Closing the Gap: Identifying Self-Reported Quality of Life Differences Between Youth with and without Intellectual and Developmental Disabilities

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Ethics Approvals

This study was approved by Duquesne University’s Institutional Review Board, protocol #2016/11/1.

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Abstract

This study measured quality of life (QOL) for transition-age youth with IDD and college youth without IDD. Transition-age youth with IDD (n=19) and college youth without IDD (n=30) were interviewed using the *Quality of Life-Questionnaire (QOL-Q)*. One-way between-subjects ANOVAs and multivariable linear regression were used to explore differences between the groups and identify QOL predictors. Youth with IDD scored significantly lower on the *QOL-Q* than college youth without IDD. While they scored lower in *Independence*, *Community Integration*, and *Productivity*, no significant difference was found in *Satisfaction*. While studies have examined QOL for children, youth with ASD, and adults, additional research is needed on the factors that contribute to QOL among transition-age youth with IDD in order to improve the quality of their transition to adulthood.

Keywords: Intellectual disability, intellectual and developmental disabilities, transition-age youth, quality of life, quality of life predictors

Quality of life (QOL), or success and happiness with one's life, consists of the same components for people with and without disabilities: emotional, economic, and physical well-being; opportunities for interpersonal relationships and personal development; social inclusion; self-determination; and access to basic human rights (Watson & Keith, 2002). While the components that lead to a quality life are generally the same for all people, QOL has been measured as significantly lower for people with intellectual and developmental disabilities (IDD) than for peers without disabilities (Simões & Santos, 2016a). People with IDD experience QOL and health-related QOL disparities to a greater degree due to long-standing histories of marginalization, low levels of employment and social capital, low socioeconomic status, poorer social determinants of health, high chronic health needs, and decreased access to specialty health services and providers (Emerson & Brigham, 2014; Ervin, Hennen, Merrick, & Morad, 2014; Lysaght & Cobigo, 2014). Thus far, most of what is known about QOL for people with IDD has been gathered from adults (Balboni, Coscarelli, Giunti, & Schalock, 2013; Nota, Soresi, & Perry, 2006; Simões & Santos, 2016a; Simões & Santos, 2016b). However, far less research exists on QOL among youth with IDD, especially those in transition from high school to post-secondary life.

While intellectual disability (ID) and developmental disabilities often coexist, they are not the same. Developmental disabilities typically emerge before the age of 22 and last throughout an individual's lifespan (AAIDD, n.d.). Developmental disabilities can manifest physically, intellectually, or affect both physical and intellectual functioning. An intellectual disability is one type of developmental disability that primarily impacts an individual's cognitive skills, such as learning, reasoning, and problem-solving, as well as adaptive behavior skills, which include conceptual skills, social skills, and the ability to complete practical activities of daily living (AAIDD, n.d.). People with intellectual disability comprise approximately 1% of the world's population (McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016). The percent of transition-age youth with a cognitive or intellectual disability, between the ages of 16-20, is roughly 4.4% of the United States (US) population, according to the American Community Survey (Erickson, Lee, & von Schrader, 2017). Because the large majority of youth who participated in this study had both an intellectual disability (ID) and a developmental disability (90%), the term ‘IDD’ is used to describe the study population.

Transition-age youth with IDD are students preparing to leave their high school experience who are “in a critical time during which the supports, instruction, and linkages [they] and their families receive can directly shape their in- and post-school outcomes” (Boehm, Carter, & Taylor, 2015, p. 396). The transition from high school into adulthood can be a particularly challenging time for youth with IDD as they manage physical, interpersonal and educational changes (Biggs & Carter, 2016). As structured supports and services taper post-high school, youth with IDD have few post-secondary options and experience key educational and employment disparities when compared to their peers without disabilities (Bureau of Labor Statistics, 2017; Think College, 2018). It is important to measure the QOL of transition-age youth with IDD, and explore the factors that contribute to it, so that human service providers, support professionals, and family/caregivers can understand their post-secondary wants and needs. Subsequently, they can tailor long-term supports and services (LTSS) to youth with IDD during a critical period of their lives and into adulthood.

QOL research that has involved youth with IDD typically report data gathered from parent and/or caregiver proxies rather than from youth themselves (Biggs & Carter, 2016; Kraemer, McIntyre, & Blacher, 2003; McIntyre, Kraemer, Blacher, & Simmerman, 2004;

Watson & Keith, 2002). However, Rapley (2003) recommends that subjective measurement of a person's QOL is not only an "essential ethical requirement" (p. 64), but also allows researchers to more accurately measure the construct of QOL. Additional research suggests that by engaging youth with IDD in the transition planning process, their self-determination, autonomous decision-making, and post-secondary outcomes improve (van Heumen & Schippers, 2016; Wehmeyer, Palmer, Lee, Williams-Diehm, & Shogren, 2011). Therefore, this study explored self-reported QOL for a sample of youth with IDD who attended a transition program on a university campus and were seeking post-secondary education and/or employment opportunities.

QOL has been studied among people with disabilities for decades. However, in recent years, policymakers and regulatory bodies, researchers, human service providers, and support professionals have taken a renewed focus on QOL (Friedman, 2019; Kober & Eggleton, 2009). In the US, Medicaid serves as the primary mechanism of reimbursement for services, funding 78% of LTSS for people with IDD (Braddock et al., 2015). In response to rising Medicaid costs, many state IDD service systems have moved towards Medicaid Managed Care or Accountable Care Organization (ACO) models that utilize value-based payment arrangements (Lewis, Eiken, Amos, & Saucier, 2018). These value-based payment structures give incentives to organizations that provide person-centered assessment and make efforts to improve the overall health and QOL of the people they support (Braddock et al., 2015). Through the use of QOL and person-centered assessment, support professionals can work together with transition-age youth with IDD to prepare for adulthood by identifying their wants, needs, and priorities for the future, develop a plan for meeting them, and track their post-secondary outcomes.

Studies on QOL for people with IDD have generally focused on adults, students in kindergarten to 12th grade (K-12), or on specific populations of youth with disabilities (e.g., youth with ASD) (Balboni, Coscarelli, Giunti, & Schalock, 2013; Biggs & Carter, 2016; Nota, Soresi, & Perry, 2006; Simões & Santos, 2016a; Simões & Santos, 2016b; Watson & Keith, 2002). Many of these studies relied on parent/caregiver- or proxy-reported QOL rather than on a youth's perspective of their QOL (Biggs & Carter, 2016; Kraemer et al., 2003; McIntyre et al., 2004). Biggs and Carter (2016) used the KIDSCREEN-27 to measure parent-reported QOL for samples of youth with ASD (n=232) and ID (n=157), and compared their QOL to that of a normative sample of youth without disabilities (The KIDSCREEN Group Europe, 2006). The researchers detected significantly lower scores on three out of the five KIDSCREEN-27 domains for both youth with ASD and ID when compared to youth without disabilities, with the lowest scores obtained in *'Social Support and Peers'*. Across multiple KIDSCREEN-27 domains, younger age, greater participation in community and religious/faith activities, and the expression of positive traits/strengths were predictors of higher QOL scores among participants with ASD and ID. While this study gathered valuable data from a large sample and explored potential predictors of QOL, data was collected solely from the parents of participants with ASD/ID, and not from the youth. Kraemer at al. (2003) and McIntyre et al. (2004) also measured QOL for youth with moderate to severe ID using Schalock and Keith's (2004) *Quality of Life Questionnaire* (*QOL-Q*). In both studies, *QOL-Q* assessments were completed by parents/caregivers of participating youth and did not represent self-reported data from the youth with ID. While these studies made strong contributions to understanding QOL for youth with IDD, collecting data from proxies, and not from youth themselves, can lead to potential measurement errors and an inability to accurately identify self-perceived QOL for youth with IDD.

Studies that have gathered self-reported QOL data from people with disabilities have rarely focused on transition-age youth with IDD (Clark, Magill-Evans, & Koning, 2015; Knüppel, Telléus, Jakobsen, & Lauritsen, 2018; Watson and Keith, 2002). Watson and Keith (2002) conducted one of the first self-report studies of QOL among children and youth with IDD. They used the student version of the *QOL-Q*, the *Quality of Student Life Questionnaire (QOL-SQ),* to assess QOL for a sample of students enrolled in grades K-12. They found significantly lower mean total *QOL-SQ* scores among the students with disabilities (n=76) when compared to students without disabilities (n=64); however, Watson and Keith (2002) studied students K-12 and not transition-age youth. Some researchers have attempted to gather and corroborate self-reported and proxy-reported QOL data for transition-age youth with disabilities. These studies yielded score inconsistencies between youth and parental ratings, and were conducted largely with youth with ASD, which is not representative of youth with ID or other developmental disabilities (Clark, Magill-Evans, & Koning, 2015; Egilson et al., 2017; Knüppel, Telleus, Jakobsen, & Lauritsen, 2018). The present study was based solely on self-reported QOL data from transition-age youth with a variety of IDD.

This study aimed to: a) gather self-reported data from transition-age youth with IDD in an effort to better understand their perspectives of QOL, b) identify potential differences in QOL between youth with and without IDD, and c) explore factors that may predict QOL among transition-age youth with IDD. Factors associated with QOL differences between youth with and without IDD were also explored. The study's guiding research questions were:

1) How do transition-age youth with IDD score on a self-reported QOL measure, the *QOL-Q*?

2) What QOL differences exist between transition-age youth with IDD and youth without IDD attending college?
3) What individual and social characteristics predict QOL outcomes for samples of transition-age youth with IDD and college youth without IDD?

This study was part of an ongoing effort to bring inclusive post-secondary education (IPSE) to the university in which the transition program is located. Therefore, researchers had a secondary aim of gathering baseline QOL data for the transition-age youth with IDD, as a portion of them plan to enroll in IPSE programs post-transition. For these individuals, the *QOL-Q* will be repeated, with additional consents obtained prior to repeat participation.

Methods

This exploratory study measured QOL for transition-age youth with and without IDD. Individual and social factors that may have influenced each sample's *QOL-Q* scores were analyzed. Ethics approval for this study was obtained from the university Institutional Review Board (protocol #2016/11/1).

Setting

This study was conducted at a mid-size private, Catholic university in the mid-Atlantic region of the US. Youth with IDD who agreed to participate in the study attended a transition program co-located on the university campus. Youth with IDD were eligible to attend the transition program after completing four years of high school and in response to an identified need for additional educational, vocational or life skills training in the 'transition plan section' of their Individualized Education Program (IEP). Students attend the transition program five days a week until age 21, or until they move into post-secondary education, day programming, or employment. While the transition program is co-located on the university campus, it is not directly affiliated with or funded by the university. Instead, students' program tuition is subsidized by their local school districts. Daily programming consists of life skills training at an off-campus mock apartment one time per week; educational reinforcement in reading, math, and/or budgeting skills; pre-vocational volunteer experiences; and travel training. Participants rotate through volunteer experiences 1-2 times per week in housekeeping, maintenance, food service, mailroom, and/or office support; however, these experiences are not matched to a participant's interests based on person-centered planning or vocational/interests assessments. The program also provides youth with IDD with social and leisure opportunities, primarily with peers with IDD. Because of the program structure, students enrolled in the program have limited exposure to college peers without IDD. For example, youth who attend the program do not have access to IPSE courses on the university campus; they eat lunch at university dining halls, but mostly with other peers with IDD; and the program is located in an isolated part of campus. This transition program is not an IPSE program, but will serve as a feeder for the new IPSE program at the university. College youth without IDD who participated in the study were full-time students who lived on-campus in university residence halls, or off-campus and commuted to school daily.

Participants

Forty-nine participants were recruited to the sample, which was comprised of both youth with IDD (n=19), aged 17-23, who attended a transition program during the 2016-2017 or 2017-2018 school years, and college youth without IDD (n=30), aged 17-23, who attended the university during the 2016-2017 or 2017-2018 academic years. Youth from the transition program who agreed to participate had a diagnosed learning disability or developmental disability including, but not limited to, intellectual disability, Down syndrome, ASD, Cerebral

Palsy, or Fragile X syndrome. College youth without IDD reported no learning and/or developmental disabilities.

Data Collection

Youth from the transition program were recruited through individual informational sessions provided by the research team. Following each informational session, informed consent or assent was obtained from youth who expressed interest. To obtain informed consent from parents and/or caregivers, informational letters were sent by mail to each youth's home. Individuals in the comparison group, the group of college youth without IDD, were recruited via flyers posted throughout the university campus. Similarly, individual informational sessions were provided to each interested college student and informed consent was obtained for those who expressed interested in participating.

Each youth completed a demographic survey prior to participation in the QOL interview. For youth with IDD who struggled to provide answers to either the demographic survey and/or QOL interview questions, the research team contacted a proxy (e.g., the youth's parent/guardian or a transition program staff person who knew them well) to verify accurate information. Demographic items collected from all participants included: *age, gender, self-identified race, employment status, place of residence, self-rated health status, number of close friends/family members (*or *perceived social support),* and *significant life stressors in the last six months*. Because the sample was largely White/Caucasian, *self-identified race* was analyzed dichotomously as people from 'ethnic/racial minorities' and those who were 'White/Caucasian'. *Self-rated health status* was gathered using a visual analogue scale (VAS) to represent six Likert-scale ratings: 'excellent', 'very good', 'good', 'fair', 'poor', and 'very poor'. This VAS helped transition-age youth with IDD to better understand the self-rated health scoring options. Because there were no participants that reported ‘poor’ or ‘very poor’ self-rated health, and only one participant reported ‘fair’ health, data were analyzed as ‘excellent’, ‘very good’, and ‘good’ (with the one ‘fair’ rating combined with the ‘good’ category). The *perceived social support* variable was operationalized as the range of family and friends that a person felt closely connected to. This range was given from: 0-5 close family/friends, 6-10 close family/friends, 11-15 close family/friends, and 16+ close family/friends. Additional demographic items were collected only from transition-age youth with IDD and included: *type of developmental disability*, *level of intellectual disability*, and the *number of IDD support services each student received*.

QOL was measured for all participants using a 40-item rating scale, the *QOL-Q*. The *QOL-Q*, developed by Schalock and Keith (2004), was standardized and normed for use with people with IDD, but has since been used to measure QOL for a variety of populations including people with other types of disability, people with disabilities who are non-English speaking, older adults, and those without disabilities (Caballo, Crespo, Jenaro, Verdugo, & Martinez, 2005; Keith & Ferdinand, 2000; Sexton, O’Donovan, Mulryan, McCallion, & McCarron, 2016). The *QOL-Q* is administered in a semi-structured interview format and information is rated using a 3-point Likert scale to measure QOL across four subscales: a) *Satisfaction*; b) *Competence/Productivity*; c) *Empowerment/Independence*; and d) *Social Belonging/Community Integration* (Schalock & Keith, 2004). The maximum total *QOL-Q* score is 120. The *QOL-Q* has been found to have high inter-rater reliability (.73-.83) and internal consistency (.90). Previous studies utilizing the *QOL-Q* have also found it to have fair concurrent validity (.57) with the Lifestyle Satisfaction Scale (Schalock & Keith, 2004). Rater agreement was established between the study’s research team members prior to recruiting and interviewing participants. To establish rater agreement, the researchers observed and individually scored practice interviews until 85% agreement was obtained among ratings.

QOL-Q items were administered to participants with minimal paraphrasing in order to grade items to each participant's level of understanding (e.g., rather than asking, "How satisfied are you with your current home or living arrangement?", interviewers asked, "How happy are you with where you live and who you live with?"). The order in which questions were presented to participants was also modified. Questions were grouped together by similar content areas and the interview was organized so that information of a less sensitive nature, on participants' daily routines and activities, was asked first and items representing information of a more sensitive nature were asked last. This created a more conversational flow and allowed researchers to build rapport with each participant before asking items that may have been perceived as personal, sensitive, or more abstract (e.g., "How many times per month do you feel lonely?" or "Do you ever feel out of place in social situations?"). As per the *QOL-Q* manual, these are acceptable modifications for participants with IDD (Schalock & Keith, 2004).

All interviews were performed in a private location so that information discussed remained confidential and participants felt comfortable discussing topics openly. Participants were informed that the interview could be stopped at any time and were encouraged to skip any questions that made them feel uncomfortable. Upon listening to each participant's responses, the researcher scored each response using the *QOL-Q*'s 3-point Likert scale. Raw scores for each domain ranged from 10 to 30 and were totaled for an overall *QOL-Q* score (Schalock & Keith, 2004). Upon completion of *QOL-Q* interviews, researchers attempted to obtain missing data directly from participants, or by contacting program staff or parents/caregivers, to ensure a robust data set. For missing responses, item scores were estimated from the average of item scores on the same psychometric scale.

Analysis

Descriptive statistics were analyzed including frequencies and percentages for categorical predictors, as well as means, standard deviations, skew, and kurtosis for continuous predictors. One-way between-subjects ANOVAs were conducted to compare total and subscale mean *QOL-Q* scores for the youth with IDD and college youth without IDD. To explore differences in QOL between youth with and without IDD across the levels of age, gender, race, employment, self-rated health, and perceived social support, between-subjects ANOVAs including interaction terms were used. Because there were violations to distributional assumptions, bootstrapping was used (Efron & Tibshirani, 1986). The bootstrapped ANOVA models were conducted in SPSS 25.0 with 2,500 bootstrapped samples using the GLM (General Linear Model) Univariate procedure. Multivariable linear regression was also used to understand predictors of QOL for both the transition-age youth with IDD and college youth without IDD. Due to little variation in the distribution of age, self-identified race, and place of residence, these variables were not included in the linear regression models. Therefore, the linear regression models included the variables of gender, employment status, perceived social support, and self-rated health status. Developmental disability type and the level of intellectual disability were additional variables included in the linear regression model for youth with IDD.

Results

Table 1 provides a summary of descriptive statistics for both samples. The mean age of participants across both groups was 19.8 years. Sixty-three percent (63%) of participants from the transition program were male, while 83% of the college participants were female. The racial and ethnic distribution of both samples was largely White/Caucasian, comprising almost 90% of the sample of youth with IDD and 67% of the college youth. Most participants from the transition (68%) and college (83%) samples rated their health as 'excellent' or 'very good'.

Discrepancies were found between transition-age youth with IDD and college youth without IDD in the areas of living situation, employment status, and level of perceived social support. All transition-age participants with IDD lived at home with their parents (100%), while 67% of the college participants lived on-campus and 30% off-campus. Only 26% of the youth with IDD were employed part-time, while 57% of the college youth without IDD were employed part-time. None of the participants held full-time jobs. The transition-age youth with IDD generally reported having fewer close family and friends in their social support networks, with only 16% of participants with IDD reporting 11 or more family/friends. Nearly twice as many college youth without IDD (31%) had 11 or more close family/friend connections.

Insert Table 1 Here

Descriptive statistics specific to the sample of transition-age youth with IDD are presented in Table 2. Most youth with IDD were diagnosed with Down syndrome (37%) or Autism Spectrum Disorder (32%), and the large majority had a concurrent intellectual disability (90%). Those with intellectual disability functioned in the mild (26%) to moderate (58%) range. Transition-age youth who received outside LTSS had, on average, 1.2 services in addition to transition program supports. The service most frequently utilized by transition-age youth with IDD and their families was Pennsylvania State Supports Coordination (62%), or Medicaid case management.

Insert Table 2 Here

The mean total *QOL-Q* score for the transition-age youth with IDD was 84.4 (SD = 11.2), while the mean total score for the college youth without IDD was 101.5 (SD = 8.8). One-way between-subjects ANOVAs were run on both the mean total and subscale *QOL-Q* scores to assess differences between youth with and without IDD. The sample of transition-age youth with IDD had significantly lower total *QOL-Q* scores ($p < .001$), and lower *Productivity* ($p = .005$), *Independence* ($p < .001$), and *Community Integration* ($p < .001$) subscale scores than the college youth without IDD. However, no significant difference was noted between *Satisfaction* scores ($p = .15$).

Results from the bootstrapped between-subjects ANOVA including interaction terms are provided in Table 3. Significant differences in mean total *QOL-Q* scores were found between the youth with and without IDD across the levels of age ($p = .005$), perceived social support ($p = 0.014$), self-rated health ($p = 0.010$), and employment status ($p = 0.028$). A marginal interaction effect was found between program and gender ($p = 0.089$).

Insert Table 3 Here

The following figures provide an illustration of the interaction effects indicated by the between-subjects ANOVA results. Figure 1 shows the simple slopes for age predicting *QOL-Q* total score for students with and without IDD. Figures 2, 3, 4, and 5 show profile plots for the mean total *QOL-Q* scores for youth with and without IDD across the levels of perceived social support, self-rated health status, employment status, and gender respectively.

Insert Figure 1 Here

Insert Figure 2 Here

Insert Figure 3 Here

Insert Figure 4 Here

Insert Figure 5 Here

Individual and social characteristics identified as predictors of *QOL-Q* scores differed between the transition-age youth with IDD and college youth without IDD. For youth with IDD, perceived social support was the sole significant predictor of *QOL-Q* scores (B = 21.503, p = 0.004) when controlling for gender, employment status, self-rated health status, level of ID, and type of DD. Youth with IDD who reported having greater than five close friends/family members scored, on average, 21.5 points higher on the *QOL-Q* than those with fewer than five close friends/family members. Youth who reported self-rated health status as 'very good' had lower *QOL-Q* scores than those with 'excellent' health (B = -15.318, $p < 0.001$) in the simple linear regression model; however, when controlling for gender, employment status, perceived social support, level of ID, and type of DD, self-rated health status fell to non-significance.

For college youth without IDD, employment status was the only significant predictor of QOL (B = -16.650, $p < 0.001$) when controlling for gender, perceived social support, and self-rated health status. College youth who were unemployed or doing volunteer work scored an average of 16.7 points lower on the *QOL-Q* than those who were employed. When self-rated health status (B = 6.949, p = 0.031) and perceived social support (B = 11.333, p = 0.004) were in separate simple linear regression models, they were each associated with higher average *QOL-Q* scores; however, when controlling for other variables, self-rated health and perceived social support no longer remained significant predictors of QOL.

Discussion

This study adds to existing literature in that it measured QOL for a sample of transition-age youth with IDD from *their* perspective, rather than from the perspectives of parent or caregiver proxies. Parent proxies were used only to verify information in which there was ambiguity regarding a youth's self-reported data. The study also explored a variety of factors that may contribute to QOL differences between youth with and without IDD. Transition-age youth with IDD who participated in the study scored significantly lower on the *QOL-Q* than their college peers without IDD. Mean total *QOL-Q* scores for the transition-age youth with IDD were similar to those of other samples of youth with IDD in prior QOL studies, but on average 10 points higher than these samples (McIntyre et al., 2004; Schalock & Keith, 1993; Watson & Keith, 2002). While transition-age youth with IDD reported significantly lower self-perceived *Productivity*, *Independence* and *Community Integration* scores on *QOL-Q* subscales than their college peers, their scores on the *Satisfaction* subscale did not significantly differ from college youth without IDD. The latter finding warrants further investigation, but may be due to less experience with and exposure to a range of social, community and employment participation possibilities among the youth with IDD and, thus, less awareness of missed opportunities. The *Satisfaction* subscale finding may also be due to a generally more positive outlook among the youth with IDD.

Age, perceived social support, self-rated health status, and employment status were all associated with significant differences in *QOL-Q* scores between transition-age youth with IDD and college youth without IDD in this study. Whereas mean *QOL-Q* scores showed minor increases with each additional year of age for college students without IDD, a consistent downward trend in *QOL-Q* scores existed for transition-age students with IDD as they aged. While speculative, this could be due to a tapering of formalized supports and social connectedness felt by youth with IDD as they detach from their high school experiences and enter adult life. However, because the youth with IDD enrolled in the study still attended formal transition programming, this finding speaks to a need for further research regarding the impact of transition programs on QOL and post-secondary outcomes. Mean *QOL-Q* scores remained high for the college youth without IDD regardless of their perceived levels of social support, but scores for transition-age youth with IDD were much lower for those who had less perceived social support, particularly for those with only 0-5 close family/friends. As demonstrated by the multivariable linear regression, social support had a significant impact on transition-age youth with IDD's QOL, much more so than the college youth without IDD. Low levels of social capital and inclusion among people with IDD have been linked to fewer work opportunities, fewer friendships and relationships, and increased loneliness (Amado, Stancliffe, McCarron, & McCallion, 2013). Despite the fact that this sample of youth with IDD attended a transition program co-located on the university campus, they all lived at home with their parents and were not fully included in the campus community, which may have ultimately impacted their perceived social capital and QOL.

Differences in mean *QOL-Q* scores also existed between the transition-age youth with IDD and college youth without IDD across the various levels of employment. The college youth without IDD who worked part-time or seasonally demonstrated higher *QOL-Q* scores; however, transition program youth who worked seasonally, on a volunteer basis, or who were unemployed did not display much difference in their QOL scores. Youth with IDD who were employed part-time, in fact, had higher *QOL-Q* scores. The lack of differentiation in QOL scores among youth with IDD who worked seasonally, volunteered, or did not work may be explained by the limited range of opportunities and lack of person-centered, individualized options presented to them. While approximately 26% of the youth with IDD in this sample were employed part-time, more than 60% engaged solely in volunteer experiences through the transition program. Youth with IDD who volunteered as part of the program were given these opportunities 1-2 times weekly in the areas of housekeeping, maintenance, food service, mailroom, and/or office work. These experiences were not assigned based on person-centered planning, QOL or vocational/interests assessment. This lack of personal decision-making regarding volunteer and/or employment experiences may have led to limited satisfaction gained from work among this sample of youth with IDD.

Implications for Practice

Being attuned to the factors that contribute to QOL is vital to supporting a seamless transition for youth with IDD. The present study, similar to Biggs and Carter's (2016), identified lower QOL scores for youth with IDD who had low perceived social support. Both studies also found that youth with IDD who were older experienced lower QOL. Support professionals, such as school/transition personnel and Medicaid case managers, should explore means of increasing social capital for youth with IDD, especially as they approach transition to adulthood (Brucker, 2015; Johnson, Blaskowitz, & Mahoney, 2019). This may involve brokering connections with community groups that match the strengths and interests of youth with IDD (as specified in a QOL/person-centered planning assessment process) prior to/during their transition to potentially combat the impact of limited social support for this population. Support professionals can use a variety of QOL/person-centered planning tools, in conjunction with a *Self-Directed IEP* process, to better understand their social participation and community inclusion goals including the *QOL-Q*, Personal Outcomes Measures for Children/Youth or Adults, Self-Determination Learning Model of Instruction, or Goal Attainment Scaling (Agran, Blanchard, & Wehmeyer, 2000; The Council on Quality and Leadership, n.d.; Martin et al., 2006; Shogren, Wehmeyer, Burke, & Palmer, 2017; Schalock & Keith, 2004). The AIR Self-Determination Scale and *Charting the LifeCourse* are especially effective in providing a 365^{o} view of a youth's priorities from the perspective of the person, family, and other involved team members, which helps to better identify descrepancies between youth and parent/caregiver input (Grotto, Reynolds, Palmer, & Chiang, 2019; Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994).

Youth with IDD who were not involved in paid work opportunities also scored significantly lower on the *Productivity* subscale of the *QOL-Q*. To increase a sense of productivity, support professionals can support youth with IDD to identify post-secondary employment goals (IDEA, 2004). Medicaid case managers should work in concert with transition teams so that youth with IDD can access Office of Vocational Rehabilitation (OVR) Services as part of their *Self-Directed IEP* process, and while the student is still in high school. OVR counselors can arrange for eligible youth with IDD to participate in Pre-Employment Training Services (Pre-ETS) under the US Workforce Innovation Opportunity Act (WIOA) of 2014. The WIOA also mandates that OVR set aside 15% of a state's annual federal funds to support and implement Pre-ETS activities (e.g., job exploration and counseling, work-based learning, community experiences, comprehensive transition programs, self-advocacy training). Early adoption of supported and/or customized employment services can also provide youth with IDD with increased exposure to a variety of work options and much-needed training in vocational soft and hard skills for those who have an expressed desire to work. It is imperative that all support professionals make efforts to identify QOL and post-secondary outcomes related to meaningful employment as part of the transition process.

Limitations and Implications for Future Research

This study aimed to measure self-reported QOL for youth with IDD, explore factors associated with it, and identify differences in QOL for youth with and without IDD. While the researchers found significant differences in *QOL-Q* scores between the transition-age youth with

IDD and college youth without IDD across the levels of age, perceived social support, self-rated health status, and employment status, results of this study should be interpreted cautiously. A primary limitation of this study was its small sample size and lack of representativeness of US transition-age youth. Most participants were White/Caucasian and clustered around the same age. The homogeneity of the sample combined with small sample sizes limited the depth of statistical analysis. In addition, a number of variables (e.g., socioeconomic status, level of community engagement/inclusion, a stronger measure of social capital, etc.) were not collected by the research team, and thus could not be examined as potential contributors to QOL differences between the youth with and without IDD. Future research on this topic should broaden recruitment efforts to collect a more widely representative sample of youth, with variation in individual, social and environmental factors so that a greater number of independent QOL predictors can be examined. Additional research should also explore the impact of individual outlook and perceptions of satisfaction on overall QOL.

Confounding factors worth considering in interpretation of this study's findings include: a) all of the transition-age students with IDD lived at home with their families, and b) gender was not balanced between the transition-age youth with IDD and college youth. This study compared two disparate groups, as it focused on QOL for youth with and without IDD. Future studies would benefit from measuring self-reported QOL for transition-age youth at multiple timepoints -- at the start of their transition process and again closer to graduation, in order to understand how transition programming impacts QOL. Additional research should also compare QOL for youth with IDD enrolled in transition programming to that of youth with IDD who are not involved in transition and/or college-based programs to evaluate effects of these programs on post-secondary outcomes. An examination of how QOL assessment impacts the self-determination, *Self-Directed IEP* process, and post-secondary outcomes of transition-age youth with IDD would also significantly add to the literature base.

Conclusion

This study was unique in that it measured self-reported QOL for transition-age youth with IDD and compared their QOL scores to those of college youth without IDD. Findings from the study provide valuable information on QOL from the perspective of transition-age youth with IDD and suggest that, despite attempts to support greater QOL for youth with IDD, there is still work to be done. QOL and person-centered planning assessment, as well as *Self-Directed IEPs*, incorporate autonomous decision-making on behalf of youth with IDD and are vital to supporting students in achieving post-secondary educational, employment and social/community inclusion goals of *their* choosing. QOL and person-centered planning assessment elicit the voice of youth with IDD as they transition into adulthood, with the aim of closing disparity gaps for this population at a critical time in their lives.

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Figure 1

Simple Slopes for Youth with and without IDD Predicting QOL-Q Total from Age

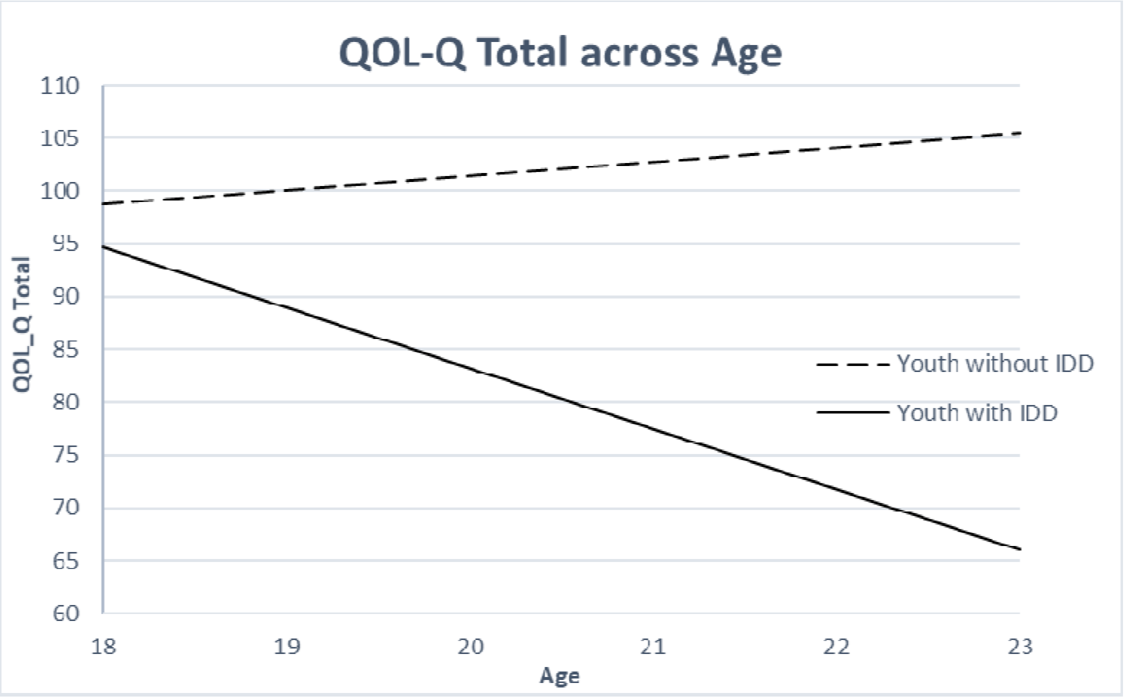

Figure 2

Mean Profile Plots of QOL-Q Total Scores by Social Support for Youth with and without IDD

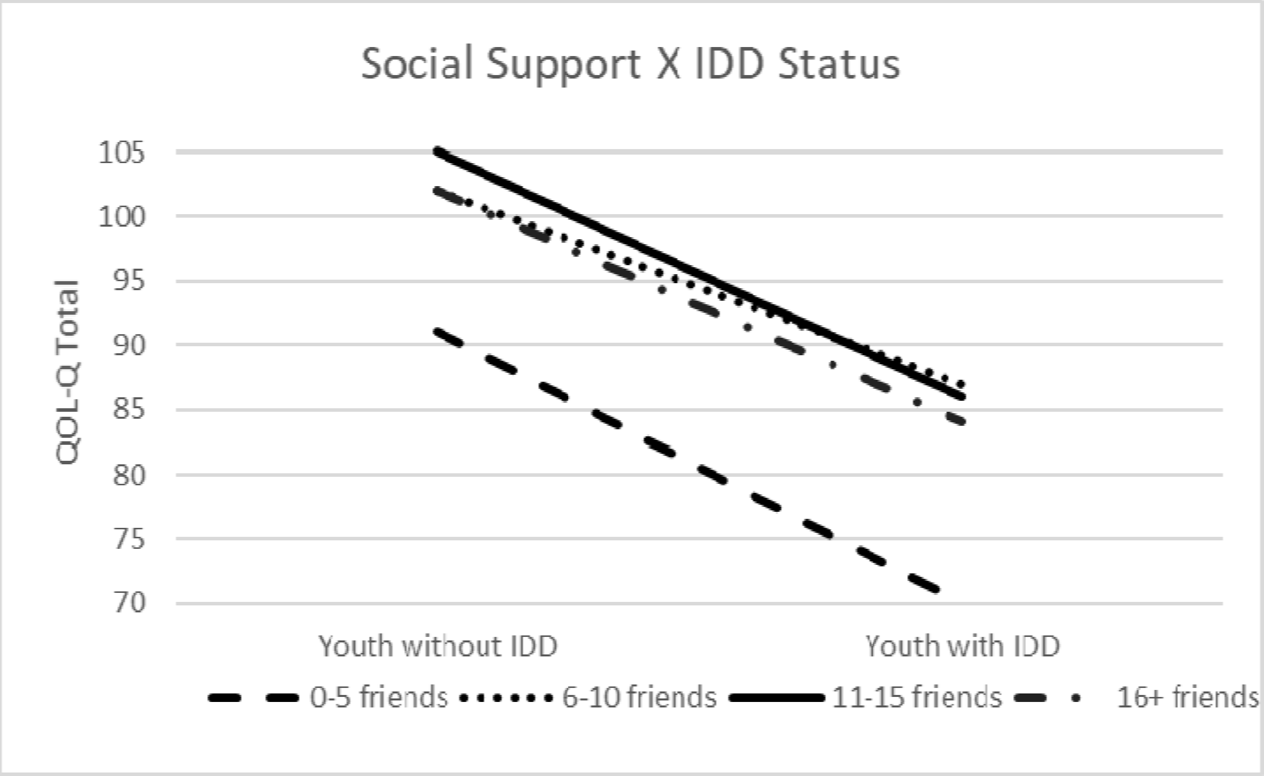

Figure 3

Mean Profile Plots of QOL-Q Total Scores by Health Status for Youth with and without IDD

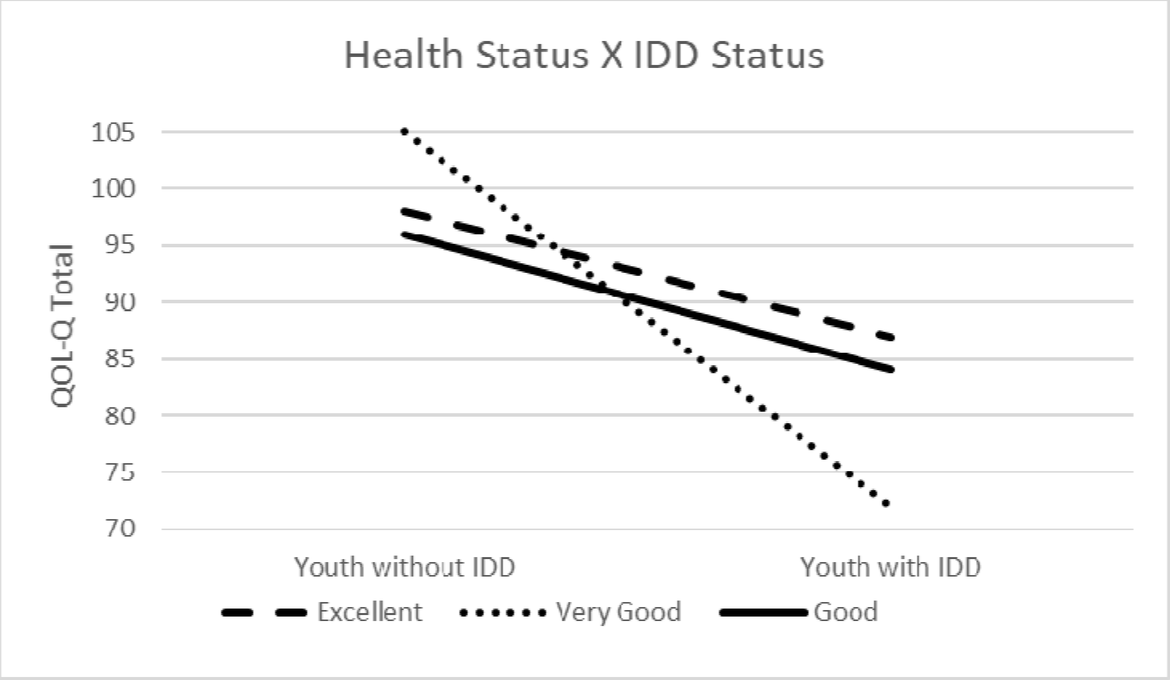

Figure 4

Mean Profile Plots of QOL-Q Total Scores by Employment Status for Youth with and without IDD

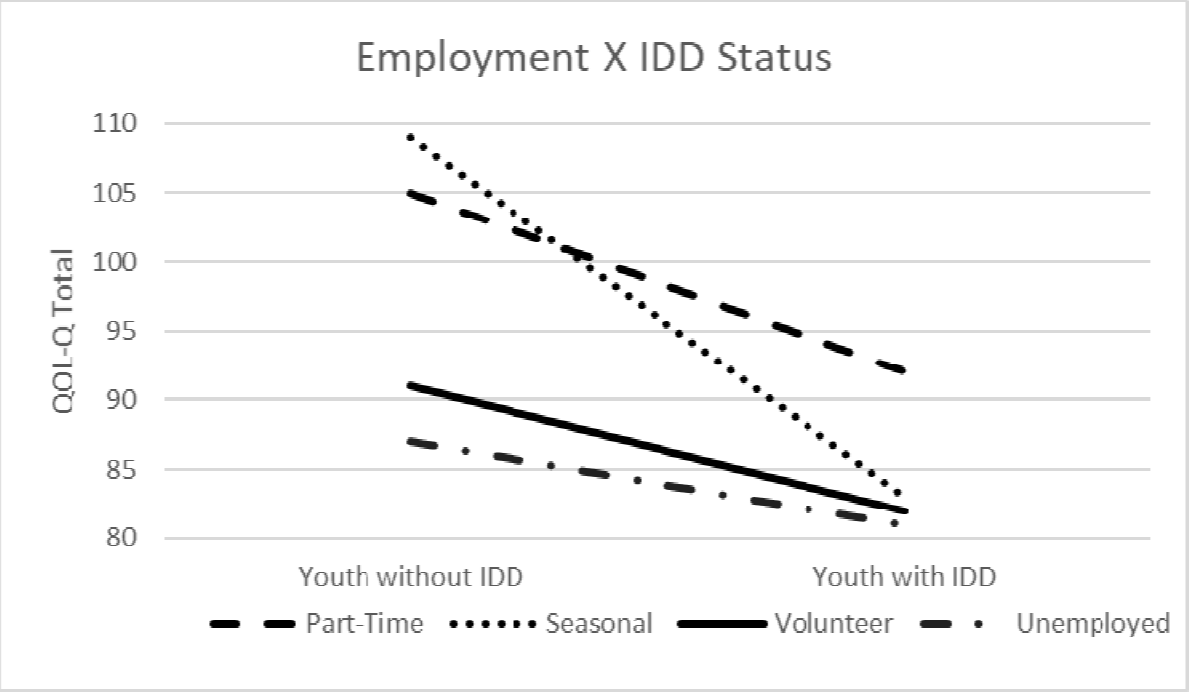

Figure 5

Mean Profile Plots of QOL-Q Total Scores by Gender for Youth with and without IDD

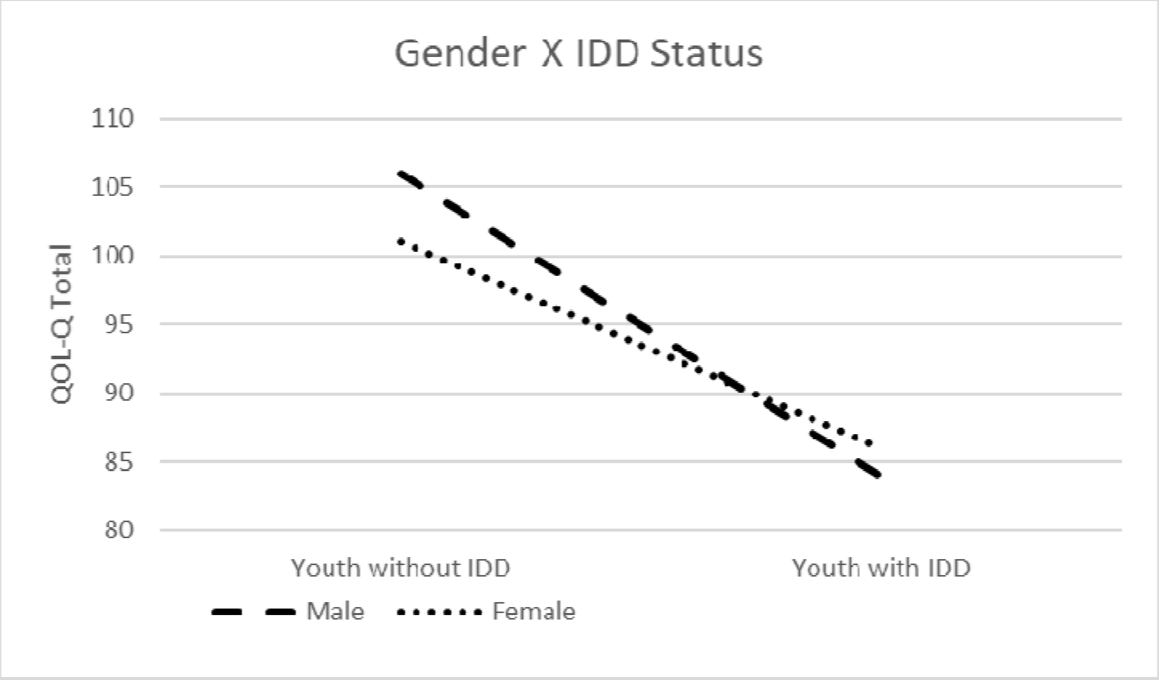

Table 1

Participant Demographics

Individual Characteristics	Youth with IDD (n = 19)	Youth without IDD (n = 30)
Age, mean (SD), skew [kurtosis]	19.8 (1.1), -.12 [-.08]	19.8 (1.5), .44 [-.97]
Gender, n (%)		
Female	7 (36.8)	25 (83.3)
Male	12 (63.2)	5 (16.7)
Race, n (%)		
White/Caucasian	17 (89.5)	20 (66.7)
Asian American	1 (5.3)	7 (23.3)
African American/Black	1 (5.3)	2 (6.7)
Biracial	0 (0)	1 (3.3)
Employment Status, n (%)		
Full-time	0 (0)	0 (0)
Part-time	5 (26.3)	17 (56.7)
Seasonal	2 (10.5)	4 (13.3)
Volunteer Work	3 (15.8)	2 (6.7)
Unemployed	9 (47.4)	5 (16.7)
Other	0 (0)	2 (6.7)
Self-Rated Health, n (%)		
Excellent	11 (57.9)	8 (26.7)
Very Good	2 (10.5)	17 (56.7)
Good	5 (26.3)	4 (13.3)
Fair	1 (5.3)	1 (3.3)
Poor	0 (0)	0 (0)
Very Poor	0 (0)	0 (0)
Residential Situation, n (%)		
Lives on campus	0 (0)	20 (66.7)
Lives off campus	0 (0)	8 (26.7)
Lives with family at home	19 (100)	2 (6.7)
Social Support, n (%)		
0-5 friends/family	2 (4.1)	3 (6.1)
6-10 friends/family	9 (18.4)	12 (24.5)
11-15 friends/family	3 (6.1)	6 (12.2)
16-20 friends/family	5 (10.2)	5 (10.2)
21+ friends/family	0 (0)	4 (8.2)

Table 2

Characteristics of Transition-Age Youth with IDD

Individual Characteristics	**Youth with IDD (n=19)**
Type of Developmental Disability (DD), n (%)	
Down syndrome	7 (36.8)
Autism Spectrum Disorder	6 (31.6)
Intellectual Disability	4 (21.1)
Cerebral Palsy	1 (5.3)
Neurological Disorder	1 (5.3)
Level of Intellectual Disability (ID), n (%)	
No ID	2 (10.5)
Mild ID	5 (26.3)
Moderate ID	11 (57.9)
Severe ID	1 (5.3)
Number of LTSS, mean (SD), skew [kurtosis]	1.2 (1.2), 1.35 [1.71]

Table 3

Results from Bootstrapped Between-Subjects ANOVA

Factor	df	MS	F	Significance
Program	1	182.423	5.832	0.024
Gender	1	20.958	0.584	0.477
Minority	1	106.586	106.586	0.078
Employment	3	257.260	8.225	0.001
Health	2	141.736	4.531	0.022
Social Support	3	195.691	6.256	0.003
Age	1	281.196	8.990	0.006
Program*Gender	1	98.791	3.158	0.089
Program*Minority	1	65.657	2.099	0.161
Program*Employment	3	113.116	3.616	0.028
Program*Health	2	177.071	5.661	0.010
Program*Social Support	3	136.399	4.361	0.014
Program*Age	1	297.342	9.506	0.005
Error	23	31.279		