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ORIGINAL PAPER

# Quality of Life for Transition-Age Youth with Autism or Intellectual Disability

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**Abstract** We examined the subjective health and well-being of 389 transition-age youth with autism or intellectual disability using the parent proxy version of the KIDSCREEN-27. Parents reported well-being of youth with autism and youth with intellectual disability lower than a normative sample in the domains of Physical Well-being, Psychological Well-being, and Social Support and Peers. For both groups of young people, the lowest ratings were reported in Social Support and Peers. Higher ratings of well-being in one or more domains were predicted by minority status, youth character strengths, involvement in community activities, and religious faith. Challenging behaviors, autism, age, and speech as the primary mode of communication were predictive of lower ratings of well-being. We discuss implications for special educators and service providers and offer directions for future research.

**Keywords** Adolescence · Quality of life · Intellectual disability · Autism · Transition

## Introduction

The transition to adulthood can be a challenging period for almost any young person. Indeed a host of physical, interpersonal, educational, and other changes emerge throughout adolescence and into early adulthood. Although navigating these myriad transitions can be difficult for anyone, youth with disabilities often experience elevated challenges during this particular period of development (Forte et al. 2011; Wei et al. 2015). Among those students who may struggle most are youth with autism and youth with intellectual disability (ID). Considerable attention has focused on connecting these young people to the services, supports, and relationships needed to experience a high quality of life during and after high school (e.g., Carter et al. 2014; Foley et al. 2012; Test et al. 2014).

Despite growing recognition in the field of special education that enhancing quality of life is an important investment (Kober 2011; Turnbull et al. 2003), relatively little is known about subjective aspects of quality of life for youth with autism or ID during their transition through secondary school into early adulthood. Instead, most attention has focused on documenting and predicting the objective outcomes of these young people in areas such as employment, postsecondary education, and community inclusion after they graduate (e.g., Carter et al. 2010; Haber et al. 2015). Moreover, few descriptive studies addressing the quality of life of these adolescents have anchored findings to a normative sample of peers without disabilities. For example, studies focused on students with autism spectrum disorders, including both younger students and adolescents, have suggested these students have lower quality of life ratings when compared with typically developing peers (Kamp-Becker et al. 2010; Kamp-Becker et al. 2011; Kuhlthau et al. 2010, 2013; Shipman et al. 2011; Tavernor et al. 2013). However, there has been limited research addressing comparisons of subjective quality of life for individuals with and without ID. For example, in a small sample of adults, participants with ID were found to have lower objective quality of life scores in several domains when compared with matched controls

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without disability; however, they had slightly higher average ratings of subjective domains and only rated their satisfaction lower than controls in the area of health (Hensel et al. 2002). We know of no study making these comparisons for transition-age youth who have ID. Because students with autism and students with ID have related or overlapping needs, they often are served in common transition programs or on the caseloads of the same special educators. Therefore, we wanted to examine the quality of life of a group of young people receiving special education services under both of these categories. However, recognizing that important differences exist between these groups, we also wanted to learn whether differences may exist on the basis of these disability categories and how assessments of students with autism or with ID might each compare with those of their peers without disabilities across various quality of life domains.

An understanding of the various factors that may influence quality of life also is needed to inform the design of transition services for youth with autism or ID. A focus on the contributions of demographic- and disability-related characteristics to quality of life has dominated this area of the literature (Felce and Perry 2007; Schalock 2004). For example, age, gender, race/ethnicity, socioeconomic status, measures of adaptive behavior, and indicators of cognitive functioning have all been explored widely in previous studies (e.g., Kamp-Becker et al. 2010; Kuhlthau et al. 2010; Tilford et al. 2012). Although such demographic- or disability-related characteristics are important to consider, they are also fairly static or stable variables (i.e., slow or unlikely to change). Far less is known about other more malleable factors that might play a role in shaping quality of life for young people in transition.

We sought to explore the extent to which other variables might also influence quality of life for students with disabilities. The personal traits of students offer one set of factors to consider. For example, positive character strengths such as hope, optimism, courage, and empathy have been linked to broad measures of life satisfaction for young adults (Proctor et al. 2011; Shogren et al. 2006). Similarly, a person's capacity to be self-determining has been linked to a range of positive post-school outcomes for young people with disabilities (see Wehmeyer and Abery 2013).

Another set of salient factors falls under the category of support and personal connections. A large literature documents a link between quality of life indicators and markers of social relationships and/or community connections (Umberson and Montez 2010). For example, Kraemer et al. (2003) investigated factors associated with the Satisfaction subscale of the Quality of Life Questionnaire (Schalock and Keith 1993) using a sample of 188 young adults with moderate or severe ID. They found social resources (i.e., caregiver happiness with family support, size of a young adult's social network) to be predictive of higher ratings of quality of life. Renty and Roeyers (2006) found that support characteristics—including informal or social support—were related to quality of life in individuals with high-functioning autism spectrum disorder, even though disability-related characteristics were not. More extensive participation in community activities may provide increased opportunities for these important social connections to develop (Mahoney et al. 2006). Similarly, a stronger religious faith and connection to a congregational community may introduce important social supports and relationships that also improve one's quality of life. Yet each of these factors has received limited attention in research involving students with autism or ID.

The purpose of this study was to investigate the quality of life of young people served under the special education categories of autism or ID. We sought to answer three research questions. First, how do parents depict the quality of life of their sons and daughters with disabilities across different domains? We anticipated these ratings would be moderately low and reflect considerable variability across individual domains. Second, to what extent do ratings of quality of life differ from normative sample ratings based on special education category (i.e., autism, ID without autism)? We anticipated both of these groups would have lower ratings than a normative sample across all of quality of life domains. Third, what factors predict ratings of quality of life for transition-age youth with ASD or ID? We hypothesized personal traits and connections (i.e., self-determination, strengths, community activities, religious faith) would have predictive power over and above demographic- and disability-related characteristics (i.e., age, gender, race/ethnicity, socioeconomic status, communication, presence of challenging behaviors, functional abilities, support needs). The first and third questions focused on the entire sample of youth, while the second question divided the sample into youth with or without autism.

We used the parent-proxy version of the KIDSCREEN-27 (The KIDSCREEN Group Europe 2006) to answer these questions. This validated and widely used measure for assessing the subjective quality of life of children and adolescents addresses five domains: Physical Well-being, Psychological Well-being, Autonomy and Parent Relations, Peers and Social Support, and School Environment. We focused on parent ratings because parents know their child well, are able to speak to their child's relationships and experiences beyond the school day, and have an important vantage point on the quality of life of their child. Proxy respondents are commonly used to provide helpful insights into quality of life for individuals with severe disabilities (e.g., Kraemer et al. 2003; Kuhlthau et al. 2013). Although using parent proxy-report has limitations, it is an appropriate alternative when reliable self-report is challenged by the presence of complex communication challenges or cognitive impairments (Clark et al. 2015; Dey et al. 2013).

## Method

### Participants

Participants included 389 parents or other caregivers of young adults with a disability. To be included in our analyses, respondents must have had a son or daughter with autism or ID who was between the ages of 13 and 21 and lived in the state of Tennessee. We focused on this lower age criterion because school-based transition services in almost half of states must be written into the first Individualized Education Program (IEP) in effect when student is 14 years of age, which includes many students who are 13 years of age. Parent participants ranged in age from 31 to 72 years ($M = 48.0$, $SD = 7.7$). The majority of parent participants (84.3 %) identified themselves as the mother (including step- and adoptive mother); 9.3 % identified themselves as the father (including step- and adoptive father); and 6.4 % identified themselves in another type of primary relationship (e.g., aunt, legal guardian, grandparent). Other parent demographics are included in Table 1.

Each respondent completed a series of measures addressing the demographics of their son or daughter. To determine disability type, we asked respondents to identify their child's primary special education category by indicating all of the following that applied: *autism*, *intellectual (cognitive) disability*, or *other disabilities*. We included in our sample youth with a special education category of autism, ID, or both. Most youth (59.6 %, $n = 232$) received services under the category of autism; 54 of whom also received services under ID. The remaining youth (40.3 %, $n = 157$) were served under the category of ID and did not have autism. The average age of these young people was 16.4 years ($SD = 2.5$), and most (69.7 %) were male. Verbal speech was reported as the primary form of communication for most of the youth (84.3 %); 10.8 % relied primarily on gestures, facial expressions, or body language to communicate, 1.8 % on vocalizations, 1.8 % on an electronic communication device or computer, and 1.3 % on manual signs or sign language. Additional child demographic information can be found in Table 1.

### Recruitment

Data for these analyses came from a statewide study focused on assessing the strengths, supports, spiritual expression, and well-being of youth and young adults with autism or ID. We recruited families across the state by contacting various family and disability organizations who could share information with parents meeting our inclusion criteria. To extend invitations broadly across the state, we developed a strategy to involve a large number of different disability groups, formal parent and disability networks, pediatricians, schools, congregations, and recreation programs. In addition to families who were members of advocacy or disability groups, we took steps to identify parents not affiliated with these networks in order to be more representative of the state. A total of 151 networks, groups, individuals, and organizations distributed study invitations, including: Special Olympics area programs ($n = 22$), disability service providers ($n = 16$), autism support/advocacy groups ($n = 15$), other sports and recreation programs ($n = 14$), churches and faith-based ministries ($n = 13$), Arc chapters ($n = 10$), family support programs ($n = 10$), parent support groups ($n = 10$), Down syndrome support/advocacy groups ($n = 7$), school-based programs ($n = 6$), University Centers of Excellence in Developmental Disability programs ($n = 6$), health service providers ($n = 5$), individuals ($n = 5$), employment service providers ($n = 3$), social service providers ($n = 3$), civic organizations ($n = 2$), statewide advocacy organizations ($n = 2$), and other organizations ($n = 2$).

Each organization provided recommendations about how to best reach families. Over two thirds of organizations (69 %) shared invitations through email and over half of the organizations (52 %) extended invitations through postal mail. Organizations with the capacity to search their databases for families meeting our eligibility criteria used targeted mailings; those lacking this search capacity used general mailings, in which invitations were sent to everyone in their database. In addition, approximately one third of the organizations (32 %) posted fliers containing shorter descriptions of the study. Some organizations extended announcements through email newsletters (9 %), websites (7 %), or print newsletters (3 %). All invitations were also available in Spanish and provided directions for requesting participation by mail, email, phone, or online.

We mailed a packet of assessments to all individuals who contacted us to request participation. Materials were only distributed and returned through the mail, and no online versions were available. We requested all assessment measures be returned within 2 weeks. If they were not returned within that timeframe, we made up to three follow-up emails or phone calls. Families returning the packet were sent a thank you note and a $20 gift card to a gas station or retail store. We distributed 599 assessment packets to parents requesting participation; 80.6 % ($n = 483$) were returned completed. Of the returned packets, we excluded 33 from our analyses because the family lived outside of the state or because the young person with the disability was outside of the age range. We excluded an additional 31 packets because the respondents indicated their son or daughter had a disability other than autism or ID. The remaining sample

**Table 1** Parent and child characteristics by disability and across all youth

| Demographic variables | Intellectual disability (without autism) $n = 157$ | Autism $n = 232$ | All participants $N = 389$ |
|---|---|---|---|
| Child's age[a] | | | |
| 13–15 | 46 (29.3) | 109 (47.0) | 155 (39.8) |
| 16–18 | 62 (39.5) | 71 (30.6) | 133 (34.2) |
| 19–21 | 49 (31.2) | 52 (22.4) | 101 (26.0) |
| Child's gender[a] | | | |
| Female | 68 (43.3) | 50 (21.6) | 118 (30.3) |
| Male | 89 (56.7) | 182 (78.4) | 271 (69.7) |
| Child's race/ethnicity[a] | | | |
| African American/Black | 22 (14.0) | 30 (12.9) | 52 (13.4) |
| Asian | 0 (0.0) | 1 (0.4) | 1 (0.3) |
| Hispanic, Latino, or Spanish origin | 2 (1.3) | 6 (2.6) | 8 (2.1) |
| Native American | 0 (0.0) | 2 (0.9) | 2 (0.5) |
| Other or multiple | 7 (4.5) | 5 (2.2) | 12 (3.1) |
| White | 126 (80.3) | 188 (81.0) | 314 (80.7) |
| Eligible for free/reduced-price meals at school[a] | | | |
| No | 90 (60.8) | 145 (65.9) | 235 (63.9) |
| Yes | 58 (39.2) | 75 (34.1) | 133 (36.1) |
| Information not provided | 9 | 12 | 21 |
| Respondent's age[b] | 49.4 (8.0) | 47.1 (7.3) | 48.0 (7.7) |
| Respondent's relationship to child[a] | | | |
| Father | 16 (10.2) | 20 (8.6) | 36 (9.3) |
| Mother | 125 (79.6) | 203 (87.5) | 328 (84.3) |
| Other | 16 (10.2) | 9 (3.9) | 25 (6.4) |
| Respondent's highest level of education[a] | | | |
| 12th grade or less (no high school diploma) | 8 (5.1) | 7 (3.1) | 15 (3.9) |
| High school graduate | 13 (8.3) | 22 (9.5) | 35 (9.0) |
| Some college | 41 (26.3) | 52 (22.4) | 93 (24.0) |
| Trade/technical/vocational training | 6 (3.8) | 20 (8.6) | 26 (6.7) |
| College graduate | 50 (32.1) | 79 (34.1) | 129 (33.2) |
| Postgraduate | 38 (24.4) | 52 (22.4) | 90 (23.2) |
| Information not provided | 1 | 0 | 1 |
| Respondent's marital status[a] | | | |
| Married/living as married | 117 (74.5) | 159 (68.5) | 276 (71.0) |
| Single/divorced/separated/widowed | 40 (25.5) | 73 (31.5) | 113 (29.0) |

Percentages are based on the number of participants who completed the given item

[a] Number of respondents (Percentage)

[b] Mean (Standard deviation)

included 416 parents and caregivers; however, missing data narrowed our final sample to 389 participants (64.9 % of all who requested participation).

## Measures

We asked parents to complete a printed packet of measures that included standardized and researcher-created measures addressing a variety of constructs. In this paper, we present findings related to a multi-domain quality of life measure and 13 predictor variables. We selected these predictor variables based on our desire to explore the contributions personal traits and connections make to quality of life, as well as demographic- and disability-related characteristics. We present descriptive statistics for all measures in Tables 2 and 4.

### *Quality of Life*

We chose the KIDSCREEN-27 (The KIDSCREEN Group Europe 2006) because it (a) addresses multiple quality of life domains, (b) has strong psychometric properties, (c) has been validated with a large sample of adolescents, (d) allows for normative comparisons, and (e) includes a validated parent-proxy version. This measure was developed as a part of a multi-country project to create and validate an appropriate instrument for measuring the quality of life of children and adolescents. The instrument was developed over the course of 3 years through literature reviews, expert consultation, focus groups, and item reduction before being pilot tested across countries (Ravens-Sieberer et al. 2005). The KIDSCREEEN instrument includes multiple versions, including a full version with 52 items across 10 dimensions, a short version with 27 items across 5 dimensions, and a brief 10-item index of quality of life. Each version has the option of a self-report or proxy-report designed to be completed by someone who knows the child or youth well. We selected the 27-item proxy-report based on our need for a shorter measure that still addressed multiple dimensions. This version assesses five dimensions: Physical Well-being (5 items), Psychological Well-being (7 items), Autonomy and Parent Relations (7 items), Peers and Social Support (4 items), and School Environment (4 items; see Table 2 for actual items). Physical Well-being addresses levels of physical activity, energy, and fitness as well as the extent the child feels well. Psychological Well-being addresses feelings of positive emotions and satisfaction with life. Autonomy and Parent Relations addresses the quality of interactions between the child and caregiver as well as aspects of feelings of love and support, autonomy, and financial security. Social Support and Peers addresses the quality of interaction and support between the child and peers. School Environment addresses feelings about school, learning, concentration, and relationships with teachers (The KIDSCREEN Group Europe 2006). Respondents rated each item using a 5-point, Likert-type scale to assess frequency levels (1 = *never* to 5 = *always*) or intensity levels (1 = *not at all* to 5 = *extremely*) within a 1-week timeframe. Because raw scores are difficult to interpret and compare, we transformed raw scores in each domain into T values. (See The KIDSCREEN Group Europe 2006 for a full description of these transformations.) T values are standardized and have means around 50 and standard deviations around 10, enabling us to anchor parent ratings to a common scale and make comparisons to norm data. Higher values reflect higher ratings of quality of life.

The KIDSCREEN-27 was validated with a sample of over 22,000 children and adolescents from across 13 European countries (Ravens-Sieberer et al. 2007). This sample included adolescents who were physically and mentally healthy and ill, as well as youth with disabilities. Two-week test–retest reliability for the measure assessed with the intra class correlation coefficient (ICC) varied between .61 and .74 (Ravens-Sieberer et al. 2007). The KIDSCREEN-27 parent-proxy version was tested to be satisfactory with agreement between self- and proxy-reports ($ICC = .51$–.60; The KIDSCREEN Group Europe 2006). This is in a range similar to other parent-proxy reports of quality of life (Davis et al. 2007). Ravens-Sieberer and colleagues (2007) reported good construct validity for the KIDSCREEN-27 based on moderate to high correlations ($r = .36$–.63) with other quality of life measures. In addition, correlations with corresponding scales of the KIDSCREEN-52 were satisfactory ($r = .63$–.96). In our sample, Cronbach's alpha for each individual domain was .75 for Autonomy and Parent Relations, .81 for School Environment, .83 for Physical Well-being, .87 for Psychological Wellbeing, and .94 for Social Support and Peers.

### *Predictor Variables*

We selected a limited number of predictor variables with strong empirical or conceptual support involving people with and without disabilities. We included several demographic-related variables in our analyses and coded them as follows: ethnic/racial background (0 = White only, 1 = other races/ethnicities), age (range 13–21), gender (1 = female, 0 = male), and eligibility to receive free or reduced-price meals at school (1 = eligible, 0 = not eligible). We also included five disability-related characteristics. These included disability type (1 = special education category of autism, 0 = no autism), as well as communication mode, challenging behaviors, functional abilities, and support needs. However, our primary interest was in the predictive value of two measures of personal traits (i.e., self-determination, character strengths) and two measures of personal connection and support (i.e., involvement in out-of-school activities, strength of religious faith) that have received less attention in the transition literature (Koenig et al. 2012; Mahoney et al. 2006; Proctor et al. 2011; Wehmeyer and Abery 2013).

*Communication* The youth's primary mode of communication was included in the model as a binary variable (1 = speech, 0 = other). Children who were coded as "other" included those whose primary form of communication was reported as anything other than verbal speech (i.e., gestures, facial expressions, body language, vocalizations, manual signs or sign language, electronic communication device or computer).

**Table 2** Parent responses on KIDSCREEN-27 scale items assessing quality of life

| Domain/item | Percentage of responses | | | | | *T* value M (SD) |
|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | |
| Physical well-being | | | | | | 42.5 (10.5) |
| In general, how would your child rate her/his health?[a,*] | 2.4 | 7.5 | 24.6 | 39.9 | 25.6 | |
| Has your child felt fit and well?[b] | 3.1 | 7.2 | 27.1 | 41.0 | 21.6 | |
| Has your child been physically active (e.g., running, climbing, biking)?[b] | 20.6 | 19.8 | 29.0 | 16.5 | 14.1 | |
| Has your child been able to run well?[b] | 15.9 | 21.3 | 30.3 | 21.1 | 11.3 | |
| Has your child felt full of energy?[c] | 5.1 | 10.3 | 40.1 | 30.6 | 13.9 | |
| Psychological well-being | | | | | | 43.6 (10.2) |
| Has your child felt that life was enjoyable?[b] | 2.1 | 5.5 | 31.2 | 41.6 | 19.6 | |
| Has your child been in a good mood?[c] | 0.3 | 2.1 | 31.7 | 51.0 | 14.9 | |
| Has your child had fun?[c] | 0.3 | 2.1 | 34.8 | 46.9 | 16.0 | |
| Has your child felt sad?[c,*] | 4.6 | 32.7 | 56.7 | 5.2 | 0.8 | |
| Has your child felt so bad that he/she didn't want to do anything?[c,*] | 31.5 | 36.2 | 27.9 | 2.8 | 1.6 | |
| Has your child felt lonely?[c,*] | 24.1 | 28.3 | 39.1 | 5.2 | 3.1 | |
| Has your child been happy with the way he/she is?[c] | 1.6 | 7.9 | 28.8 | 43.1 | 18.5 | |
| Autonomy and parent relations | | | | | | 50.2 (10.0) |
| Has your child had enough time for him/herself?[c] | 0.0 | 1.6 | 12.5 | 54.2 | 31.8 | |
| Has your child been able to do the things that he/she wants to do in his/her free time?[c] | 2.6 | 2.1 | 23.5 | 53.5 | 18.3 | |
| Has your child felt that his/her parent(s) had enough time for him/her?[c] | 2.1 | 3.9 | 22.0 | 47.6 | 24.3 | |
| Has your child felt his/her parents treated him/her fairly?[c] | 0.5 | 3.9 | 18.5 | 49.5 | 27.6 | |
| Has your child been able to talk to his/her parent(s) when he/she wanted to?[c] | 6.6 | 1.1 | 8.8 | 40.4 | 43.1 | |
| Has your child had enough money to do the same things as his/her friends?[c] | 5.8 | 6.9 | 23.5 | 29.3 | 34.5 | |
| Has your child felt that he/she had enough money for his/her expenses?[c] | 6.9 | 6.6 | 19.9 | 34.0 | 32.6 | |
| Social support and peers | | | | | | 37.4 (15.2) |
| Has your child spent time with his/her friends?[c] | 16.5 | 21.3 | 39.4 | 14.4 | 8.4 | |
| Has your child had fun with his/her friends?[c] | 14.2 | 14.5 | 32.2 | 25.1 | 14.0 | |
| Have your child and his/her friends helped each other?[c] | 16.9 | 19.1 | 38.4 | 16.9 | 8.6 | |
| Has your child been able to rely on his/her friends?[c] | 20.1 | 22.0 | 35.9 | 15.3 | 6.7 | |
| School environment | | | | | | 48.2 (10.1) |
| Has your child been happy at school?[b] | 4.1 | 10.2 | 30.4 | 37.0 | 18.2 | |
| Has your child got on well at school?[b] | 2.5 | 6.4 | 30.0 | 40.6 | 20.6 | |
| Has your child been able to pay attention?[c] | 1.9 | 8.5 | 45.1 | 36.8 | 7.7 | |
| Has your child got along well with his/her teachers?[c] | 0.5 | 1.6 | 15.3 | 44.3 | 38.3 | |

Percentages of responses are based on the number of participants who completed the given item

[a] Response options reflect overall health quality ranging from 1 = *poor* to 5 = *excellent*

[b] Response options reflect intensity levels ranging from 1 = *not at all* to 5 = *extremely*

[c] Response options reflect frequency levels ranging from 1 = *never* to 5 = *always*

* Indicates that item score is reverse coded when reflected in *T* value for the domain

*Challenging Behavior* We gauged the occurrence of challenging behavior using a one-item measure asking, *How often does your child exhibit challenging behaviors (such as aggression, self-injury) outside of the home?* Responses were provided on a 4-point, Likert-type scale: 1 = *never*, 2 = *rarely*, 3 = *sometimes*, 4 = *often*. Therefore, the possible range of scores was 1–4 with higher scores reflecting higher parent perceptions of challenging behaviors.

*Functional Abilities* We determined functional abilities using a 4-item scale developed for the National Longitudinal Transition Study-2. The items focused on the child's ability to independently (a) tell time on a clock with hands, (b) count change, (c) read and understand common signs, and (d) look up phone numbers to make phone calls. Each item was rated on a 4-point, Likert-type scale (1 = *very well*, 2 = *pretty well*, 3 = *not very well*, 4 = *not at all* *well*). We reverse coded the items and then calculated the overall mean of the items to use as the total score so that higher scores (possible range 1–4) reflect higher levels of functional abilities. Cronbach's alpha in our sample was .85.

*Support Needs* We measured support needs using a measure adapted from Lee et al. (2008). Parents and caregivers reported how much support their son or daughter typically needed across seven domains (i.e., home living, community and neighborhood, social, school participation, school learning, health and safety, advocacy). Ratings of support needs for each domain was reported on a 5-point, Likert-type scale ranging from 1 = *no extra support needed* to 5 = *total support needed*. We calculated an overall support needs score using the overall mean of the seven items (possible range 1–5); higher scores indicated higher levels of support needs. Cronbach's alpha in our sample was .91.

*Involvement in Out-of-School Activities* We asked parents to report on the extent to which their son or daughter participated in each of 17 out-of-school activities (e.g., taking a sports lesson, using a computer, using the library, working at a part-time job or internship; Carter et al. 2010). Parents indicated if their child participated in each activity (a) in the past 2 weeks, (b) in the past year, or (c) not at all in the last year. Space was also provided to write in additional activities not listed. We used the total number of activities the young person was involved in at any point during the prior year as an indicator of community involvement. Possible scores ranged from 1 to 20 (i.e., 17 listed items plus up to 3 additional activities written in by parents), where higher scores reflect participation in more out-of-school activities.

*Strength of Religious Faith* We asked parents to report on the strength of religious faith of their child using a researcher-adapted proxy version of the Santa Clara Strength of Religious Faith Questionnaire—Short Form (Plante and Boccaccini 1997). This scale asked parents to reflect on their child's faith using five statements: *My child prays daily, My child looks to his/her faith as providing meaning and purpose in his/her life, My child considers himself/herself to be active in his/her faith or congregation, My child enjoys being around others who share his/her faith, My child's faith impacts many of his/her decisions.* Each statement is rated using a 4-point, Likert-type scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. We derived a total score using the overall mean of the individual item ratings (possible range 1–4); higher scores reflected a stronger religious faith. Cronbach's alpha in our sample was .93.

*Self-Determination* We asked respondents to assess the self-determination of their son or daughter using the capacity section of the AIR Self-Determination scale, parent version (Wolman et al. 1994). This 6-item scale addresses youths' knowledge, ability, and perception of self-determination behaviors and asks parents to report about their child on a 5-point, Likert-type scale ranging from 1 = *never* to 5 = *always*. Consistent with other studies (Carter et al. 2013), we used the overall mean of ratings on these six items as a total score for the youth's capacity for self-determination (possible range 1–5); higher scores reflect greater capacity for self-determination. The widely used AIR Self-Determination scale was developed and tested with a sample of 450 students with and without disabilities in California and has strong reliability and validity. Cronbach's alpha in our sample was .89.

*Strengths* Parents reported on the strengths of their child using the Assessment Scale for Positive Character Traits—Developmental Disabilities (ASPeCT-DD; Woodard 2009). The ASPeCT-DD is a 26-item proxy scale describing various character traits across 10 domains (i.e., courage, empathy, forgiveness, gratitude, humor, kindness, optimism, resilience, self-control, and self-efficacy). Response options were on a 5-point, Likert-type scale ranging from 1 = *not at all characteristic* to 5 = *extremely characteristic*. We calculated a total score (possible range 1–5) using the overall mean of the scores for the individual items; higher scores reflect stronger reported character strengths. Woodard (2009) demonstrated convergent validity by comparing total ASPeCT-DD scores with a child behavior rating scale. Cronbach's alpha in our sample was .92.

## Data Analysis

We conducted the following analyses to answer our research questions. First, we used descriptive statistics to determine how parents assessed the quality of life of our overall sample of all youth. Item-level descriptive statistics and average T values summarizing each domain are included in Table 2. Second, we compared two subsamples to a normative sample: (a) youth who received special education under the category of autism (with and without ID) and (b) youth who received special education only under the category of ID. We chose the division for these two subsamples because (a) prior studies focusing on students with autism have also included participants with and without co-occurring ID (e.g., Kuhlthau et al. 2010) and (b) in our sample, average quality of life domain ratings for young people with both eligibility categories were notably similar to ratings for young people receiving special education services under the category of autism without co-occurring ID. We used independent samples *t*-tests to make these comparisons with normative scores, using normative data from the European KIDSCREEN field survey which involved 22,296 children and adolescents and 16,888 proxy respondents across 11 countries (The KIDSCREEN Group Europe 2006). We used a subset of data from this field survey specifically focusing on parent proxy-reports of adolescents. We used Student's *t* test when the assumption of equal variances between the samples was met and Welch's *t* test when it was not. To address multiple comparisons, we set alpha at a more conservative .01. We calculated Cohen's *d* (1988) by dividing the difference in means of the subsample and norm group by the pooled standard deviation to gauge the magnitude of any differences between groups of youth. Following conventions outlined by Cohen (1988), we interpreted effect size magnitudes of .20, .50, and .80 as small, moderate, and large effects, respectively.

Third, we computed Pearson correlation coefficients to examine associations between predictor and dependent variable. We then used linear regression analysis to identify predictive factors of each domain of quality of life for our entire sample of youth with autism or ID. We examined the unstandardized regression coefficients, semipartial correlation coefficients, and significance of each predictor variable in the model to isolate the predictive value and weight of each variable, holding other variables in the model constant. The unstandardized regression coefficients are the amount of predicted change of the dependent variable (i.e., KIDSCREEN-27 domain T value) given an increase of one unit of the predictor variable. Unstandardized regression coefficients are expressed in the scale units of the predictor of interest. A negative regression coefficient represents a negative relationship between the predictor and dependent variables. Semipartial correlations are a measure of relative importance or explanatory value of each predictor variable through the amount of variance explained. Squared semipartial correlations can be interpreted as the proportion of criterion variance from the full model associated uniquely with each predictor variable.

Prior to running our analyses, we made decisions about missing data. Of the 416 participants and caregivers meeting our inclusion criteria, 368 (88.5 %) were not missing any data for predictor variables. Eligibility for free or reduced-price meals was missing in 7.5 % of cases. We used logistic regression to predict and impute eligibility using family size (i.e. total number of children), marital status, and parent education (Harrell 2001). After this, 389 participants had no missing values for any of the remaining predictor variables. We examined participants with missing predictor variables to determine that no pattern of missing data was evident. We excluded these participants and used the sample of 389 participants for all analyses. To address missing data in KIDSCREEN-27 domains, we followed guidelines described by its developers. We scored domains when no more than one item per scale was left unanswered. When just one item was missing, we used the responses on the remaining answered items in the same domain to estimate the domain T-value (The KIDSCREEN Group Europe 2006). When participants had more than one item missing in a domain, we did not calculate a domain score. Thus, the number in the sample for the regression analysis of each domain varies slightly.

## Results

### How Do Parents Depict the Quality of Life of Transition-Age Youth with Disabilities?

Parents' descriptions of the quality of life of their sons and daughters varied widely by domain (see Table 2). The highest domain ratings were found for Autonomy and Parent Relations ($M = 50.2$, $SD = 10.0$), followed by School Environment ($M = 48.2$, $SD = 10.1$), Psychological Well-being ($M = 43.6$, $SD = 10.2$), and Physical Well-being ($M = 42.5$, $SD = 10.5$). The lowest rated domain was Social Support and Peers ($M = 37.4$, $SD = 15.2$).

The lowest rated individual items were also found within Social Support and Peers. When asked to think within the timeframe of the last week, 37.8 % of parents indicated their child *never* or *rarely* spent time with his/her friends and 28.7 % of parents indicated their child *never* or *rarely* had fun with his/her friends. When asked if their child and his/her friends helped each other, 36.0 % of parents indicated this was *never* or *rarely* true. When asked if their child had been able to rely on his/her friends, 42.1 % of parents indicated this was *never* or *rarely* true. Individual items in the Physical Well-being domain were also rated somewhat lower by parents. For two items, more than 40 % of parents indicated the statement was *not at all* or *slightly* true for their child in the past week. These items asked whether their child had been physically active and whether their child had been able to run well.

### To What Extent Does Quality of Life Differ from a Normative Sample of Young People?

We report *p* values and effect sizes for each analysis in Table 3. Significant differences were found between both of our subsamples and norm data for three of the five domains. For Physical Well-being, we found statistically significant differences between youth with autism and the normative sample, $t(10{,}594) = 9.64$, $p < .0001$, and between youth with ID and the normative sample,

**Table 3** Comparisons of KIDSCREEN domain ratings with adolescent norm data for youth with autism and youth with ID

| KIDSCREEN domain | Parent-proxy adolescent norm data | | Intellectual disability (without autism) | | | | Autism | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | *n* | *M* (*SD*) | *n* | *M* (*SD*) | *ES*[a] | *p* | *n* | *M* (*SD*) | *ES*[a] | *p* |
| Physical well-being | 10,365 | 48.60 (9.99) | 157 | 42.97 (10.80) | −0.54 | <.0001 | 231 | 42.19 (10.39) | −0.63 | <.0001 |
| Psychological well-being | 10,367 | 49.10 (10.10) | 154 | 46.04 (10.02) | −0.30 | .0002 | 230 | 41.90 (10.04) | −0.71 | <.0001 |
| Autonomy and parent relations | 10,314 | 49.63 (10.16) | 146 | 50.86 (10.75) | 0.12 | .1467 | 218 | 49.69 (9.45) | 0.01 | .9311 |
| Social support and peers | 10,325 | 49.77 (10.30) | 147 | 42.19 (14.23) | −0.61 | <.0001 | 226 | 34.35 (15.02) | −1.20 | <.0001 |
| School environment | 10,381 | 48.47 (9.73) | 148 | 50.27 (9.55) | 0.19 | .0254 | 213 | 46.84 (10.22) | −0.16 | .0156 |

[a] Cohen's *d* calculated by dividing the difference in means between the subsample and norm group by the pooled standard deviation. Conventional criteria for interpreting: ≤0.20 = small; .0.21–0.79 = moderate; ≤0.80 = large. *ES* effect size

$t(10{,}520) = 7.00$, $p < .0001$. Both groups of youth with disabilities had lower scores than the norm sample; the effect sizes for youth with autism ($d = -.63$) and ID ($d = -.54$) were moderate (Cohen 1988). For Psychological Well-being, youth with autism, $t(10{,}595) = 10.69$, $p < .0001$, and youth with ID, $t(10{,}519) = 3.73$, $p = .0002$, had lower ratings than the normative sample. The effect size for youth with autism ($d = -.71$) was moderate, and for youth with ID ($d = -.30$) it was small. Using Welch's $t$ test for the Social Support and Peers domain, we found that youth with autism had significantly lower ratings than the normative sample, $t(229) = 15.35$, $p < .0001$, as did youth with ID, $t(148) = 6.43$, $p < .0001$. The effect size for youth with autism ($d = -1.20$) was large; the effect size for youth with ID ($d = -.61$) was moderate.

### What Factors Predict Quality of Life for Transition-Age Youth with Disabilities?

Each of the five KIDSCREEN-27 domains was significantly correlated with multiple variables (see Table 4). Strengths had the strongest positive correlation with each domain with the exception of Physical Well-being. Self-determination, strength of religious faith, and participation in out-of-school activities were also strongly positively correlated with several domains. Variables with strong negative associations with quality of life domains included having autism, higher support needs, and more challenging behaviors. Although many predictor variables were correlated with one another and some of the correlations were moderate to large in strength (e.g., functional behaviors and support needs $r = -.67$; Cohen 1988), the size of the correlations were not substantial enough to warrant concerns about multicollinearity (Harrell 2001).

We used multiple regression analyses to identify factors predicting quality of life in each of the five domains. A summary of unstandardized regression coefficients and semipartial (i.e., part) correlation coefficients for each of the 13 predictor variables is provided in Table 5. For Physical Well-being the model accounted for 22 % of the variance, $R^2 = .22$, $F(13, 374) = 8.06$, $p < .001$. Higher Physical Well-being scores were predicted by minority status (i.e., not white; $p = .02$) and higher ratings of total strengths ($p = .02$). Physical Well-being was also associated with age ($p < .001$); in our sample an increase in age was predictive of lower ratings in this domain. The model for Psychological Well-being accounted for 31 % of the variance, $R^2 = .31$, $F(13, 370) = 12.93$, $p < .001$. Having autism ($p = .03$) and age ($p = .03$) predicted lower ratings of Psychological Well-being. Higher ratings of total strengths ($p < .001$) predicted higher Psychological Well-being scores. The model for Autonomy and Parent Relation accounted for 32 % of the variance, $R^2 = .32$, $F(13, 350) = 12.60$, $p < .001$. Higher ratings on both the faith ($p = .004$) and strengths ($p < .001$) measures were associated with higher scores in the domain. For Social Support and Peers, the model accounted for 32 % of the variance, $R^2 = .32$, $F(13, 359) = 12.96$, $p < .001$. Having autism predicted lower ratings in the domain ($p = .02$). Participation in a greater number of out-of-school activities ($p < .001$), higher ratings on the faith measure ($p < .001$), and higher ratings on the strengths measure ($p < .001$) were significant predictors of increased scores in the Social Support and Peers domain. The model for School Environment accounted for 31 % of the variance, $R^2 = .31$, $F(13, 347) = 12.10$, $p < .001$. Using speech as the primary communication mode ($p = .04$) and having challenging behaviors ($p = .01$) predicted lower scores for School Environment. Higher scores for the domain were predicted by higher ratings of total strengths ($p < .001$).

## Discussion

Improving the quality of life of students with disabilities is considered a central purpose of special education and transition services (Turnbull et al. 2003). Knowing how

**Table 4** Bivariate correlation matrix and descriptive statistics for all outcome and predictor variables

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | *M* | *SD* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| KIDSCREEN Physical | – | – | | | | | | | | | | | | | | | | 43.6 | 10.2 |
| KIDSCREEN Psychological | .43** | – | | | | | | | | | | | | | | | | 43.6 | 10.2 |
| KIDCSREEN Parent | .32** | .48** | – | | | | | | | | | | | | | | | 50.2 | 10.0 |
| KIDSCREEN Social & peers | .34** | .39** | .41** | – | | | | | | | | | | | | | | 37.4 | 15.2 |
| KIDSCREEN School | .29** | .53** | .40** | .40** | – | | | | | | | | | | | | | 48.2 | 10.2 |
| Autism | −.04 | −.20** | −.06 | −.25** | −.17** | – | | | | | | | | | | | | 0.6 | 0.5 |
| Minority ethnicity | .10* | −.04 | −.10 | .02 | .03 | −.01 | – | | | | | | | | | | | 0.2 | 0.4 |
| Child age | −.20** | −.04 | −.02 | −.02 | .03 | −.16 | .03 | – | | | | | | | | | | 16.4 | 2.5 |
| Female | −.05 | .04 | .08 | .14** | .13* | −.23** | −.04 | .02 | – | | | | | | | | | 0.3 | 0.5 |
| Free/reduced price meals | −.04 | −.16** | −.19** | −.04 | −.09 | −.04 | .28** | −.01 | −.04 | – | | | | | | | | 0.4 | 0.5 |
| Speech | .20** | .07 | .26** | .14** | .06 | .06 | −.11* | −.04 | .04 | −.10 | – | | | | | | | 0.8 | 0.4 |
| Behaviors | −.09 | −.28** | −.28** | −.26** | −.36** | .18** | .04 | −.06 | −.09 | .24** | −.16** | – | | | | | | 2.2 | 1.0 |
| Functional abilities | .19** | .02 | .19** | .08 | .10 | .29** | −.01 | −.07 | −.10 | −.16** | .52** | −.25** | – | | | | | 2.5 | 0.9 |
| Support needs | −.27** | −.15** | −.29** | −.23** | −.23** | −.09 | .04 | .02 | .05 | .18** | −.50** | .36** | −.67** | – | | | | 3.4 | 1.0 |
| Activities | .34** | .14** | .24** | .37** | .17** | −.11* | .02 | .06 | .10 | −.04 | .41** | −.18** | .38** | −.46** | – | | | 10.2 | 4.2 |
| Faith | .08 | .16** | .32** | .36** | .24** | −.11* | .02 | .05 | .09 | −.01 | .17** | −.21** | .22** | −.26** | .30** | – | | 2.6 | 0.9 |
| Self-determination | .27** | .25** | .27** | .27** | .25** | −.08 | .06 | .00 | .00 | −.04 | .34** | −.23** | .45** | −.56** | .40** | .34** | – | 2.4 | 0.8 |
| Strengths | .26** | .52** | .52** | .47** | .52** | −.20** | −.02 | .06 | .11* | −.16** | .26** | −.43** | .18** | −.38** | .40** | .40** | .53** | 3.2 | 0.7 |

*N* = 389. Autism (1 = autism); Minority ethnicity (1 = minority); Female (1 = female); Free/reduced price meals (1 = eligible for free/reduced price meals); Speech (1 = speech); Behaviors (possible range 1–4; higher scores reflect higher levels of challenging behaviors); Functional abilities (possible range 1–4; higher scores reflect higher levels of functional abilities); Support needs (possible range 1–5; higher scores reflect higher levels of support needs; Activities (possible range 1–20; higher scores reflect participation in greater number of out-of-school activities; Faith (possible range 1–4; higher scores reflect stronger religious faith); Self-determination (possible range 1–5; higher scores reflect greater capacity for self-determination; Strengths (possible range 1–5; higher scores reflect stronger reported character strengths)

* $p < .05$. ** $p < .01$

**Table 5** Regression analysis for KIDSCREEN quality of life domains

| Variable | Physical well-being ($n = 388$) | | Psychological well-being ($n = 384$) | | Autonomy and parent relations ($n = 364$) | | Social support and peers ($n = 373$) | | School environment ($n = 361$) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | *B*[a] | *sr*[b] | *B* | *sr* | *B* | *sr* | *B* | *sr* | *B* | *sr* |
| Autism | −1.05 | −.04 | −2.34* | −.10 | .92 | .04 | −3.75* | −.10 | −.92 | −.04 |
| Minority ethnicity | 3.04* | .11 | −.04 | <−.01 | −1.48 | −.06 | .90 | .02 | .58 | .02 |
| Child age | −.95** | −.22 | −.41* | −.10 | −.17 | −.04 | −.60* | −.10 | −.12 | −.03 |
| Female | −1.83 | −.08 | −1.06 | −.05 | .62 | .03 | 1.21 | .04 | 1.63 | .07 |
| Free/reduced meals | −.76 | −.03 | −1.79 | −.08 | −1.30 | −.06 | .54 | .02 | .42 | .02 |
| Speech | .89 | .03 | −1.20 | −.03 | 2.63 | .07 | −.83 | −.02 | −3.27** | −.10 |
| Behaviors | .45 | .04 | −.70 | −.06 | −.38 | −.03 | −.93 | −.05 | −1.42* | −.12 |
| Functional abilities | −.28 | −.02 | −.43 | −.03 | .05 | <.01 | −1.45 | −.06 | .18 | .01 |
| Support needs | −.98 | −.06 | .08 | .01 | −.66 | −.04 | −.95 | −.04 | −1.28 | −.08 |
| Community activities | .61 | .20 | −.09 | −.03 | −.04 | −.01 | .76** | .17 | −.11 | −.04 |
| Religious faith | −.92 | −.07 | −.56 | −.04 | 1.56** | .13 | 3.08** | .16 | .37 | .03 |
| Self-determination | .79 | .05 | .17 | .10 | −.75 | −.05 | −.47 | −.02 | −.56 | −.03 |
| Strengths | 2.45* | .11 | 7.88** | .38 | 6.58** | .32 | 6.01** | .19 | 7.05** | .33 |
| $R^2$ | .22 | | .31 | | .32 | | .32 | | .31 | |
| Adjusted $R^2$ | .19 | | .29 | | .29 | | .30 | | .29 | |
| *F* | 8.06** | | 12.93** | | 12.60** | | 12.96** | | 12.10** | |

[a] Unstandardized regression coefficient

[b] Semipartial correlation coefficient

* $p < .05$ (two-tailed test), ** $p < .01$ (two-tailed test)

transition-age students with autism or ID fare on the cusp of adulthood—and the factors that may shape their well-being—can have important implications for the design and delivery of services and supports during this critical time period. We examined the subjective quality of life of a large sample of young people with autism or ID and identified key predictors across five domains. Our findings extend the literature in several ways.

First, parents' ratings of the quality of life of their sons and daughters with autism or ID were significantly lower than a normative sample of similar-age youth in the areas of Social Support and Peers, Physical Well-being, and Psychological Well-being. These findings are consistent with research focused on younger children with autism spectrum disorders and young adults with high-functioning autism (e.g., Kamp-Becker et al. 2010; Kuhlthau et al. 2010, 2013; Shipman et al. 2011). We found the domain with the lowest ratings in our sample was Social Support and Peers. This is similar to previous studies involving preschool children with developmental disabilities (Lau et al. 2006), young adults with high-functioning autism (Kamp-Becker et al. 2010), and adolescents with autism spectrum disorders (Clark et al. 2015). The social, communication, and behavioral difficulties sometimes present among students receiving special education services for autism or ID may have an impact on the social well-being of young people with these labels. However, other influences are also important to consider. For example, the educational experiences of these students often look dramatically different than those of their peers without disabilities. Limited involvement in inclusive classrooms, extracurricular activities, and other school or community activities can constrain opportunities to meet peers and develop friendships or other supportive relationships (Shattuck et al. 2011). These findings emphasize the importance of implementing effective social-related intervention strategies and supporting inclusive learning opportunities in high school for adolescents with autism or ID (Carter and Hughes 2013).

Second, comparisons with normative scores suggest some differences in quality of life based on special education category. While youth with autism and youth with ID had lower ratings than peers without disabilities in the areas of Physical Well-being, Social Support and Peers, and Psychological Well-being, the effect sizes demonstrated an even greater difference for youth with autism. Other descriptive studies confirm the social networks of adolescents with autism are even more limited than adolescents with ID (Wagner et al. 2003). Similarly, autism may be accompanied by co-occurring mental health difficulties (Ratcliffe et al. 2015). These findings highlight the need for special educators and other service providers to be mindful of difficulties that young people with disabilities may experience in these domains and aware that young people with autism may experience even greater challenges. Researchers should explore whether and how interventions and supports to promote quality of life in different domains have differential effects for youth served under different special education categories.

Third, our findings call attention to the diverse factors that may influence quality of life during the transition period. We found that greater involvement in out-of-school activities was associated with higher ratings in the Social Support and Peers domain. Other studies involving youth with and without disabilities have linked involvement in extracurricular or community activities to a range of positive outcomes (e.g., Mahoney et al. 2006). Involvement in shared activities outside of the home—such as participating in athletics, fine arts programs, extracurriculars, internships, volunteer experiences, or other community activities—may provide a context for young people with disabilities to connect with others, develop friendships, and enhance social-related skills. Unfortunately, community involvement of youth with autism and ID is limited and numerous barriers can limit participation in these types of activities. One implication for special educators, family members, and service providers is to address planning for community and extracurricular involvement and seek to remove barriers that may limit participation in these types of activities.

Strength of religious faith was predictive of two quality of life domains: Social Support and Peers and Autonomy and Parent Relations. Hundreds of studies have documented strong associations among spirituality, faith community involvement, and indicators of well-being among people without disabilities (e.g., Koenig et al. 2012). However, research addressing faith and spirituality among youth with autism or ID has been limited (e.g., Liu et al. 2014). Involvement in a faith community may have provided youth with opportunities to worship, fellowship, and serve alongside others in ways that led to new relationships and social supports. Although spirituality will not be important in the life of every young person, this finding extends the large literature exploring connections among spirituality and quality of life (Koenig et al.), as well as provides additional impetus for religious organizations to ensure young people with autism or ID have sufficient opportunities and supports to strengthen their faith and participate fully within congregational life (Carter et al. in press).

The strengths of these young people—as measured by the ASPeCT-DD—emerged as the one of the strongest predictors of higher quality of life across all five domains. Prior studies have linked positive traits (e.g., hope, optimism) to broader measures of well-being and life satisfaction among young adults without disabilities (Proctor et al. 2011) and adolescents with and without ID (Shogren et al. 2006). A focus on the strengths of young people with disabilities during the transition period, however, is surprisingly limited (Carter et al. 2015). Our findings suggest the expression of positive characteristics such as courage, empathy, forgiveness, gratitude, humor, kindness, optimism, resilience, self-control, and self-efficacy can be associated with increased quality of life across multiple domains. Although additional research is needed to more clearly understand the pathways between individual strengths and these specific domains, these findings reinforce the importance of transition mandates within IDEA (2006) requiring educators take “into account the child’s strengths, preferences, and interests” when designing transition services and supports (34 CFR 300.43(a)).

Fourth, we were somewhat surprised by the factors not found to predict quality of life in our sample, including most demographic- and disability-related factors. Neither ratings of support needs nor functional abilities emerged as significant predictors in any of our five models. The literature reports mixed findings related to the association between indicators of disability severity and quality of life (e.g., Kamp-Becker et al. 2010; Kuhlthau et al. 2013; Tilford et al. 2012). In addition, challenging behaviors predicted lower well-being in just one domain—School Environment. Previous studies have found that some types of aberrant behaviors were associated with lower quality of life while other types were not (Kuhlthau et al. 2010, 2013). Finally, one of the personal traits we hypothesized would be associated with quality of life—a young person’s capacity for self-determination—did not significantly predict ratings in any of the five domains. As prior studies have found strong associations among self-determination and positive outcomes for students with disabilities, the connection between self-determination and quality of life should be further examined. While self-determination is often defined as consisting of both an individual’s capacity for self-determination and the opportunities they have to make and act on their own choices, our study addressed only the element of capacity. The mixed nature of findings across studies for each of these variables—disability-related factors, challenging behaviors, and self-determination—may be related to sampling or measurement differences across studies. Future research should continue to investigate the potential for associations of these factors with quality of life, as well as work toward developing and evaluating a framework for how various demographic, disability, personal, and support variables influence quality of life and interact with each other. A strong theoretical or conceptual framework of this nature does not currently exist for transition-age students with autism or ID.

## Limitations and Future Research

Given the complex nature of quality of life throughout adolescence and early adulthood, our study provides only one window into this important aspect of the lives of youth with autism or ID. Several limitations to this study suggest areas for future research. First, this study presents a snapshot of quality of life at a single point in time. Cross-sectional data can highlight important associations, but it cannot provide casual evidence for how individual variables impact quality of life. Future research is needed to explore longitudinal questions related to how quality of life develops over time with and without intervention.

Second, despite having a large sample of nearly 400 parents, all of the youth who were the focus of this study lived in a single state. Although the racial/ethnic backgrounds of participants were fairly representative of the state, the demographic, religious, and cultural backgrounds of participants may not mirror those of youth in other states or parts of the world. Moreover, our sample slightly underrepresented youth from families with lower socioeconomic status. Future researchers should focus on other samples reflecting different cultural, linguistic, socioeconomic, geographic, and/or religious backgrounds, to determine how the findings of this study converge and diverge across samples.

Third, our study incorporated a single measure of subjective quality of life. Although the KIDSCREEN is a well-accepted measure with strong reliability and validity, quality of life is a multi-dimensional concept that can be defined in myriad ways. Future research involving different measures or methodologies to assess and describe quality of life would contribute to a more comprehensive understanding.

Fourth, we addressed the quality of life of these young people from a single vantage point using parent proxy-reports. We chose to use parent reports because our sample included many young people with complex communication and cognitive impairments, as well as because we were confident parents could speak to the indicators reflected on the KIDSCREEN measure and offer a valuable perspective. Using parent-proxy reports is a validated methodology for administering the KIDSCREEN (The KIDSCREEN Group Europe 2006). However, studies involving both self- and proxy-reports for youth with disabilities suggest parents may provide lower quality of life ratings than the self-report ratings (e.g., Clark et al. 2015; Shipman et al. 2011). Additional research is needed to expand available methods for capturing the views of youth with severe intellectual and communication impairments on their own quality of life. Who does the reporting (e.g., mother versus father) and whether they currently live with the child may also shape views on the constructs in this study. Because our respondents were primarily mothers and we did not inquire about residential status, researchers should explore these possibilities in future studies.

## Conclusion

The purpose of this study was to examine the quality of life for young people with disabilities during the transition to adulthood, as well as to investigate whether several factors related to personal traits and connections were associated with higher ratings of quality of life above and beyond demographic- or disability-related characteristics. Our findings highlight domains in which the quality of life of youth with autism or ID was rated lower than a representative sample of their peers without disabilities, providing impetus for attention to supports and interventions that may address these areas. In addition, our study provides insight into potential contributions of community involvement, religious faith, and character strengths to several areas of quality of life. By better understanding factors contributing to overall quality of life, this line of research may promote the flourishing of young people during this critical period of transition.

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