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Self-determination contributes to quality of life in young adults with autism spectrum disorders

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Conflict of interest

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Abstract

The aim of this study was to examine the relationship between self-determination (SD) and perceived quality of life (QoL) for young adults with autism spectrum disorder (ASD) who do not have an intellectual disability (ID), as well as to explore any possible relationships between intellectual functioning and QoL in this population. Participants were 30 Canadian young adults with ASD who did not have ID. Correlational analyses indicated that two measures of SD were significantly associated with QoL. Intellectual functioning, however, was not significantly associated with QoL. Regression analyses indicated that individuals with higher SD scores on each of the SD measures reported higher perceptions of life satisfaction. Subsequent research should examine how best to promote SD in young adults with ASD, as well as how to implement this aim in policy and practice.

Keywords: autism spectrum disorder self-determination, quality of life, young adults

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During the past decade, researchers and practitioners have become increasingly interested in alternatives to traditional deficit-based perspectives (Jimerson, Sharkey, Nyborg, & Furlong, 2004). The field of Positive Psychology is considered to be particularly influential as it de-emphasizes the deficit-based or medical model to promote a strengths-based or social model (Jimerson et al., 2004). This trend is being incorporated into the field of disability, where research and practice are starting to reflect life possibilities for people with disabilities (e.g., Autism Spectrum Disorder), quality of life, self-determination, strengths and capabilities, normalization, and the provision of individual supports (Shogren, Wehmeyer, Buchanan & Lopez, 2006; Wehmeyer & Schalock, 2001). Researchers have championed the importance of examining social constructs such as quality of life, as they have implications for both positive individual outcomes (e.g., employment, education) and for practice (Schalock, 2000).

Researchers in the field of Autism Spectrum Disorder (ASD) are beginning to incorporate the notion of QoL into their methodologies. ASD is a lifespan diagnosis that continues to impact opportunities in the community and quality of life (QoL) into adulthood. Outcome studies highlight that adults with ASD are generally fairing poorly. For instance, in a review of the literature, Levy and Perry (2011) found that 50-60% of adults with ASD leave school without educational or vocational qualifications, 76% are unable to find gainful employment, and 90-95% do not establish romantic relationships or meaningful friendships. These patterns parallel research from the USA (Farley et al., 2009), the UK (Howlin, Goode, Hutton, & Rutter, 2004), Sweden (Billstedt, Gillberg, & Gillberg, 2005), and Canada (Eaves & Ho, 2005). The few studies that describe outcomes for adults with ASD in relation to IQ levels tend to report that higher IQ levels are associated with relatively better outcomes but that variability in individual outcomes remained (Farley et al., 2009; Howlin et al. 2004). For example, Howlin et al. (2004) followed up in adulthood with a group of children who were grouped according to IQ levels. They reported that a fifth of their sample of 68 people with ASD obtained some academic qualifications (e.g., complete or partial college, undergraduate, or graduate degree), a third were employed, and only about a quarter of the group reported having friends with shared interests or activities. Furthermore, six individuals were in paid employment and also showed a higher level of independence, while the rest of participants remained highly dependent on their families. Regardless of the positive outcomes attained by some, young adults with ASD without an ID are significantly disadvantaged regarding employment, community involvement, social relationships, physical and mental health, and QoL relative to their typically developing peers (Howlin & Moss, 2012). These comparatively poor outcomes highlight the need to focus on enhancing QoL for young adults with ASD without ID.

Within the field of disability, the most prevalent definition of QoL is, “a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights” (Schalock, 2000, p. 121). With this definition in mind, “quality” related to the excellence associated with human values (e.g., happiness, success, wealth, and satisfaction); whereas, “life” suggests that the concept refers to important aspects of human existence (Brown et al., 2000; Schalock et al., 2002). Consequently, QoL is used as an effort to explain and comprehend the conditions that enhance and engender a life of satisfaction (e.g., food, shelter, safety) and a life of enrichment (e.g., values, beliefs, needs, interests) (Brown et al., 2000). Focusing on QoL therefore suggests that we value quality and that we want to maintain or improve the quality of the lives of people with

ASD (Schalock, 2000). Hence, QoL is a social construct that has become implicated in social policy for people with ASD in developing individualized services and accessing inclusive environments.

QoL is a multidimensional construct that can be conceptualized into notions of "core ideas" and "core principles" (Schalock et al., 2002). The core ideas reflect a framework for conceptualizing QoL and include domains of well-being, inter- and intra-personal variability, personal context, a life-span perspective, holism, values, choices and personal control, perception, self-image, and empowerment (see Schalock et al., 2002 for a review of the core ideas and principles). The core principles provide a framework for QoL measurement and application. For example, one significant principle is that QoL is influenced by a multitude of personal and environmental factors (Schalock et al., 2002). As such, researchers have identified eight core QoL dimensions that results from complex person-environment interactions: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Cummins, 1996; Felce & Perry, 1996; Schalock, 1996, 2000).

The development of a conceptual model of QoL has been underway since 2002 (Cummins, 2005; Schalock et al., 2002), however, the field has not yet adopted a unified construct for its measurement. In fact, many researchers debate which indicators constitute a satisfactory QoL, or whether some indicators are more important or predictive of QoL for different populations (Burgess & Gustein, 2007). Thus, a universal conceptual framework to guide the measurement process is still unresolved, as a significant variety of conceptualizations of QoL exist explaining the diverse amount of methodological approaches to measuring it.

Outside of the disability field, QoL is holistically measured using both objective (e.g., having a job, number of doctor visits, material success, social relations) and subjective (e.g., identifying values and matching them to perceptions of personal satisfaction and happiness) indicators (Saldana et al., 2009; Schalock et al., 2002) to better reflect the core dimensions of the construct (Cummins, 1996; Felce & Perry, 1996; Schalock, 1996). However, the vast majority of studies in the field of disability have relied uniquely on objective measures of QoL that do not always require input from study participants. The objective approach to QoL utilizes rating scales, participant observation, and questionnaires. For instance, using ordinal rating scales, researchers can ask "*How many civic or community clubs do you belong to?*" (Schalock, 2000). This approach utilizes more objective and performance-based measures, which may provide invaluable feedback to service providers about how to change or improve their services.

In contrast, the subjective approach to QoL requires researchers to ask a person about their level of satisfaction related to various aspects of their life. For instance, in Schalock and Keith's (1993) *Quality of Life Questionnaire (QoL-Q)*, respondents are asked "*How satisfied are you with your current home or living situation*" using a 3- to 5-point Likert scale indicating their level of self-perceived satisfaction. Advocates of both the subjective (Edgerton, 1996) and objective (Casas, 1997) approaches provide equally strong rationales in the literature for using either approach. However, the significant transition towards the social model of disability led to an increased focus and interest on more outcome-based evaluations that included the person's preferences and interests to better reflect the subjective nature of QoL (Schalock, 2000). As such, a person's measured level of satisfaction became the most commonly used dependent measure in assessing one's perceived QoL, allowing practitioners to measure the relative value of the respective dimensions to an individual him or herself (Cummins 1996; Felce & Perry, 1996; 1997). This approach supports the positive psychology and self-advocacy movements where a person with ASD would be viewed as an expert on their own life.

Researchers have investigated QoL during adulthood for people with ASD with ID, but limited data focus on people with ASD without an ID. Furthermore, most studies evaluated QoL using proxy respondents (Saldana et al., 2009) or through indirect measures (Persson, 2000). In a study examining subjective QoL (i.e., importance and satisfaction) of people with ASD by proxy, almost half of the participating families were not able to approximate the satisfaction and importance of QoL of the person with ASD (Saldana et al., 2009). This suggests the need to include the voices of people with ASD in evaluating their own QoL, as we do in the present study.

The notion of self-determination (SD) originates from Ryan and Deci (2000)'s self-determination theory in the field of psychology, where SD is considered as an innate need that motivates an individual to engage in behaviours (i.e., "self-actualizing"). Ryan and Deci noted the importance of fulfilling individual needs for autonomy, competence and relatedness. More specifically, when these needs were satisfied, individuals exhibited optimal motivation and well-being (Ryan & Deci, 2000). In the most common conceptual model of SD in the field of disability, Wehmeyer (1992) defines SD as "the attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (p. 305). However, he later noticed that what was missing from the original definition was the notion that small or large, SD actions contribute to one's QoL. Wehmeyer (1996) thus adapted his definition to include "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (p. 22).

In 1999, Wehmeyer delineated four essential characteristics that comprise SD: behavioural autonomy, self-regulation, psychological empowerment, and self-realization. Specifically, individuals are deemed self-determined if they acted autonomously, exhibited self-regulated behaviours , initiated and responded to the events in a psychologically empowered manner, and acted in a self-realizing manner (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). These essential characteristics led to Wehmeyer's current and revised definition of self-determined behaviour as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117).

Thus, SD is inextricably linked to, and may even be best understood within, the context of a person's overall QoL. That is, people who are self-determined act autonomously, self-regulate their behaviour, are self-realizing, and are psychologically empowered which results in more positive adult outcomes (Wehmeyer & Palmer, 2003). More specifically, SD has been associated with various post-secondary outcomes, including employment and independence in managing personal finances for young adults with ID at 1 and 3 years post-high school graduation (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998).

Two of the most common SD frameworks include Wehmeyer's functional theory and Mithaug's self-determined learning theory. Wehmeyer's (1999, 2001, 2005) functional theory views SD as a *dispositional characteristic of individuals*. More specifically, the concepts of causal agency and volitional action are central to this perspective. In this framework, SD emerges across the lifespan and is acquired through specific learning experiences as individuals learn skills and develop attitudes that enable them to be causal agents in their lives and to act volitionally (Wehmeyer, Sands, Doll, & Palmer, 1997; Wehmeyer, 1999). These skills and attitudes are known as "component elements" of self-determined behaviour and include: choice-making, decision making, problem-solving, goal setting and attainment, self-monitoring, self-advocacy, an internal locus of control, perceptions of self-efficacy and outcome expectancy, self-awareness and self-knowledge (see Wehmeyer, 1999 for a review of the component elements).

The second framework, self-determined learning theory (Mithaug, Mithaug Agran, Martin, & Wehmeyer's, 2003), focuses on *the process by which individuals become self-determined learners.* More specifically, this theory tries to explain how individuals "interact with opportunities to improve their prospects of getting what they want and need in life" (Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994, p. 4) and how SD depends on both capacities and opportunities. Capacity refers to the knowledge, abilities, and perceptions that enable individuals to become self-determined; while opportunity refers to the chances provided to individuals to apply their knowledge and abilities related to SD (Wolman et al., 1994). More specially, when individuals pursue opportunities, they learn to adjust and regulate their thoughts, feelings, and actions. This framework is novel in emphasizing the importance of opportunities when evaluating SD. Therefore, the two frameworks offer complementary perspectives: the functional theory focuses on the personal characteristics that lead people to act in a self-determined manner, while the self-determined learning theory focuses on the process through which people become self-determined (Shogren et al., 2008).

As Wehmeyer and Schalock (2001) noted, people who are self-determined cause things to change to accomplish a specific goal, such as obtaining employment; and these changes, by definition, are designed to optimize a person's QoL. Given this logical relationship, there has been a growing interest in exploring the relationship between the concepts of SD and QoL for people with disabilities (Chambers et al., 2007). To date, limited research provides a causal link between the two constructs (Chambers et al., 2007; McDougall, 2010). Only one study has examined the relationships between SD and various subdomains of QoL for people with chronic conditions and disabilities. Using linear regression analysis, McDougall (2010) found that SD was significantly associated with two subdomains of QoL over time. Particularly, those individuals with higher SD at baseline reported higher perceptions of satisfaction with both personal development and personal fulfillment 1 year later. Furthermore, two cross-sectional studies have specifically examined the relationship between SD and self-reported QoL in individuals with ID. Wehmeyer and Schwartz (1998) investigated the relationship between SD and QoL for 50 adults with ID; after controlling for IQ and environmental factors that were thought to contribute to higher SD, they found that SD predicted membership in a high QoL group. That is, people who were self-determined had a higher QoL, and people who lacked SD had a lower QoL. Similarly, an international study conducted by Lachapelle et al. (2005) examined this relationship in 82 adults with a mild ID living in community settings in Canada, United States, Belgium and France. They found that the essential characteristics of SD (i.e., autonomy, self-regulation, self-realization, and psychological empowerment) predicted membership in a high QoL group and that overall SD and QoL were significantly positively correlated.

Thus, these findings indicate a significant relationship between QoL and SD, such that SD contributes to enhanced QoL, as theorized by Schalock (1996) and Wehmeyer (1996). Despite the growing evidence of SD and QoL in the field of ID, limited research has examined the value of SD and QoL in young adults with ASD without an ID. The aim of this study was to elucidate the relationships between two measures of SD (that each reflect one of the two frameworks of SD) and QoL in a sample of young adults with ASD who do not have concomitant ID. Given that the two frameworks offer complementary perspectives (Mithaug,

Mithaug Agran, Martin, & Wehmeyer's, 2003; Wehmeyer's, 1999; 2001; 2005), utilizing both measures of SD will enable an investigation of the personal characteristics related to SD behaviours as well as to the process through which people become self-determined (Shogren et al., 2008). A further aim was to explore any possible relationships between IQ (i.e., non-verbal and verbal IQ) and QoL as prior research has reported a positive relationship between IQ and positive outcomes in adulthood (e.g., Howlin et al., 2004).

Method

Participants

Thirty young adults (20 males, 10 females) with ASD participated in the study after providing written consent. Participants were recruited via service agencies, newsletters, and post-secondary institutions as a part of a larger randomized control trial (RCT) study on a Transition Support Program. Data for the current study were collected prior to participation in the RCT study (i.e., the current analyses presents pre-program assessment data). Criteria for inclusion in the transition support program were: 1) being between 18 and 30 years of age; 2) diagnosis of an ASD (confirmed within the study using the procedure outlined below); 3) absence of intellectual disability based on either non-verbal (Raven's Progressive Matrices, RPM; Raven, Raven & Court, 2004) or verbal (Wechsler Abbreviated Scales of Intelligence, WASI; Wechsler, 1999) IQ scores falling within 1 SD of the typical range; 4) and the ability to communicate in English. Participants were not eligible to participate in the study if they were enrolled in another similar transition support service (i.e., a group-format service that focused on social interaction and communication, self-determination, and professional skills).

Participants ranged from 18 to 29 years old (*M* = 21.27, *SD* = 3.32) with verbal IQ (*M* = 112.23, *SD* = 15.16) and/or nonverbal IQ (*M* = 52.33, *SD* = 4.03) scores within the average range. Community diagnoses of ASD were confirmed in our study by administration of the ADOS-2 module 4 (Lord et al., 2012), using the revised algorithm for module 4 (Hus & Lord, 2014). Twenty-eight of 30 participants met ASD criteria (scores of 8 or higher) on the ADOS-2. The remaining 2 participants fell short of meeting ADOS-2 criteria based on current functioning, but did meet ASD criteria based on their early development, as reported by their parent on the SCQ (Rutter, Bailey, & Lord, 2003, scores of 15 or higher). The majority of participants were Caucasian (70%). Most participants were native speakers of English, although 6.7% spoke French as a first language but had conversational English abilities. Low employment rates were reported, with only 13.3% having a part-time job. However, approximately 90% of the participants reported completing some amount of post-secondary education (vocational programs, university preparation programs, or university). Finally, the vast majority of participants were living at home with their parents (86.7%), while one individual reported living independently and 3 individuals reported living independently but with roommates (i.e., sharing expenses).

Design

The current study is part of a larger RCT study examining a group format transition support program for adults with ASD who do not have an ID (Nadig, Flanagan, & White, in preparation). The present analysis on the relationship between Quality of Life and Self Determination measures is non-experimental and descriptive in nature.

Measures

Prior to participating in the program, participants were administered the following measures, among others. The measures were administered in person at the participant's intake and pre-program assessment visits (each visit was approximate 1.5 hours in duration). IQ testing was conducted by a senior level doctoral student in clinical psychology with experience conducting psychological assessments. Quality of Life and SD questionnaires were administered by a research team (ranging from honors undergraduate students to assistant professors), all of whom were trained and experienced in conducting assessments.

Nonverbal IQ (NVIQ). The Raven's Progressive Matrices (RPM; Raven, Raven & Court, 2004) is a norm-referenced assessment of nonverbal intellectual ability. The RPM consists of 60 diagrammatic puzzles that are divided into five sets (A, B, C, and E), and is suitable for a range of populations with retest reliabilities of .83-.93. The RPM is a widely used measure to estimate nonverbal cognitive ability for matching in studies of individuals with ASD and is considered an appropriate measure for this population (Dawson, Soulières, Gernsbacher, & Mottron, 2007; Mottron, 2004). Raw total scores were used in the analyses, as standard scores are not available.

Verbal IQ (VIQ). The Wechsler Abbreviated Scales of Intelligence (WASI; Wechsler, 1999) consists of four subtests (Vocabulary, Similarities, Block Design, and Matrix Reasoning), yields measures of Verbal IQ (VIQ), Performance IQ (PIQ), and a Full Scale IQ. The WASI is used in research setting and can be administered as two (i.e., PIQ or VIQ) or four subtests (i.e., FSIQ). The WASI manual reports excellent internal consistency and test-retest reliabilities for the three IQs. There is also evidence to support the construct validity of the VIQ and PIQ (The Psychological Corporation, 1999). For the purpose of the current study, only two subscales (Vocabulary and Similarities) were administered in order to calculate VIQ.

Quality of Life. The Quality of Life – Questionnaire (QoL-Q; Schalock & Keith, 1993) is a 40-item rating scale designed to measure QoL for people with disabilities. The 40 items are rated on a scale from 1 to 3. The maximum total score is 120, with higher scores indicating higher levels of QoL. The QoL-Q is administered in an interview format and yields data regarding total QoL score, consisting of scores from four sub-scales: satisfaction, competence/productivity, empowerment/independence, and social belonging. The QoL-Q demonstrates very good internal reliability (alpha = 0.90) as well as inter-observer reliability (r = .83), test-retest reliability (r = .87) as well as evidence of construct and concomitant validity (Schalock & Keith, 1993).

Self-determination. The Arc's Self-Determination Scale (SDS; Wehmeyer & Kelchner, 1995) and the AIR Self-Determination Scale – Student form (AIR-S; Wolman et al., 1994) were administered as measures of SD. Both the *SDS* and *AIR* were developed with the intention of measuring global SD within the context of different empirically validated theoretical frameworks (Wehmeyer & Mithaug, 2006; Wolman et al., 1994). Shogren et al. (2008) demonstrated that although the SDS and the AIR-S are related (r = .50), they measure distinct aspects of the SD construct. Shogren et al. found that combining these two measures into one global, higher order SD construct was not justified by data. Therefore, the current study employs both questionnaires as separate measures of SD in young adults with ASD.

The SDS is a 72-item scale consisting of 4 sections, including: autonomy, self-regulation psychological empowerment, and self-realization. The first section measures *Autonomy,* which is a person's level of independence and capacity to act based on their personal beliefs, values, and interests. The 32 items in this section are rated on a scale from 0 (I do not even if I have the chance) to 3 (I do every time I have the chance). The second section includes 9 items reflecting *Self-Regulation*, which includes problem solving and goal-setting and task performance. For the problem-solving section, scores are assigned on a scale of 0 to 2 points depending on the effectiveness of the participants' solution to resolve the social problem. For the goal setting and task performance section, scores are accumulated based on the presence of a goal and the steps identified to attain the goal (0 = no plan, 1 = goal without steps, 2 = goal with 1-2 steps, 3 = goal with 3-4 steps). In the third section, participant respond to 16 questions measuring *Psychological Empowerment*, that is, a person's perceptions of control, efficacy, and outcome expectations. Scores are assigned with either 0 (answer not reflecting a psychologically empowered belied) or a 1 (answer reflecting a psychologically empowered belief) point. The final section of 15 items measures *Self-Realization*, which includes self-awareness and self-knowledge. Scores of either 0 or 1 are given based on whether the answer reflects positive self-awareness and self-knowledge. Subscale scores as well as a total SD score can be calculated. The maximum total score is 148, with higher scores indicating higher levels of SD. The total score of the SDS was used in this study. The SDS was normed with 400 adults with intellectual disabilities, and has adequate construct validity, discriminative validity, internal consistency (Chronbach alpha = 0.83) and factorial validity (Wehemeyer & Bolding, 1999).

The AIR-S (Wolman et al., 1994) examines individual capacity for, as well as opportunity to practice SD. The AIR-S has 24 questions and yields three Capacity sections (ability, knowledge, and perceptions) and two Opportunity sections (opportunity at school and at home) using a scale of 1 (never) to 5 (always). The AIR-S Capacity subscale consists of two domains: Things I Do, related to SD, and How I Feel, about performing these behaviors. The AIR-S Opportunity subscale includes questions about the opportunities students have to engage in SD behaviors at home and school. Capacity and Opportunity subscale scores can be calculated as well as a total SD score, which combines the two subscales and has maximum total score of 120, with higher scores indicating higher levels of SD. The total score of the AIR-S was used in this study. The AIR-S was developed and normed with 450 students with and without disabilities between the ages of 6 and 25 years of age in California and New York (Wolman et al., 1994). The AIR-S was demonstrated to have adequate reliability and validity (Mithaug, Campeau, & Wolman, 2003) in the measurement of SD for students with and without disabilities. Given that most of the individuals in the current study were in school and under the age of 25, the AIR-S was a suitable measure (henceforth referred to as *AIR*).

Data Collection

Data were collected in a one-on-one assessment session where a member of our research team administered questionnaires. If requested or needed, written questionnaire items were verbally provided and each response was recorded to ensure a complete data set. The data from paper protocols were later entered into Statistical Package for the Social Sciences (SPSS) by a trained research assistant, and then double-checked by a second trained research assistant for accuracy prior to analyses. Due to the nature of administration there was no missing data.

Analysis

To explore the relationship between SD and QoL, correlational analyses of the QoL-Q, AIR, and SDS total scores (continuous variables) were conducted. To explore possible relationships between QoL and both verbal (WASI VIQ standard score) and non-verbal IQ (RPM raw total score), correlational analyses were conducted between these continuous variables. Furthermore, two simple linear regression analyses with QOL-Q as the criterion variable, and either the AIR total score or the SDS total score as the predictor variable were conducted to investigate the impact of each measure of SD on QoL.

Results

Descriptive statistics on our measures of interest were: QoL-Q Total score (M = 79.23, SD = 13.19, range = 57-103), SDS Total score (M = 81.40, SD = 19.39, range = 50-124), and

AIR-S Total score (M = 85.63, SD = 16.90, range = 57-116), Verbal IQ via the WASI (M = 112.23, SD = 15.16, range = 85-143), and Non-Verbal IQ via the RPM (M = 52.33, SD = 4.03, range = 42-59).

As shown in Table 1 correlational analyses demonstrated a significant positive correlation between total SDS and AIR scores (r = .529, p = .003). In addition, both the SDS (r = .426, p = .019) and the AIR (r = .435, p = .016) were positively related to total QoL. To examine if QoL was related to intellectual abilities in our sample we also conducted correlations with verbal and nonverbal IQ. Neither of these variables was significantly related to QoL; therefore verbal IQ (r = -.305, p = .101), nonverbal IQ (r = -.098, p = .606) were not examined further.

Insert Table 1

Two separate simple regression models, presented in Table 2, examined the predictive value of each self-determination scale in explaining variance in QoL ratings. SDS scores explained a significant amount of the variance in QoL ratings (F (1, 28) = 6.213, p = .019, R^2= .182, $R^2_{Adjusted}$ = .152). AIR total scores also explained a significant amount of the variance in QoL ratings (F (1, 28) = 6.520, p = .016, R^2= .189, $R^2_{Adjusted}$ = .160). These results suggest that SD contributes significantly to QoL in young adults with ASD. Both of the SD questionnaires we employed explained approximately 18% of the variance in QoL ratings. This indicates that the more self-determined people are, the higher they rate their perceived quality of life.

Insert Table 2

Discussion

The goal of this study was to better understand the relations between SD and QoL in a sample of young adults with ASD who do not have concomitant ID, as well as to explore any possible relationships between intellectual functioning and QoL.

There has been little research examining SD as it relates to QoL for individuals with ASD, and especially for those without ID. Given the possible different profiles of strengths and challenges among people with ASD with and without ID, we focused our research on this underserved group. Our results indicate a significant positive relationship between SD and QoL for adults with ASD without ID, thus supporting similar findings in groups with concomitant ID. Our results are very similar to the association reported by Shogren et al. (2008) for a US sample of 407 high school students with disabilities (e.g., ID, learning disability, emotional and behavioural disorders, autism).

Interestingly, in our sample of adults with ASD without ID, IQ was not significantly related to QoL, and the associations that were found were in the negative rather than positive direction. This is consistent with the idea that in this population disability is more accurately captured by the level of adaptive functioning, than by IQ or language ability, with the former falling behind the latter by 2 or 3 standard deviations on standardized tests (Klin et al., 2005). Our most important finding is that SD, as measured by either the SDS or the AIR, was found to be significantly and positively associated with QoL ratings. This emphasizes the potential importance of developing SD skills in young adults with ASD to improve their QoL. That is, SD-focused services and supports may ensure the QoL of young adults with ASD as they transition to adulthood. This is not surprising given that people who are more self-determined cause things to happen in their own lives (e.g., obtaining employment), which in turn may enhance their QoL.

Limitations

It is important to exercise caution in generalizing the results to a wider audience. Specifically, the primary limitation of the current study is the small sample described. However, given the novel area of study we believe that our study is an initial step to providing evidence for the important relationship between SD and QoL among young adults with ASD. Although the sample size was too small to conduct more complex multivariate analyses to further explore the relationship between QoL and SD and to determine the nature and direction of that relationship, our findings have important implications. Ultimately, this knowledge could help to influence practice by promoting SD in curricula to positively impact the lives of people with ASD without an ID. Furthermore, the SD measures, in particular the AIR, should be used with caution when investigating older adults, as it has been normed for students up to 25 years of age. Fortunately, the majority of the participants were attending school and were able to complete the school opportunities subdomain. Future studies should consider using the SDS or removing the school opportunities subdomain from analyses.

Implications for Theory

As the field of disability is shifting from a medical model of disability to a social model of disability, constructs are being created and/or re-constructed. QoL and SD are two of these constructs, which can be seen as important vehicles for attaining positive outcomes. However, the constructs of QoL and SD are not static; they are confirmed or challenged with every research article published. And, given that they are inextricably linked, future research is required to examine the nature and direction of the relationship between QoL and SD. To date, limited research provides a causal link between the two constructs (Chambers et al., 2007; McDougall, 2010). Once this causal link is established, we could strengthen our understanding of both constructs by developing one theoretical or conceptual model that captures both constructs and their related nuances.

There seems to be a hierarchy to the core domains of QoL (see Schalock, 2000), however, the theoretical framework of SD does not really define how people with disabilities can prioritize their needs and focus on the costs and benefits of satisfying some needs to the detriment of others (e.g., finishing homework before connecting socially). This is important knowledge as QoL and SD can mean different things to different people at different time points across lifespan. Additionally, a hierarchical model of SD may elucidate a better understanding of the dynamic interplay among the essential characteristics and point to ways of including this information in best practices for service provision at different developmental periods.

Implications for Practice

SD and QoL might be best viewed together as constructs to guide policy and practice in order to improve life conditions and to empower people with ASD to live the life that they desire. SD-focused services and supports may ensure the QoL of young adults with ASD as they transition to adulthood. In fact, Wehmeyer and Schalock (2001) argue that if educational, health, and social service professionals are serious about promoting QoL among individuals with disabilities, examining SD becomes essential.

Although the above-mentioned practical implications would allow for better provisions for individuals with ASD, the varying theoretical and conceptual views of QoL and SD in the literature may make it difficult to interpret what researchers and practitioners mean when they refer to enhancing QoL and SD. This can also result in confusion and misunderstanding, therefore resulting in poor application. For example, Brown and Brown (2005) stated that although the notion of QoL is generally accepted, it is often misunderstood in practice due to the variation in professional interpretation. Given the numerous definitions of SD within the field of disability, this poor application of SD might also exist despite best efforts to develop empirically validated theoretical models of SD (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003) that have practical value. Nevertheless, the *SDS* and *AIR* may be viable tools to help assess SD in adults with ASD. These assessments could help with transition services and could allow clinicians to better meet the SD needs of young adults with ASD.

Implications for Policy

We hope that our findings will be of value to practitioners and policymakers as they highlight the positive relationship between SD and QoL among young adults with ASD who do not have ID. Together, these constructs may be used to catalyze the service delivery system because of their combined power as a social construct, and their unifying and inclusive properties (Schalock, 2000).

Future Research

Although researchers are starting to acknowledge the importance of investigating QoL and SD together, further investigation is warranted. Future studies should explore the relation between QoL and SD for individuals with ASD in larger longitudinal studies to understand potential long-term impacts of SD on QoL. We should also further our understanding of the construct of SD and its potential value as an outcome measure to evaluate interventions for individuals with ASD. Future research should also examine how the components of SD are valued or expressed in individuals with ASD. We often equate SD with specific objective outcomes (e.g., goals, employment), which is somewhat contradictory to SD because it impacts freedom of choice (Browder et al., 2001). We need to remember that promoting SD means respecting personal choices, even if they do not reflect the outcomes that are valued by someone else (Schalock et al., 2005). Finally, further research is warranted on the contexts surrounding the notion of QoL as satisfaction, the usual metric is highly dependent on one’s environment (Wehmeyer, 1999). For example, research has begun to document the influence of diverse intra-individual factors and environmental factors that serve as mediating or moderating variables in the efforts to promote SD (Nota et al., 2007; Shogren et al., 2007; Stancliffe, Avery, & Smith, 2000; Wehmeyer & Bolding, 2001). For instance, Shogren et al. (2007) revealed that gender, inclusion status, and cognitive functioning significantly predicted SD among youth with disabilities. However, more research is needed in the field of ASD as less is known about the factors that influence QoL for individuals with ASD. Such research could help to identify and categorize the contextual factors that may influence the theoretical and practical notions of QoL and SD to potentially improve the lives of individuals with ASD.

Conclusion

Given the history of service practices that compromised the QoL of people with disabilities (e.g., large segregated institutions), many organizations’ policies now aim to increase QoL, yet a gap between policy and practice remains (Townsend-White, Pham & Vassos, 2012). The current results suggest that SD-focused services and supports could be an effective method of promoting QoL by encouraging SD skills and by creating opportunities for young adults with ASD as they transition to adulthood. Consequently, SD should be considered an important element of high-quality transition services and disability supports and services for young adults with ASD who do not have an ID.

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Table 1

Correlational Analyses (N = 30)

Variable	1	2	3	4	5
1. QoL-Q Total Score	-	.426*	.435*	-.305	-.098
2. SDS Total Score		-	.529**	.115	-.007
3. AIR Total Score			-	-.259	-.328
4. Verbal IQ				-	.497**
5. Non-Verbal IQ					-

Note. * p < .05, ** p < .01

Table 2

Summary of Simple Regression Analyses Predicting Quality of Life-Questionnaire scores Using either the SDS or the AIR (N = 30)

	Criterion Variable: QoL-Q		
Predictor Variable	*B*	*SE B*	*β*
SDS*	.626	.251	.426
AIR*	.557	.218	.435

Note. R^2 = .182 (p < .05) for SDS and R^2 = .189 (p < .05) for AIR