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A Lifespan Approach to Patient-Reported Outcomes and Quality of Life for People on the Autism Spectrum

Laura Graham Holmes , Casey J. Zampella , Caitlin Clements , Joseph P. McCleery, Brenna B. Maddox , Julia Parish-Morris , Manisha D. Udhani , Robert T. Schultz , and Judith S. Miller

Autistic self-advocates, family members, and community organizations have called for greater emphasis on enhancing quality of life (QoL) for people with autism. To do this, it is critical to understand how QoL unfolds across the life course and to clarify whether gender affects QoL, health, and functioning for people with autism. The purpose of this study was to curate and test a lifespan QoL measurement tool using freely available and well-constructed National Institutes of Health Parent-Reported Outcomes Measurement Information System (PROMIS). To develop the PROMIS Autism Battery—Lifespan (PAB-L), we identified PROMIS scales relevant for autism, reviewed each item, consulted with a panel of autism experts, and elicited feedback from autistic people and family members. This battery provides a comprehensive portrait of QoL for children ages 5–13 (through parent proxy), teens 14–17 (parent proxy and self-report), and adults 18–65 (self-report) with autism compared to the general population. Participants and parent informants ($N = 912$) recruited through a children's hospital and nationwide U.S. autism research registry completed the PAB-L online. Results indicate that compared to general population norms, people with autism of all ages (or their proxies) reported less desirable outcomes and lower QoL across all domains. Women and girls experienced greater challenges in some areas compared to men and boys with autism. The PAB-L appears to be a feasible and acceptable method for assessing patient-reported outcomes and QoL for autistic people across the life course. *Autism Res* 2020, 00: 1–18. © 2020 International Society for Autism Research, Wiley Periodicals, Inc.

Lay Summary: We developed a survey to measure the quality of life of children, teens, and adults with autism using free National Institutes of Health PROMIS questionnaires. People with autism and family members rated the PROMIS Autism Battery—Lifespan as useful and important. Some reported a good quality of life, while many reported that their lives were not going as well as they wanted. Women and girls reported more challenges in some areas of life than men and boys.

Keywords: quality of life; patient-reported outcomes; sex/gender; women with autism; life span/lifespan; life course; adults

Introduction

The World Health Organization (WHO) defines quality of life (QoL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p. 1; [World Health Organization & Division of Mental Health and Prevention of Substance Abuse, 1997]). Autistic self-advocates and their families have called for greater societal and research investment in efforts that address specific, practical obstacles to achieving optimal QoL [Ne’eman, 2010; Pellicano, Dinsmore, & Charman, 2014; Robertson, 2010]. Furthermore, the WHO and the Interagency Autism Coordinating

Committee (IACC) have highlighted the need for a better understanding of how services, supports, and care models can maximize QoL across the life course [Interagency Autism Coordinating Committee (IACC), 2017; World Health Organization, 2013]. Factors identified as potentially negatively impacting QoL for autistic adults include perceived stress [Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016], depression [Park et al., 2019], repeated experiences of being bullied [Hong et al., 2016] or unmet formal support needs [Renty & Roeyers, 2006] and female sex [Mason et al., 2018]. For youth, factors include sleep issues [Delahaye et al., 2014] and poorer executive functioning [De Vries & Geurts, 2015]. Factors associated with higher QoL for autistic adults include perceived social

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support [Bishop-Fitzpatrick, Mazefsky, & Eack, 2018] and participation in recreational activities [Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2017]; for youth, positive factors include having friends and regular sports participation [Cottenceau et al., 2012].

Despite increased attention, research on factors associated with QoL in autism is still in its infancy, and important questions remain about how to measure it in a meaningful way [Bal et al., 2018]. Billstedt, Gillberg, and Gillberg [2011] combined parent proxy ratings with a measure of autism-friendly environment to understand QoL in adulthood (e.g., caregivers have autism knowledge, individualized treatment plan, occupation matching capacity), which covers important aspects of life but does not incorporate the individual's goals or standards. Recently, research groups have validated self-report measures for autistic adults including the Medical Outcomes Study Short-Form Health Survey, version 2 [SF-12; Khanna et al., 2015] and the World Health Organization Quality of Life—Brief (WHOQOL-BREF; [World Health Organization, 1995] and WHO Disabilities module [McConachie et al., 2018; McConachie et al., 2019]. Based on stakeholder input, McConachie and colleagues added nine autism-specific items covering topics such as sensory issues, healthcare access barriers, financial security, and autistic identity. For youth, the Pediatric Quality of Life Inventory (PedsQL; [Varni, Seid, & Rode, 1999] is commonly used but has not been validated [Ikeda et al., 2016]. Our approach was to leverage the patient-reported outcome (PRO) measures developed by the National Institutes of Health (NIH; described below) and assess feasibility to provide a comprehensive portrait of QoL in autism, across age groups and genders.

Importance of a Lifespan Approach to QoL

Evidence suggests that people with autism experience poorer QoL across childhood, adolescence, and adulthood compared to those without autism [Ayres et al., 2018; van Heijst & Geurts, 2015]. Youth with autism tend to score lower on QoL measures than youth with other chronic conditions or healthy controls [Cottenceau et al., 2012; Lee, Harrington, Louie, & Newschaffer, 2008]. Adults with autism also rate their QoL lower than adults without autism (e.g., [Kamio, Inada, & Koyama, 2013], and report being less satisfied with work or education, partner relationships, and imagined future when compared with adults with other psychiatric disorders diagnosed in childhood [Barneveld, Swaab, Fagel, van Engeland, & de Sonnevile, 2014]). A recent meta-analysis highlighted the need for more studies of QoL in adults, particularly older adults [van Heijst & Geurts, 2015]. Several studies using the WHOQOL-BREF in small samples of older autistic adults have been conducted. While Moss, Mandy, and

Howlin [2017] found that older age was associated with poorer physical health only, Mason et al. [2019] reported mean scores for their sample of 55+ years that were 1 *SD* below normative scores for the UK. In another study, Mason and colleagues reported that autistic adults aged 17–25 years reported higher environmental and psychological QoL compared to older age groups, with small effect sizes. The authors suggested that inconsistencies may result from small samples or heterogeneity and recommended longitudinal QoL research.

It has been difficult to understand QoL and functioning across development because most measurement tools are not designed for lifespan research. Many tools used to measure QoL are only appropriate for children (e.g., PedsQL; [Varni et al., 1999]). Tools targeting adults typically tap global constructs and lack nuances relevant to people with autism (e.g., broad subscales related to social relationships and psychological health on the WHOQOL-BREF). The absence of a sensitive QoL measure that seamlessly bridges developmental stages has hindered our ability to evaluate QoL in autism throughout the life course. In response to this need, we curated the Lifespan Autism Battery using the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) measures, a comprehensive set of measures that spans multiple domains of functioning and is appropriate for both youth and adults.

Gender Differences in QoL

In the general population, girls and boys report similar QoL, according to a large study of European 8-year-olds ($N = 21,590$) [Michel, Bisegger, Fuhr, Abel, & The KIDSCREEN Group, 2009]. However, adult women consistently report poorer QoL than men (e.g., [Orfila et al., 2006]). Similarly, limited research on gender QoL disparities within autism has found no gender differences in children ages 2–17 or in elderly adults with autism [Kuhlthau et al., 2010; Totsika, Felce, Kerr, & Hastings, 2010]. However, among autistic adults ages 18–49, women report poorer psychological and social QoL than men [Kamio et al., 2013]. Understanding the role of gender in QoL across the lifespan and relative to the general population may be particularly helpful for developing appropriate supports for women and girls with autism [Halladay et al., 2015]. The present study specifically examines gender differences in various domains of QoL in childhood, adolescence, and adulthood.

Benefits of PRO

PRO measures capture patients' own experiences, and thus hold promise for facilitating the clinical research process, improving healthcare quality, informing policy, and contributing to cost-benefit analyses for evidence-

based interventions and services [Black, 2013; Burgess & Gutstein, 2007; Cella et al., 2007; World Health Organization, 2013]. Moreover, PROs validate patients' subjective experiences and enhance self-advocacy via active engagement in medical decision-making [Barry & Edgman-Levitan, 2012; Bevens, Ross, & Cella, 2014; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; Hendriks & Schouten, 2002; Lohr & Zebrack, 2009]. In 2004, the NIH launched the Patient-Reported Outcome Measurement Information System (PROMIS®; www.nihPromis.org) [Reeve et al., 2007] project to offer free, well-constructed PRO measures for a variety of diseases and outcomes. PRO measurement is particularly salient for understanding QoL because QoL exists relative to each person's own expectations and standards, and thus cannot be fully captured through clinician-rated tools. By highlighting the difference between hopes/expectations and reality, PRO QoL measures reveal the most important targets for interventions and services.

Given that improving QoL is the ultimate goal of many interventions and services and that autism is a complex, lifelong condition, a specific and accurate measure of lifespan QoL in autism is needed to determine client needs, review progress, inform intervention priorities, and evaluate service effectiveness and appropriateness. In response to this need, we leveraged PROMIS to curate a PRO battery especially for assessing lifespan QoL in autism. Critically, this battery assesses functioning and well-being across many domains and allows for comparison to population norms. The aims for this study were as follows: (a) Test the feasibility and acceptability of the Lifespan PROMIS Autism Battery (PAB-L); (b) Compare PAB-L scores in autism to the general population across three developmental stages (childhood, adolescence, and adulthood); and (c) Examine gender differences in PAB-L scores across the life course. Examining lifespan QoL with this level of detail has the potential to highlight QoL domains that are most important to monitor and opportunities for intervention and services development at different developmental stages.

Methods

Participants and Procedures

This was a national cross-sectional study. This study underwent an ethics review for research involving human subjects and was approved by the Children's Hospital of Philadelphia (CHOP) Institutional Review Board. Individuals with autism and their families completed an online survey comprised of PROMIS scales for measuring QoL. In total, 912 participants were enrolled and 856 completed at least one PROMIS scale (Fig. 1). Participants were recruited via two sources between November 2017 and June 2018. The first recruitment source

($n = 520$) was the CHOP. This included emails to people in the Center for Autism Research participant registry, to patients with autism diagnoses in their electronic medical records, and flyers in outpatient and hospital clinics and at local colleges in Philadelphia. The second source ($n = 392$) was the Interactive Autism Network (IAN) Research Registry and Database (Johns Hopkins Medicine IRB #NA_00002750; PI: Dr. Paul H. Lipkin). IAN is an online platform developed by the Kennedy Krieger Institute and the Simons Foundation to support research recruitment. IAN has verified reports of autism diagnoses for subsets of participants through clinical assessment and medical records reviews [Daniels et al., 2011; Lee et al., 2010]. Study data were collected and managed using REDCap [Harris et al., 2009].

Survey participants were divided into three age groups: childhood, adolescence, and adulthood. In the child group (ages 5–13), a primary caregiver completed PROMIS measures about the child with autism (parent proxy). In the adolescent group (ages 14–17), both a primary caregiver and the adolescent with autism, if possible, completed PROMIS measures (parent proxy and pediatric self-report, respectively). In the adult group (ages 18+), the adult with autism completed PROMIS measures (adult self-report). Hereafter, the *participant* will refer to the individual with autism about whom information was collected, and the *informant* will refer to the individual who completed the survey.

Eligibility criteria for *informants* were English fluency and the ability to complete the survey independently. Eligibility criteria for *participants* included a formal medical diagnosis of ASD, per informant report. For the adolescent group, we originally targeted only participants able to self-report, but ultimately included participants of any ability level, based on stakeholder feedback.

This study was completed entirely online. Informants completed a demographic questionnaire (DQ), PROMIS scales, and items about feasibility and acceptability. Random ordering of scales to address the possibility of order bias was not possible in REDCap. Instead, participants were randomized into two conditions, each with a different and random ordering of PROMIS scales, allowing us to test for order bias between conditions. Based on input from stakeholders and experts, informants were encouraged to complete the survey in one sitting, with brief breaks as needed to manage fatigue or distraction. A visual indicator conveyed progress. All informants who completed a survey received a \$20 gift card. Written informed consent was obtained in accordance with CHOP institutional review board guidelines.

Curation of the PROMIS Autism Battery—Lifespan Version

PROMIS scales are broadly organized into the domains of physical health (e.g., sleep, sexual function), mental

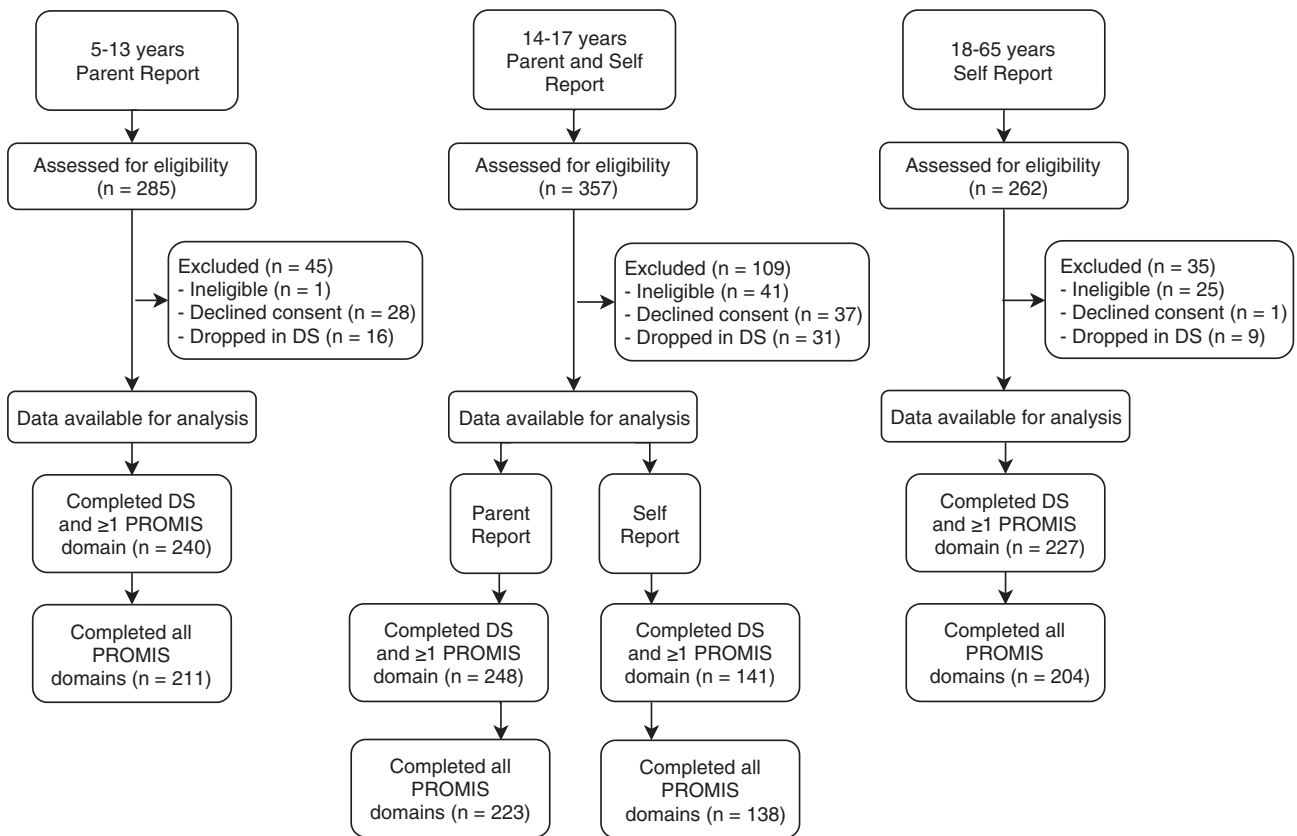


Figure 1. CONSORT diagram showing number of individuals screened, excluded, and included in the survey.

health (e.g., emotional distress, cognitive function, and positive psychological function), social health (e.g., peer relationships, social support), and global health (i.e., general evaluations of health) [Cella et al., 2010]. Scales are available in three formats: parent proxy (for 5–17-year-olds), pediatric self-report (for 8–17-year-olds), and adult self-report (for 18+ year-olds). In addition, most scales are available in both short-form (SF) versions (usually four and eight items) and as a full, uncalibrated bank of all available items (usually around 44 items). SF data are used in scoring through the Assessment Center, while full item banks were created for the purpose of computerized adaptive testing.

To develop the PAB-L, the study team reviewed all PROMIS scales and identified those most potentially relevant for people with autism. These included central aspects of QoL (e.g., emotional distress, subjective well-being) and common co-occurring conditions (e.g., sleep disturbance) but not scales more associated with the physical conditions PROMIS is commonly used for (e.g., pain, fatigue, upper extremity mobility, and constipation). Users of the PAB-L may choose to add other relevant PROMIS scales to the core PAB-L battery in order to track functioning and symptoms. We gave preference to SF scales to reduce participant burden, in line with the original PROMIS validation guidelines. However, we included

particularly several potentially novel uncalibrated item banks that we anticipated might result in differential item functioning for this population (e.g., social isolation); these analyses are outside of the scope of this article. All individual items were reviewed to ensure applicability for people with autism. Scales with reference to an acute medical condition with a specific onset were not included. This resulted in the initial group of 11 scales for children and adolescents, and 15 for adults. Next, a panel of autism experts working in clinics throughout CHOP provided feedback on the scales and perceived feasibility issues. Based on their feedback, two additional scales (sleep disturbance and sleep impairment) were added. Additionally, based on feedback from pilot participants, the anger scale was added in January 2017. Previous informants were given the opportunity to complete the anger scale retroactively. Our final battery was comprised of 14 scales for the child and adolescent age groups, and 18 scales for the adult age group.

Measures

Demographic Questionnaire

Adult participants and parent informants completed an online DQ designed for this study, which included

38 items for adult self-report and 70 or 80 items for parent proxy (for one- and two-parent households, respectively). Items covered participants' age, gender, family and other social relationships, developmental and medical diagnoses, mental health diagnoses, medication and service use, socioeconomic status, and work and leisure activities.

PROMIS Scales

The list of PROMIS measures used for the PAB-L, and instructions on how to re-create the PAB-L in REDCap, are available at www.centerforautismresearch.org and the NIH public forum (<http://www.healthmeasures.net/resource-center/user-community/forum/promis>). The entire library of PROMIS measures is available at www.healthmeasures.net. For all PROMIS scales, *T*-scores ($M = 50$, $SD = 10$) can be derived using manuals available on the PROMIS website or for free through the Assessment CenterSM (www.assessmentcenter.net) [Cella, Gershon, Bass, & Rothrock, 2017]. The scales were originally constructed and then validated with participants drawn from U.S. clinical sites and the general population. The goal was a U.S. population representative sample that was also diverse in terms of health conditions and functioning [Cella et al., 2010]. The approach to measure development generally included a qualitative item review of similar measures, patient interviews or focus groups to identify critical measurement constructs and elicit feedback on candidate items, followed by empirical testing of candidate items [e.g., Cella et al., 2010; Liu et al., 2010; Rothrock et al., 2010]. PROMIS measures have demonstrated clinical validity [Cook et al., 2016] and responsiveness to change across multiple conditions [e.g., Pilkonis et al., 2014]. More information can be found at <http://www.healthmeasures.net/explore-measurement-systems/promis/measure-development-research/validation>.

For this study, PROMIS SF *T*-scores were obtained from the PROMIS Assessment Center website, with the default (relevant) calibration sample selected for each domain [Irwin et al., 2010]. For all scales, higher scores indicate more of the measured construct (i.e., in some cases, higher scores indicate more desirable outcomes, and in others less desirable outcomes). For most scales, scores are based on retrospective reports on the previous 7 days, with a minority of scales based on the past month. Two sets of interpretive guidelines exist for PROMIS scales. The original guidelines across PROMIS scales were anchored to the mean, with scores 0.5–1.0 *SD* from the mean indicative of mild differences, 1.0–2.0 *SD* moderate, and 2.0 *SD* extreme [Cella et al., 2010]. We use the original guidelines for ease of comparison across scales. Readers interested in recent guidelines designed to increase the sensitivity of specific scales are referred to as the PROMIS website.

PROMIS Autism Battery—Youth (Parent Proxy and Pediatric Self-Report)

The PROMIS Autism Battery—Youth (PAB-Y) included 14 PROMIS scales, addressing the constructs of emotional distress (depression, anxiety, anger, psychological stress experiences) [Quinn et al., 2014], subjective well-being (meaning and purpose, positive affect, life satisfaction) [Forrest et al., 2018; Forrest et al., 2018; Ravens-Sieberer et al., 2014], social health (peer and family relationships) [Bevans et al., 2017; DeWalt et al., 2013; Irwin et al., 2012], cognitive function (i.e., memory and concentration) [Lai et al., 2011; Lai et al., 2014], sleep and physical activity [Bevans et al., 2018; Forrest et al., 2018; Tucker et al., 2014a, 2014b], and a measure of global health [Forrest et al., 2014; Forrest et al., 2016]. Scales ranged in length from 5 to 43 items. We used the SF version of all but two scales (life satisfaction, cognitive function) and SF *T*-scores for all scales are reported in analyses.

PROMIS Autism Battery—Adult (Self-Report)

The PROMIS Autism Battery—Adult (PAB-A) included 18 PROMIS scales, addressing the constructs of emotional distress (depression, anxiety, anger) [Pilkonis et al., 2014; Yu et al., 2011], subjective well-being (meaning and purpose, positive affect, general life satisfaction) [Salsman et al., 2014], social health (companionship, social isolation, satisfaction with social roles, social support) [Hahn et al., 2010; Hahn et al., 2014], general self-efficacy [Kupst et al., 2015], cognitive functioning [Lai, Wagner, Jacobsen, & Cella, 2014], sleep disturbance and impairment [Buysse et al., 2010; Yu et al., 2011], and global health [Hays, Bjorner, Revicki, Spritzer, & Cella, 2009; Hays, Schalet, Spritzer, & Cella, 2017]. Scale lengths ranged from 5 to 32 items. We used the SF versions for all but two scales (social isolation, cognitive function) and SF *T*-scores for all scales are reported in analyses. We also included the PROMIS Sexual Function and Satisfaction v2.0 Brief Profile in the PAB-L; however, because this measure provides multiple *T*-scores for each gender, we will present those results in a future manuscript where the nuances can more fully be discussed.

Feasibility and Acceptability Items

Feasibility was evaluated in terms of time spent on PROMIS items (a priori average optimal response time ≤ 20 min) and completion rate among those who completed at least one PROMIS domain (a priori criteria of 75%). To decrease bias associated with outliers (e.g., those who may have left their browser open overnight), time-to-completion analyses included participants who completed the survey in ≤ 60 min. In pilot testing, people completed the DQ and all PROMIS items in 20–30 min, and the 75th percentile for completion of PROMIS scales

among adult informants was 31 min. Thus, at double that time, the 60 min cut-off was chosen to reduce bias while including informants who may take more time to complete surveys. Eight acceptability items were presented at the end of the survey (Supporting Information Appendix A). Informants rated their agreement with each item on a five-point Likert-type scale (1 = “Strongly disagree”; 5 = “Strongly agree”). Items addressed whether informants considered survey topics/items to be important, easy to answer, thought provoking, helpful for ongoing monitoring of functioning and QoL, and a good use of their time. One item on whether survey content was already readily available in other evaluations was reverse scored. The a priori criterion for acceptability was a median rating of four out of five for positively worded items.

Statistical Analysis

Participant characteristics and analyses include participants with complete data on the DQ and at least one PROMIS scale. The two order conditions were compared to identify potential order bias. Due to attrition, the sample size differs across PROMIS scales. Rather than completing analyses with only those who completed all PROMIS scales and introducing additional bias, we elected to use listwise deletion for analyses. Chi-squares and *t*-tests tested differences in characteristics hypothetically linked to QoL (informant income, education, participant age, adult gender, child grade-level performance) by recruitment source, order condition, and whether all PROMIS scales were completed (Completers) or not (Non-Completers). Descriptive statistics are presented for acceptability and feasibility items. Cronbach’s alpha was used to examine internal consistency within scales. We used two-tailed, one-sample *t*-tests to compare *T*-scores to 50, the normative sample mean.

Some adult participants reported identifying as transgender or gender diverse (e.g., nonbinary, agender; *n* = 15, 6.6%). Gender differences could be tested for cisgender men versus women (those for whom sex assigned at birth is congruent with gender identity), or for three groups (cisgender men, cisgender women, and transgender/gender non-conforming). We present the results in two ways, using independent samples *t*-tests for two groups, and analyses of variance for three groups. We adjusted *P*-values within each age group to account for the number of scales tested using the false discovery rate [Benjamini, Krieger, & Yekutieli, 2006], and considered adjusted *P*-values <0.05 statistically significant. Analyses were performed in SPSS version 24, with *P*-value adjustments calculated in R version 3.5.2.

Results

Participant Characteristics

5–13 years old, parent proxy. Participant and informant demographic information is provided in Table 1. There were no significant differences in parent income, education, child age, or child grade-level performance by recruitment source (CHOP vs. IAN) (*P*s > 0.162). For order condition, there was a difference in parent education (*P* = 0.001; other *P*s > 0.075) such that Order 2 had a higher proportion of participants with a Bachelor’s degree or higher (75.7%) than Order 1 (56.0%). Informants who completed the survey had older children on average than non-completers (*P* = 0.023; Completer *M* = 9.6 years, *SD* = 2.58; Non-Completer *M* = 8.4 years, *SD* = 2.53; other *P*s > 0.069).

14–17 years old, parent proxy and pediatric self-report. Participant and informant demographic information is provided in Table 1. There were no significant differences in parent income, education, or teen age by recruitment source (*P*s > 0.253). More teens functioning below grade level were recruited through IAN (*P* = 0.007). There were no significant demographic differences or differences in completion rates by order condition (*P*s > 0.539). Parents of teens functioning below grade level were less likely to complete the survey than others (*P* = 0.034; other *P*s > 0.205). There were no significant differences in demographic characteristics for parents of teens who completed self-report surveys versus those who did not (*P*s > 0.702). Teens who completed surveys were more likely to be in general education classes (*P* < 0.001) and to be performing at or above grade level (*P* < 0.001) than those who did not complete the survey.

18–65 years old, adult self-report. See Table 1 for participant demographic information. There were significant demographic differences by recruitment source. CHOP participants were younger on average (*P* < 0.001; CHOP *M* = 28.38, *SD* = 11.15; IAN *M* = 36.36, *SD* = 12.82), more likely to be in the lowest income category (*P* = 0.003) and more likely to identify as cisgender (vs. transgender) and male (*P* < 0.001) than IAN participants. For order condition, there was a significant difference in gender representation (*P* = 0.043; other *P*s > 0.341). Participants who completed the survey were older on average than non-completers (*P* = 0.020; Completer *M* = 27.83, *SD* = 8.44, Non-Completer *M* = 34.35, *SD* = 13.08). Transgender/gender non-conforming participants were less likely to complete the survey than cisgender participants (*P* = 0.049; other *P*s > 0.253).

Table 1. Demographic Information for Participants with Autism and Parent Informants

Variable	n (%)			
	5–13 years, parent proxy (n = 240)	14–17 years, parent proxy (n = 246)	14–17 years, self-report ^a (n = 141)	18–65 years, self-report (n = 227)
Participant demographics				
Age (mean [SD])	9.5 (2.60)	15.5 (1.33)	15.5 (1.11)	33.7 (12.83)
Sex/gender				
Cisgender female	56 (23.3)	68 (28.0)	37 (26.4)	105 (46.3)
Transgender/GNC	0 (0.0)	6 (2.5)	3 (2.1)	15 (6.6)
Race/ethnicity				
White	177 (73.8)	212 (86.2)	126 (89.4)	181 (79.7)
Black	18 (7.5)	11 (4.5)	6 (4.3)	8 (3.5)
Multiracial	19 (7.9)	10 (4.1)	3 (2.1)	21 (9.3)
Other	26 (10.8)	13 (5.2)	6 (4.3)	9 (4.0)
Hispanic	30 (12.5)	15 (6.1)	9 (6.4)	16 (7.0)
Mental health conditions and treatment ^b				
Any psychiatric diagnosis	105 (43.8)	129 (52.4)	76 (53.9)	149 (65.9)
ADHD	73 (30.4)	78 (31.7)	50 (35.5)	47 (20.8)
Depression or mood disorder	15 (6.3)	30 (12.2)	17 (12.0)	95 (42.0)
Anxiety disorder	46 (19.2)	77 (31.3)	47 (33.3)	111 (49.1)
Other psychiatric diagnosis	10 (4.2)	13 (5.3)	6 (4.3)	31 (13.7)
Prescribed psychiatric medication	91 (37.9)	136 (55.3)	74 (52.5)	120 (57.1)
Medical conditions and treatment ^b				
Genetic or other syndrome	14 (5.8)	20 (8.1)	9 (6.4)	18 (8.4)
Seizure disorder	17 (7.1)	17 (6.9)	4 (2.8)	12 (5.6)
Grade level performance				
Above	45 (18.8)	45 (18.3)	33 (23.4)	–
At	78 (32.5)	74 (30.1)	54 (38.3)	–
Below	117 (48.8)	127 (51.6)	54 (38.3)	–
School setting				
Public school	168 (70.0)	158 (64.2)	92 (65.2)	–
Private, charter, or online charter	34 (14.2)	46 (18.7)	29 (20.6)	–
Therapeutic	27 (11.3)	19 (7.7)	8 (5.7)	–
Homeschooled	11 (4.6)	19 (7.7)	8 (5.7)	–
Vocational program	–	4 (1.6)	4 (2.8)	–
Has an IEP	209 (87.1)	198 (80.5)	112 (79.4)	–
Has a 504 Plan	10 (4.2)	19 (7.7)	14 (9.9)	–
General education is primary classroom setting	127 (52.9)	134 (54.5)	92 (65.2)	–
Special education is primary classroom setting	113 (47.1)	112 (45.5)	49 (34.8)	–
Informant demographics				
Cisgender female	229 (95.4)	226 (91.9)	132 (93.6)	–
Race/ethnicity				
White	202 (84.2)	229 (93.1)	132 (93.6)	–
Black	22 (9.2)	9 (3.7)	5 (3.5)	–
Multiracial	8 (3.3)	6 (2.4)	3 (2.1)	–
Other	8 (3.3)	2 (0.8)	1 (0.7)	–
Hispanic	23 (9.6)	10 (4.1)	6 (4.3)	–
Education ^c				
High school or less	18 (7.5)	18 (7.3)	9 (1.4)	23 (18.5)
Some college	29 (12.1)	33 (13.4)	20 (14.2)	23 (18.5)
Associate's degree or vocational/ trade school graduate	36 (15.0)	28 (11.4)	25 (17.7)	18 (14.5)
Bachelor's degree	79 (32.9)	95 (38.6)	61 (43.3)	37 (29.8)
Graduate degree	78 (32.5)	20 (8.1)	35 (24.8)	23 (18.5)
Informant employment				
Fulltime	101 (42.1)	114 (46.3)	60 (42.6)	61 (26.9)
Part-time	66 (27.5)	46 (18.7)	26 (18.4)	43 (18.9)
Homemaker	61 (25.4)	60 (24.4)	38 (27.0)	7 (3.1)
Unemployed	4 (1.7)	5 (1.6)	3 (2.1)	31 (13.7)
On disability	4 (1.7)	17 (6.9)	13 (9.2)	45 (19.8)

(Continues)

Table 1. Continued

Variable	n (%)			
	5–13 years, parent proxy (n = 240)	14–17 years, parent proxy (n = 246)	14–17 years, self-report ^a (n = 141)	18–65 years, self-report (n = 227)
Retired	1 (0.4)	2 (0.8)	0 (0.0)	1 (0.4)
Full-time student	3 (1.3)	2 (0.8)	1 (0.7)	39 (17.2)
Married to participant's other parent	190 (79.2)	170 (69.1)	101 (71.6)	–
Household income ^d				
0–29,999	33 (13.8)	37 (15.0)	21 (14.9)	163 (71.8)
30,000–59,999	30 (12.5)	39 (15.9)	19 (13.5)	48 (21.1)
60,000–99,999	51 (21.3)	56 (22.8)	33 (23.4)	12 (5.3)
100,000–149,999	70 (29.2)	64 (26.0)	36 (25.5)	4 (1.8)
150,000+	56 (23.3)	50 (20.3)	32 (22.7)	n/a
Insurance status				
Medicare/Medicaid	37 (15.5)	34 (14.0)	21 (15.1)	74 (33.8)
Private	164 (68.9)	188 (77.4)	108 (77.7)	108 (49.3)
Medicare/Medicaid and private	20 (8.4)	13 (5.3)	8 (5.8)	22 (10.0)
None	11 (4.6)	5 (2.1)	0 (0.0)	9 (4.1)
Other	6 (2.5)	3 (1.2)	2 (1.4)	6 (2.7)
One or both parents have autism diagnosis	11 (4.6)	22 (8.9)	11 (7.8)	17 (7.5)
Participant's sibling(s) has/have autism diagnosis	51 (21.3)	45 (18.3)	25 (17.7)	27 (11.9)

GNC = Gender non-conforming; ADHD, attention-deficit/hyperactivity disorder.

^aDemographics based on parent report.

^bInformants could list multiple psychiatric or medical conditions.

^cEducational attainment item presented to a subset of participants in the 18–65 years, self-report age group (n = 124).

^dFor individuals 18–65 years, income reflects personal income. The maximum category of personal income was \$100,000+; 1.8% of individuals in this group reported income of \$100,000+.

Feasibility and Acceptability

Table 2 includes acceptability item ratings, completion rate, and time-to-completion for participants with complete survey data. Completion rates among those who completed the DQ and at least one PROMIS domain were high, ranging from 87.9–97.9%. Mean time-to-completion across

groups ranged from 19 to 23 min. Most informants rated PROMIS items as acceptable (e.g., useful, important, and thought-provoking), and covering areas of life they were already thinking about (median ratings = 3). The exception was that 14–17-year-old self-informants rated the content as both new and useful, capturing areas of life about which they had not previously considered. Additionally, while

Table 2. Median Feasibility and Acceptability Scores for PROMIS Autism Battery

	Median			
	5–13 years, parent proxy	14–17 years, parent proxy	14–17 years, self-report	18–65 years, self-report
Topics were important	4	4	4	4
Questions were easy to answer	4	4	4	4
Covered content that I had not thought about before	3	3	4	3
Helpful for tracking my/my child's QoL	4	4	3	4
Would change something about my/my child's treatment based on results	4	4	3	3
Survey was a good use of my time	4	4	3	4
Would recommend to others	4	4	4	4
Information about these topics is already available through other evaluations	3	3	3	3
Retention rate ^a	87.9%	89.9%	97.9%	89.9%
Time to completion in minutes <i>M</i> (<i>SD</i>), range ^b	19 (9), 7–55	21 (9), 7–60	23 (11), 6–54	20 (10), 5–56

Note. Items rated on five-point, Likert-type scale (1 = “Strongly disagree”; 5 = “Strongly Agree”).

^aPercentage retained of those who completed at least one PROMIS measure.

^bOutliers over 60 min not included in time to complete analyses.

parent informants generally indicated that content on the survey would influence treatment planning for their youth (median ratings = 4), teens and adults rated this item below the a priori threshold (median ratings = 3), with some adults later stating that they had no treatment plan.

Comparison to Population Norms

Figure 2 contains a visualization of lifespan data compared to the normative mean of 50. Tables 3–6 contain reliability

statistics, average *T*-scores, effect sizes, and significance for *t*-tests. Nearly all PROMIS scales demonstrated acceptable internal consistency reliability (5–13-year-old parent proxy, $\alpha = 0.778$ –0.953; 14–17-year-old parent proxy, $\alpha = 0.786$ –0.960; 14–17-year-old self-report, $\alpha = 0.771$ –0.964) [Terwee et al., 2007]. Adult PROMIS scale reliabilities were in the acceptable range (0.744–0.967), except for Global Physical Health (0.601). On average, compared to the population norms, children with autism (5–13 years) had scores that indicated significantly less desirable outcomes across all scales. Per parent proxy,

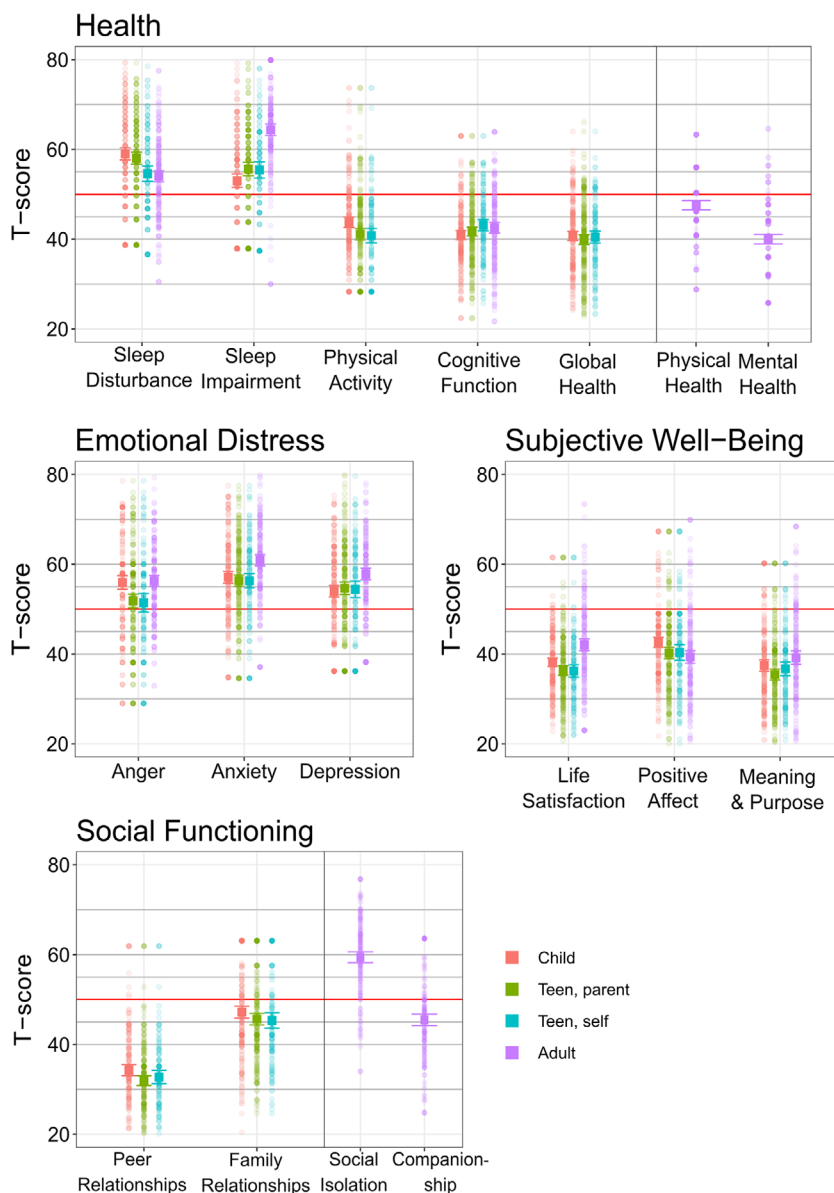


Figure 2. Comparison of mean *T*-scores for children 5–13 years (parent proxy), teen 14–17 years (parent proxy, self-report), and adult 18–65 years (self-report) to the norms of the PROMIS pediatric and adult calibration samples (default sample for each scale). Higher PROMIS scores indicate a greater presence of the measured construct. For PROMIS *T*-scores ($M = 50$, $SD = 10$), 0.5–1.0 *SD* from the mean indicates mild differences, 1.0–2.0 *SD* moderate, and >2.0 extreme. Upper and lower bars indicate standard error.

Table 3. T-Score Comparison: 5–13 years, Parent Report (*n* = 240) Versus Normative Sample (*M* = 50) and by Gender

Scale domain	<i>n</i>	Version	Cronbach's alpha	T-scores <i>M</i> (<i>SD</i>)	Norm comparison, Cohen's <i>d</i>	Gender comparison, Cohen's <i>d</i>
Subjective well-being						
Life satisfaction	223	V1, 8a	0.937	38.1 (7.6)	−1.57***	0.08
Positive affect	222	V1, 8a	0.933	42.6 (8.9)	−0.83***	0.17
Meaning and purpose	215	V1, 8a	0.925	37.5 (10.1)	−1.24***	0.19
Relationships						
Family relationships	211	V1, 8a	0.926	47.2 (10.6)	−0.27***	0.04
Peer relationships	211	V2, 7a	0.953	34.3 (9.6)	−1.64***	0.35
Emotional distress						
Depressive symptoms	222	V2, 8a	0.919	54.0 (10.1)	0.39***	0.03
Anger	204	V2	0.924	55.9 (12.0)	0.50***	0.02
Anxiety	215	V2, 8a	0.929	57.1 (10.5)	0.68***	0.07
Psychological stress experiences	214	V1, 8a	0.922	62.7 (9.6)	1.30***	0.05
Health						
Sleep disturbance	222	V1, 8a	0.917	59.0 (10.7)	0.87***	0.22
Sleep impairment	214	V1, 8a	0.951	53.0 (11.8)	0.27***	0.16
Physical activity	214	V1, 8a	0.915	43.8 (9.1)	−0.68***	0.10
Cognitive function	219	V1, 7a	0.857	40.9 (8.2)	−1.11***	0.11
Global health	240	V1 7 + 2	0.778	40.7 (7.9)	−1.17***	0.003

Note. Subscale *n* ranges from 204 to 240. Higher PROMIS scores indicate greater presence of the measured construct. For PROMIS T-scores (*M* = 50, *SD* = 10), 0.5–1.0 *SD* from the mean indicates mild symptoms/impairment, 1.0–2.0 *SD* moderate, and >2.0 severe. Cohen's *d* effect size 0.02 = small, 0.05 = medium, and 0.08 = large. Asterisks indicate false discovery rate adjusted *P*-values. Version indicates PROMIS version, number of items, and letter designation for scales with multiple forms.

P* < 0.05; *P* < 0.01; ****P* < 0.001.

Table 4. T-Score Comparison: 14–17 Years, Parent Report (*n* = 246) Versus Normative Sample (*M* = 50) and by Gender

Scale domain	<i>n</i>	Version	Cronbach's alpha	T-scores <i>M</i> (<i>SD</i>)	Norm comparison, Cohen's <i>d</i>	Gender comparison, Cohen's <i>d</i>
Subjective well-being						
Life satisfaction	230	V1, 8a	0.949	36.3 (8.6)	−1.47***	0.31
Positive affect	235	V1, 8a	0.942	40.2 (10.2)	−0.97***	0.30
Meaning and purpose	230	V1, 8a	0.936	35.4 (9.9)	−1.46***	0.09
Relationships						
Family relationships	223	V1, 8a	0.916	45.6 (10.3)	−0.43***	0.21
Peer relationships	226	V2, 7a	0.932	31.9 (8.7)	−1.92***	0.21
Emotional distress						
Depressive symptoms	233	V2, 8a	0.928	54.7 (11.0)	0.44***	0.31
Anger	221	V2	0.921	51.8 (12.1)	0.17*	0.19
Anxiety	231	V2, 8a	0.921	56.4 (10.1)	0.63***	0.52***
Psychological stress experiences	229	V1, 8a	0.934	63.1 (10.0)	1.31***	0.40*
Health						
Sleep disturbance	234	V1, 8a	0.937	58.0 (10.9)	0.77***	0.37*
Sleep impairment	224	V1, 8a	0.960	55.6 (12.0)	0.51***	0.48*
Physical activity	228	V1, 8a	0.949	41.1 (10.1)	−0.88***	0.05
Cognitive function	233	V1, 7a	0.866	41.7 (7.9)	−0.92***	0.25
Global health	246	V1 7 + 2	0.786	39.9 (8.7)	−1.08***	0.23

Note. Subscale *n* ranges from 226 to 246. Higher PROMIS scores indicate greater presence of the measured construct. For PROMIS T-scores (*M* = 50, *SD* = 10), 0.5–1.0 *SD* from the mean indicates mild symptoms/impairment, 1.0–2.0 *SD* moderate, and >2.0 severe. Cohen's *d* effect size 0.02 = small, 0.05 = medium, and 0.08 = large. Asterisks indicate false discovery rate adjusted *P*-values. Version indicates PROMIS version, number of items, and letter designation for scales with multiple forms.

P* < 0.05; *P* < 0.01; ****P* < 0.005.

Table 5. T-Score Comparison: 14–17 Years, Self-Report ($n = 141$) Versus Normative Sample ($M = 50$) and by Gender

Scale domain	n	Version	Cronbach's alpha	T-scores M (SD)	Norm comparison, Cohen's d	Gender comparison, Cohen's d
Subjective well-being						
Life satisfaction	141	V1, 8a	0.964	43.6 (10.2)	−0.63***	0.34
Positive affect	141	V1, 8a	0.933	45.6 (8.9)	−0.46***	0.21
Meaning and purpose	141	V1, 8a	0.941	41.7 (10.1)	−0.83***	0.08
Relationships						
Family relationships	141	V1, 8a	0.936	50.7 (9.7)	0.07	0.11
Peer relationships	141	V2, 8a	0.923	46.2 (5.8)	−0.46***	0.10
Emotional distress						
Depressive symptoms	141	V2, 8a	0.951	53.4 (11.4)	0.32**	0.27
Anger	140	V2	0.888	51.1 (11.1)	0.11	0.24
Anxiety	141	V2, 8a	0.927	53.1 (10.9)	0.29**	0.42
Psychological stress experiences	141	V1, 8a	0.946	59.1 (9.7)	0.92***	0.36
Health						
Sleep disturbance	139	V1, 8a	0.924	54.6 (10.4)	0.45***	0.29
Sleep impairment	136	V1, 8a	0.953	55.4 (11.0)	0.52***	0.20
Physical activity	141	V1, 8a	0.933	42.7 (8.6)	−0.78***	0.02
Cognitive function	141	V1, 7a	0.811	44.7 (6.1)	−0.64***	0.41
Global health	141	V1 7 + 2	0.771	33.1 (7.5)	−1.91***	0.21

Note. Subscale n ranges from 136 to 141. Higher PROMIS scores indicate greater presence of the measured construct. For PROMIS T-scores ($M = 50$, $SD = 10$), 0.5–1.0 SD from the mean indicates mild symptoms/impairment, 1.0–2.0 SD moderate, and >2.0 severe. Cohen's d effect size 0.02 = small, 0.05 = medium, and 0.08 = large. Asterisks indicate false discovery rate adjusted P -values. Version indicates PROMIS version, number of items, and letter designation for scales with multiple forms.

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

Table 6. T-Score Comparison: 18–65 Years, Self-Report ($n = 227$) Versus Normative Sample ($M = 50$) and by Gender

Scale domain	n	Version	Cronbach's alpha	T-scores M (SD)	Norm comparison, Cohen's d	Gender comparison, Cohen's d
Subjective well-being						
General life satisfaction	211	V1, 5a	0.897	42.1 (10.1)	0.79***	0.17
Positive affect	212	V1, 15a	0.952	39.3 (10.6)	1.04***	0.22
Meaning and purpose	217	V1, 8a	0.937	39.2 (11.5)	1.00***	0.33
Relationships						
Companionship	207	V2, 6a	0.923	45.5 (9.8)	0.45***	0.07
Social isolation	212	V2, 8a	0.935	59.4 (9.3)	0.97***	0.37*
Emotional support	216	V2, 8a	0.964	48.1 (9.1)	0.20**	0.14
Informational support	216	V2, 8a	0.957	50.3 (10.5)	0.03	0.22
Instrumental support	210	V2, 8a	0.967	49.9 (10.9)	0.01	0.29
Emotional distress						
Depression	210	V1, 8a	0.945	57.8 (9.7)	0.79***	0.18
Anger	218	V1.1, 5a	0.877	56.3 (9.2)	0.66***	0.17
Anxiety	214	V1, 8a	0.940	60.9 (9.5)	1.11***	0.29
Health						
Sleep disturbance	212	V1, 8a	0.910	54.0 (9.6)	0.41***	0.47*
Sleep impairment	216	V1, 8a	0.914	64.4 (9.9)	1.44***	0.21
Cognitive function	211	V2, 8a	0.902	42.6 (9.2)	0.78***	0.36*
Global mental health	227	V1.2, 2a	0.601	40.0 (8.2)	1.09***	0.31
Global physical health	227	V1.2, 4a	0.744	47.6 (7.9)	0.27***	0.36*
Adulthood						
General self-efficacy	215	V1, 4a	0.939	40.1 (10.1)	0.98***	0.43*
Satisfaction with social roles	217	V2, 8a	0.920	44.2 (8.1)	0.63***	0.33

Note. Subscale n ranges from 207 to 227. Higher PROMIS scores indicate greater presence of the measured construct. For PROMIS T-scores ($M = 50$, $SD = 10$), 0.5–1.0 SD from the mean indicates mild symptoms/impairment, 1.0–2.0 SD moderate, and >2.0 severe. Cohen's d effect size 0.02 = small, 0.05 = medium, and 0.08 = large. Asterisks indicate false discovery rate adjusted P -values. Version indicates PROMIS version, number of items, and letter designation for scales with multiple forms.

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

teens with autism (14–17 years) also had scores that indicated significantly less desirable outcomes across all scales. Teen self-report scores also indicated significantly less desirable outcomes across most scales, with the exception of Family Relationships (corrected $P = 0.406$) and Anger (corrected $P = 0.261$). Finally, on average, adults with autism had scores that indicated significantly less desirable outcomes across most scales, except for Informational Social Support (corrected $P = 0.692$) and Instrumental Social Support (corrected $P = 0.928$).

Gender Differences

Tables 3–6 contain significance tests and effect sizes for gender differences. For 5–13-year-old children, there were no significant differences between boys and girls with autism in any domain (corrected P s > 0.476). In contrast, parents reported that on average 14–17-year-old girls had less desirable outcomes for Anxiety (corrected $P < 0.005$), Stress (corrected $P = 0.031$), Sleep Disturbance (corrected $P = 0.031$), and Sleep Impairment (corrected $P = 0.014$) than boys in this age range. However, male and female 14–17-year-old self-report indicated no significant gender differences (corrected P s > 0.142). For 18–65-year-old participants, when gender was considered as a binary (cisgender men vs. cisgender women), women reported less desirable outcomes for Social Isolation (corrected $P = 0.040$), Sleep Disturbance (corrected $P = 0.018$), Cognitive Function (corrected $P = 0.043$), Self-Efficacy (corrected $P = 0.027$), and Global Physical Health (corrected $P = 0.041$). When cisgender men and women were compared to participants identifying as transgender/gender non-conforming, there were no significant gender differences (all corrected P s > 0.072), although power to detect effects was limited by the small sample size.

Discussion

The purpose of this study was to curate and test a PROMIS battery that can provide a comprehensive portrait of QoL for children, adolescents, and adults with autism, compared with the general population. This study also examined gender differences in QoL, including specifically exploring the experiences of women and girls versus men and boys during different developmental stages. We studied a large American sample that was representative of the broader autistic population in terms of functioning, comorbidity, socioeconomic status, and several other metrics. Consistent with previous research [Ayres et al., 2018; van Heijst & Geurts, 2015], our findings indicate that, on average, participants' QoL fell below general population norms across multiple PRO domains, including mental and physical health, emotional distress, social relationships, and subjective well-

being, with medium to large effect sizes. Still, as depicted in Figure 2, there was meaningful variability across individuals in how much QoL deviates from population norms, with many participants reporting average or above-average QoL. An accurate QoL measure with potential for longitudinal monitoring will elucidate factors associated with good QoL in autism, while also raising awareness of the challenges that people with autism face so that researchers, clinicians, and families can find ways to improve QoL.

Feasibility and Acceptability of Lifespan PROMIS Autism Battery

The PAB-L met most criteria for feasibility and acceptability, indicating that it is a useful and appropriate tool for investigating QoL across the lifespan. Participants rated items as important and easy to answer and were able to complete the PAB-L relatively quickly. Those using the PAB-L in the future may improve feasibility by choosing scales most directly relevant to their questions of interest and by using four-item rather than eight-item SFs, which have similar reliability and precision (guidelines for choosing short forms are available in PROMIS scoring manuals on the website). Parents of younger children and of teens functioning below grade level were less likely to complete the survey. Informal feedback indicated that some found it difficult to answer questions about their child's specific thoughts or emotions (e.g., "my child felt like something awful might happen"). Additionally, PROMIS self-report measures are not accessible for those who cannot read, comprehend, and respond to written questions. The use of accommodations (e.g., interview format, definitions) may improve accessibility, and the continued development of proxy measures focused on a wide range of observable experiences and abilities is encouraged.

Utility of Lifespan Approach for PROs and QoL

We found statistically significant differences between the QoL of the average person with autism in our sample compared to the population norm, regardless of age and gender. Effect sizes can be proxies for considering the clinical significance of results across QoL domains and age groups. For children and teens rated by their caregivers, the largest effect was in the domain of peer relationships, followed by (in both groups) life satisfaction, meaning and purpose, and psychological stress. In contrast, the largest effect for teen self-informants was in global health, followed by psychological stress and meaning and purpose. For adults, the largest effect was in sleep impairment, followed by anxiety, global mental health, positive affect, and meaning and purpose. Across the

lifespan, the domains with greatest effect sizes showed some similarities (e.g., subjective well-being, stress, or mental health) and some differences. These results suggest that cross-sectional or longitudinal studies of QoL using lifespan measurement tools like the PAB-L may identify stability and change in predictors of QoL across the life course. Identifying how specific domains affect QoL (singularly or in combination) could be helpful for treatment monitoring or research on developmental trajectories. Importantly, further analysis on item and scale functioning in different populations is needed.

Gender Differences in QoL and Functioning

Consistent with general population literature [Bisegger et al., 2005; Michel et al., 2009; Orfila et al., 2006], cisgender women and girls with autism reported poorer QoL than men and boys in some domains, and the association between gender and QoL became more pronounced with age. Consistent with previous research with autistic adults using the WHOQOL-BREF, women reported poorer physical health than men [Mason et al., 2018]. In the present study, women reported more social isolation, while previous research has found that men have poorer social functioning. This discrepancy may be due to differences in constructs measured; WHOQOL-BREF social questions cover satisfaction with “personal relationships,” sex life. In this study, the observed QoL differences by age among women with autism may be due to factors purported to affect women’s QoL in the general population: women experience higher prevalence of mental health conditions [Linzer et al., 1996] and chronic conditions or disabilities [Orfila et al., 2006], income disparities [Cherepanov, Palta, Fryback, & Robert, 2010], and are more likely to be widowed or divorced than men [Liu & Umberson, 2008]. Autism may also affect QoL differently for men and women. Women with autism are underdiagnosed and diagnosed later compared to men, and therefore may have less access to services, accommodations, and opportunities to develop a positive autistic identity [Kanfiszer, Davies, & Collins, 2017]. Some research suggests that women spend more energy than men in “camouflaging” or concealing their social difficulties [Lai et al., 2016], a practice linked to stress and anxiety [Cage & Troxell-Whitman, 2019]. Future research should explore whether any of these factors may be driving gender QoL differences in autism.

Future research might also target gender differences across the full gender spectrum. Individuals with autism report a relatively high prevalence of gender diversity [Glidden, Bouman, Jones, & Arcelus, 2016]. Those with “gender-dysphoric traits” have reported more symptoms of depression, anxiety, and stress [George & Stokes, 2018], suggesting that transgender/gender diverse autistic

people may be a population with different mental health needs. Qualitative studies may be helpful for understanding unique QoL challenges these minorities experience.

Limitations

First, this sample was not population-based and may not generalize to people with autism who do not take part in research studies (see Supporting Information Appendix B). In terms of recruitment sources, the greater proportion of IAN-recruited teens performing below grade level occurred because recruitment of youth who could not complete self-report surveys and IAN recruitment both occurred later in the recruitment period. Adults recruited through CHOP (vs. IAN) were younger, had lower incomes, and more likely to identify as cisgender and male. IAN self-reporting adult samples tend to have higher rates of employment, marriage, independent living, and gender diversity than are typically seen in autism outcome studies [Gotham et al., 2015]. Compared to previous reports, participants had lower rates of co-occurring psychiatric conditions [Croen et al., 2015; Simonoff et al., 2008] except for seizure disorders [Thomas, Hovinga, Rai, & Lee, 2017]. Compared to the U.S. population, fewer participants were members of groups with health disparities such as racial/ethnic minorities and uninsured persons [Berchick, Hood, & Barnett, 2018; Census Bureau, 2018] Supporting Information Appendix B). Together, this suggests that the study may represent higher QoL and functioning compared to the population of youth and adults with autism in the United States.

Participant attrition is also an important consideration in interpreting results. Parents of younger children and teens performing below grade level were more likely to drop out of this study than other groups, suggesting that the results may best represent QoL for more developmentally advanced youth with autism. However, an estimated 56% of youth with autism have IQ < 85 [Baio, 2014], and around 50% of youth in this sample performed below grade level and/or had a primary special education placement. Although they differed on few other measured variables, it is possible that non-completers may have differed from completers in systematic ways (e.g., ability to concentrate, read, and comprehend items; a higher degree of work or family obligations).

This study measured gender using a single question, whereas some recommend at least two questions to fully capture gender identity [The GenIUSS Group, 2014]. Only parent informants reported youth gender identity and it is possible that some youth may have been misclassified as cisgender by parents. Furthermore, transgender adults were less likely to complete all PROMIS scales than were cisgender adults. Techniques such as

cognitive interviewing can increase the retention of diverse participants.

Additionally, this study was cross-sectional and differences by age may reflect complex cohort effects (e.g., access to diagnosis, services, community). Children were not asked to complete self-report. However, given the high proportion of completers among the teen sample, children's self-report about their own QoL is indicated for the PAB-L. Qualitative research may illustrate the discrepancies between self and proxy reports.

Further research is necessary to determine the reliability and validity of PROMIS for autistic populations. Test-retest reliability, convergent validity with other QoL measures normed with autistic youth and adults, and item response analyses would add to confidence in using these tools. Furthermore, this project would have benefited from including autistic people at all stages of design and in choosing the scales most relevant for autistic people, and we encourage additions to this core battery in the future. Specifically, questions or measures pertaining to constructs that autistic adults have identified as important for understanding the experiences of autistic people (e.g., positive autistic identity, lack of understanding of autism in society, and sensory issues; McConachie et al., 2019) may be important for understanding QoL for individuals with autism of all ages.

Conclusions

This study demonstrated that the PAB-L is a feasible and acceptable method for assessing QoL across the lifespan in autism. Although more attention to psychometric properties, diversity, and issues of self- versus proxy-report in QoL are warranted [Sheldrick, Neger, Shipman, & Perrin, 2012; Stokes, Kornienko, Scheeren, Koot, & Begeer, 2017], the current findings place PROMIS among a variety of measures available for investigating QoL in autism. The PAB-L encompasses QoL broadly, including domains such as physical and mental health, relationships, and subjective well-being, supporting more nuanced research into how pharmacological, behavioral, educational, and recreational interventions affect the lives of people with autism across the life course. Future population-based research is critical for understanding and supporting QoL for autistic people, including those who are underrepresented in research.

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Conflict of Interest

The authors each declare that they have no conflicts of interest.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix A Supporting information

Appendix B Supporting information