High Opportunities for Change

The second relationship was not as strong as the previous interaction term. This relationship indicated that in the context of low opportunities for change there was a small positive relationship between poor health and QOL importance / satisfaction ( $r^2 = .01$ ); conversely, in the context of high opportunities for change this relationship was small and negative ( $r^2 = .02$ ). The highest QOL scores were associated with individuals with the best health and the greatest opportunities for change. Figure 4 also demonstrates that even in

cases of equivalent absence of poor health (low health composite scores), opportunities for change were associated with higher QOL.

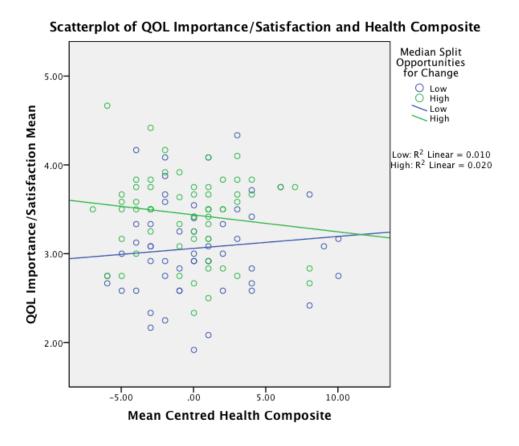


Figure 4. Grouped Scatterplot of Health by QOL Importance / Satisfaction Split by Low and High Opportunities for Change

In summary, the results of this study did not provide strong support for a straightforward prediction of QOL indicator scores from the full set of independent variables tested as potential predictors. Instead, the study supported decision making as a predictor of the QOL indicator (rather than as a moderator), while opportunities for change demonstrated a moderating effect on the influence of health and years in institution on the QOL indicator.

## **Discussion**

This study was designed to investigate the possible predictors of QOL in a sample of 114 adults with intellectual disabilities who had recently moved to community settings. Specifically, this study examined if satisfaction with the important aspects of life (the QOL indicator) could be predicted by the following factors identified as important to a person's QOL: (a) the amount of time in the institution, (b) adaptive behaviour, (c) participation in preferred community / recreational activities, (d) health, (e) mental health, and (f) problem behaviour. Three research questions and corresponding hypotheses were examined using three separate multiple regression analyses, using the same independent variables as possible predictors and a consistent outcome variable.

The first multiple regression analysis tested the influence of the six independent variables on the outcome and found that the model accounted for only eight percent of the variance in QOL importance / satisfaction. The second model included the same six independent variables as possible predictors in the first step, and included decision-making as a second step. This model accounted for 35% of the variance in QOL importance / satisfaction. The last model included the same six independent variables in the first step, and included opportunities for change in the person's life in the second step. This model accounted for 28% of the variance in the outcome. As a third step, two significant interaction terms were added to the model, years in an institutional setting and a measure of the person's health status. When the two moderating relationships were present in the stepwise linear regression, the model accounted for 35% of the variance in QOL importance / satisfaction.

Research Question 1: Do health, problem behaviour, mental health status, skill level, frequency of enjoyed activities, and number of years spent in an institution contribute to the individual's scores on a QOL indictor (satisfaction and importance) in the community after moving from an institutional setting?

As stated previously, the first multiple regression model accounted for only eight percent of the variance in QOL importance / satisfaction. The difficulty in predicting the QOL indicator using factors such as health, mental health, adaptive behaviour, problem behaviour and community access suggests a reason why this type research has not been found within the existing literature. As noted by professionals in the field, it is not that researchers have not attempted these analyses; it is that these analyses have not been successful, and therefore the results are not published (e.g., Miller, 2005; Harris, 1999). The current study also found that attempting to use logical factors hypothesized to influence a person's QOL was largely unsuccessful, indicating that our results are synonymous with the existing literature. However, this study went further than the existing literature to examine potential moderators that could help to detect influences from these logical factors.

Research Question 2: Does the degree to which individuals have self-efficacy (decision-making / control) moderate the influence of the variables on the QOL indicator?

As an extension of the first multiple regression model, it was determined that two additional models would be completed to determine the effectiveness of two possible moderating variables identified in the literature (Brown & Brown, 2003, 2009). The second model attempted to use decision-making as a moderating variable, but no significant moderating relationships were found. However, including decision-making as a predictor

was significantly more successful in examining the influence of the QOL importance / satisfaction indicator. Decision-making is the aspect of choice that involves the person determining what he or she wants and then communicating this selection to others (Brown & Brown, 2009). As was overviewed in the literature review, self-determination (which encompasses choice making; Brown & Brown, 2003) is the only significant predictor of QOL among people with ID identified in the literature (Lachapelle et al., 2005). Additionally, studies have found that persons with profound ID (the majority of our sample) have the lowest levels of self-determination (Wehmeyer & Garner, 2003; Nota et al., 2007). As the individuals in our current sample have more profound impairments and self-determination has been identified as an important factor to a good QOL among people with ID, decision-making was chosen as a moderator. This factor was included as a moderator rather than a possible predictor as it was hypothesized that this construct would change the relationships between the hypothesized predictors and the outcome. This hypothesis was not supported.

The current model accounted for 35% of the variance in a person's satisfaction with the important factors in their lives providing further evidence that decision-making is a critical aspect of a person's QOL among people with ID. It is interesting to note that within the current model, the years in an institutional setting variable was not a significant predictor of QOL, although it was in the other models. This indicates that when decision-making is accounted for in the model, the number of years a person spends living in an institutional setting does not contribute significantly to their satisfaction with the important factors in their lives. This finding suggests that the level of decision-making that a person has can counter the adverse impact of lengthy institutionalization on QOL.

It is well known that people with ID have the right to make choices for themselves; however, this knowledge is not consistently put into practice (Brown & Brown, 2009). Adults with ID in Ontario are at a high risk of being 'reinstitutionalized' in their community living settings by living lives devoid of real choice (Beadle-Brown et al., 2007). Service workers may feel anxious about giving the people they support real decision-making power as their clients may make decisions that seem as though they are not in their own best interest. Additionally, it can be difficult to balance a person's right to make decisions with a service worker's ethical responsibility to keep that person safe (Brown & Brown, 2009). However, people with ID should be granted the dignity of risk and need to be awarded their own decision-making power, as long as the risk is not too great. To adequately provide decision-making power the person may need to be empowered to make a choice, and taught how to do so. The current regression model indicates that the process of making choices is of the utmost importance to a person's QOL within this population, and demonstrates that service workers must be committed to teaching a person how to make choices, make their choices known and honouring these choices (Brown & Brown, 2009). Research Question 3: Does the degree to which opportunities for change are available to individuals moderate the influence of the variables on the QOL indicator?

As was overviewed previously, self-determination is an essential factor contributing to a person's overall QOL. Decision-making was included in the previous model as it is an important aspect of self-determination, but a person is unable to make decisions if they are not provided with opportunities for change (Brown & Brown, 2003, 2009). The last multiple regression model included opportunities for change as a potential moderator of

the relationship between the six independent variables tested as possible predictors and the outcome. In these analyses opportunities for change was examined as moderator as it was hypothesized that whether or not a person had opportunities for change would influence the relationships between the possible predictor variables and the outcome. This relationship was demonstrated through the two significant interaction terms (years in institution and health).

The effect of the interaction term years spent in an institutional setting\* opportunities for change- QOL importance / satisfaction, demonstrates an interesting relationship between the variables. As reviewed in the results, the trend shows that if a person has low opportunities for change and lived many years in an institutional setting, they are more likely to have lower scores on the QOL importance / satisfaction measure. However, if a person had spent many years in an institutional setting but is now being offered many opportunities for change, there is no relationship to their score on the QOL importance / satisfaction score. It is not surprising that this trend has not been identified in the literature, as this unique relationship is dependent on opportunities for change as a construct. However, this outcome indicates that people who are being offered an abundance of choice are more likely to have a higher QOL than their counterparts who are not being offered choice. The results demonstrate that it is very important for people with ID to be offered a variety of opportunities for change in their daily lives within community settings.

Although the relationship between a person's health, QOL importance / satisfaction and their opportunities for change is not as strong, it also denotes an interesting relationship. The relationship demonstrates that fewer opportunities for change and poor

health are associated with lower scores on the QOL importance / satisfaction. Additionally, if a person has many opportunities for change but is not very healthy, this profile is associated with slightly higher scores on the QOL importance / satisfaction score when compared to their counterparts with less opportunities for change. These findings likely relate to the research on controllability, which indicates that people can thrive if they feel they have control over their own health related outcomes (Lau, 1982). The current study may indicate that the concept of 'controllability' extends beyond health related outcomes and into QOL, indicating that people should be provided with, and encouraged to choose between a variety of outcomes as this may have positive influences on their overall health as well as their QOL.

As the current model also accounts for 35% of the variance in QOL importance / satisfaction, this study provides additional evidence that factors relating to self-determination are a critical part of a person's QOL. As opportunities for change was examined for a moderating effect rather than the typical predicting relationship, the current analyses indicated that the relationship between self-determination and QOL may be more complex than the current research is indicating, further supporting its critical importance to the QOL indicator.

As opportunities for change has been identified as a critical aspect of self-determination, and important to the enhancement of a person's QOL, it is essential that people are being provided with numerous opportunities for change within their lives.

Brown and Brown (2009) indicate that a better QOL is more likely when there is a range of opportunities available to the person. This can be more difficult in congregate care settings, as multiple people's wishes have to be accommodated on limited resources, but it must

remain a priority. If it is not possible for a wide array of opportunities to be offered to a person, at the very least they must be provided with the choice to say yes or no (Brown & Brown, 2009). This is not ideal, but is the very lowest expectation for services workers to achieve. Additionally, Brown and Brown indicate that the choices being offered to the person must be familiar to them, as people with ID may have difficulty imagining themselves in new or dissimilar situations. This means service workers must help people with ID experience a wide range of possible options before providing opportunities for change.

# **Wider Implications**

The current research focuses on an area that is understudied in the literature; the factors that influence QOL in persons with ID who have moved from institutional settings. The current research begins to fill the existing void in the research by providing evidence to support the closure of institutional settings, as in two of the models the number of years a person has spent in an institutional setting is associated with the person's QOL importance / satisfaction score, with more years in an institutional setting being associated with lower scores on the QOL indicator.

Additionally, this research is valuable for persons with ID as it has implications for their support agencies, their clinical teams, and the research community. Knowing the factors that influence a person's QOL inherently aids in the understanding of what factors are important to focus on when attempting to enhance QOL and when developing person centred plans. The current study demonstrates that self-determination (encompassed by decision-making and opportunities for change) is of the utmost importance to improving

the QOL of persons with ID, and safeguards must be put in place to ensure people can demonstrate their self-determination in their community homes.

Small changes can be made to increase a person's self-determination, such as including them in the creation and revisions of their own person centred planning (Forrester-Jones, 2005). Additionally, choice can be honoured in small life decisions such as where to sit, what to eat, who to be friends with, how to decorate, when to do things, what outings to attend, and who will visit (Brown & Brown, 2009). When small choices are learned successfully, more important choices can be included, and the person can be supported through these decision-making opportunities. Support staff must remember that encouraging a person to make choices for themselves does involve an element of risk, as the person may not choose the path that seems most appropriate, but risk and duty of care can be balanced (Brown & Brown, 2009). Specific training can be provided to support care staff in order to manage these questions and determine what risks are acceptable, and what risks are not. Throughout the process it is critical to remember the goal: to provide people with ID with opportunities for change and the ability to exercise their own choice making to increase their self-determination and their overall QOL.

# **Strengths**

A strength of the current study is that the participants were spread across the last three government institutions in Ontario, rather than the majority of research studies on deinstitutionalization, that typically involve the closure of one institutional setting. Also, participants were spread across Ontario in their new community homes, rather than being limited to one city or county. These factors reduce biases in our sample regarding location or institutional setting.

Research indicates that measures of QOL should be culturally sensitive and relative (Buntinx & Schalock, 2010). This means that the measure should take into account the customs and norms of the people within the culture the measure is attempting to assess (Buntinx & Schalock, 2010). In the current study a measure created in Ontario, and tested on Ontario residents with ID (the Quality of Life Other Person Interview; Raphael et al., 1996) was used on a sample of individuals with ID living in Ontario. This indicates that the present study used a culturally sensitive measure of QOL that accounted for the norms, ideals and customs of this area. Therefore increasing the strength of the current study and the results obtained from it.

Additionally, the current analyses provide insight into a population that is infrequently studied in relation to their QOL, adults with ID who have low adaptive behaviour and minimal verbal abilities. Information from these participants is not obtained frequently, and the current research strives to begin to fill that void.

# Limitations

Proxy respondents were used in the current study. As discussed in the literature review, it is always ideal to have a person answer questions on their own behalf.

Unfortunately, in the current sample, participants had little to no verbal ability and were unable to answer questions on their own behalf. In a few cases, obtaining information directly from the person was attempted, but the information was never fully obtained from the person with an ID due to confusion or exhaustion and data collection was redone with the proxy respondent (to ensure consistency). Upon inception of the larger Facilities

Initiative Project, it was decided that collecting this information by proxy was better than the alternative, not collecting information about this sample of people at all (Condillac et al.,

2012). Additionally, it would have been ideal to included more objective measures of QOL but this was not possible within the scope of the current study.

Response bias is another possible limitation among the current sample; meaning participants may have willingly or unwillingly answered questions favourably or unfavourably. To safe guard against this, research assistants on the Facilities Initiative team were trained to assure participants that all of their answers would be kept confidential and anonymous, and no specific information would be provided back to the agencies they were employed by or MCSS. This limitation is not limited to proxy respondents, as participants answering questions on their own behalf may purposefully answer favourably or unfavourably depending on their individual goals.

An additional limitation of the current study relates to the sample size. Although the sample is not small, analyses would have had more power with a larger sample size. This is especially true in the analysis involving moderators. However, it is significant that the moderators were influential in the current study as the sample size is quite small for these analyses. These results provided further evidence to the strength of the relationship between the moderators, the possible predictors and the outcome. Also, due to the extensive data collection for each participant, many factors were excluded from analyses that may have been influential on QOL. It was simply not plausible to include all of the factors that may have contributed to life quality, and as such, relevant factors may be missing.

Although it is considered a strength of the current study that participants with low verbal and adaptive abilities were sampled, it can also be interpreted as a limitation as it represents a restricted sample. Additionally, participants in the current sample were a part

of the older population and had (for the most part) spent most of their lives in institutional settings. As such, results of the current study should not be generalized to dissimilar populations, such as individuals with higher verbal abilities or adaptive abilities, younger populations or individuals who have lived their lives in community living settings.

Additionally, the results may be slightly skewed due in the present sample as six individuals were removed who accessed their community significantly less than those included in the sample.

Lastly, there is a potential confound in the results as the moderators in the current study come from the same measure as the outcome variable. However, there is no overlap in the questions, the answers in the questions to each subsection (importance / satisfaction, decision-making and opportunities for change) were unique, and there was no evidence of multicollinearity. Additionally, internal consistencies of each of the subscales were very high (ranging from .86 to .92). Perhaps the most significant defence to this potential limitation is the results of the present study. The unique relationships presented above indicate that the three subscales used were related to the predictors in dissimilar ways, and in ways that are consistent with the current research base.

## **Further Research**

The present research provides more insight into the importance of decision-making and opportunities for change in a person's life for people with ID, and demonstrates that further research should be conducted to determine how choice and opportunities for change can be effectively provided to people with ID.

Further research should be conducted, preferably with larger samples, predicting OOL using decision-making or opportunities for change (i.e., self-determination) as

moderators within these analyses. These studies can further confirm (or deny) the current hypothesis that QOL can be more adequately predicted when using self-determination as a moderating variable. Further research using self-determination as a moderator with dissimilar factors predicting QOL would also expand the current research base.

Additionally, further research should be conducted regarding how individuals with ID are doing in their community settings, within Ontario as well as across Canada. This research will ensure the research is up to date regarding what persons with ID need to increase their life satisfaction. For the provinces within Canada and the countries around the world that still operate institutional settings, further action is needed to close these facilities and integrate those living within them into community living settings.

The results of the scatterplot analysis between health, opportunities for change and QOL indicate that further research should be conducted to determine the relationship between 'controllability' and a person's overall QOL. This research extension may determine if the aspects of 'controllability' extend beyond their health related outcome and into a person's overall life quality.

## **Summary and Conclusion**

It is clear that self-determination is associated with the QOL of adults with ID who had recently moved from institutional settings. Two key aspects of self-determination, decision-making and opportunities for change, have different relationship to the QOL indicator score in this study. Decision-making and years spent in the institution were significant predictors of the QOL indicators, while the other variables that are typically studied as outcomes of deinstitutionalization and hypothesized to influence QOL were not. Opportunities for change had a moderating effect, indicating that it changes the

interactions between health and years in institution and the outcome variable, the persons' satisfaction with the important aspects of their lives. Of note is that the number of years spent in an institutional setting may be influential to a person's satisfaction with the important aspects of their lives, but providing the person with an abundance of opportunities for change can diminish this influence. The present study provides strong support for the need for providing people with ID with opportunities for change and decision-making, as an intentional strategy to improve QOL.

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