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Trends and Normative Data for a Sample of Adults with Autism and Related Developmental Disabilities on the Stress Survey Schedule (SSS)

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Abstract

Objectives The purpose of this research was to expand upon the available normative data on the Stress Survey Schedule (SSS) for a group of adults with intellectual disabilities and autism spectrum disorder (ASD). This scale was originally designed in 2001 to measure stress in persons with ASD. Normative data were previously collected for a group of children and adolescents, and a secondary aim of this study was to compare the present adult data set to the historical child/adolescent data set.

Methods This was a retrospective observational study that utilized SSS collected between 2021 and 2023. Survey response data were collected on 89 adults with intellectual disability and ASD, ages 22 to 66. Normative data were generated and explored and then compared to the historic child/adolescent sample.

Results The average "Ritual-related" subscale score was significantly higher and the "Pleasant Events" subscale score was significantly lower compared to all other average subscale scores in the overall adult group. There were very few differences in the average subscale, average total, or raw total scores by age group or autism diagnosis status. Survey items frequently scored as high or low stress were consistent with these results. In comparing younger and older participant data, significant differences were found in average subscale scores in a number of areas, mainly with higher scores for the adult sample.

Conclusions For adults, high stress often stems from events related to ritualized behavior, and events that are pleasant are typically endorsed as low stress for both adult and child samples. Stress levels appear to peak in early adulthood and then slowly diminish. There are significant differences between the child and adult samples, but social and environmental changes since the SSS was created in 2001 suggest the need for separate and revised versions of the survey.

Keywords Stress Survey Schedule · Autism · Stress · Measurement · Intellectual disability · Adults

In the early 1970s, Selye, (1974) described stress as a physiological reaction such as increased heart rate or increased blood pressure to a variety of happy or unhappy life events. The stress demand on the organism was suggested to disturb homeostasis, and then typically, there is an effort to regain equilibrium. Enduring or intense stress demands on the organism with typical coping resources were suggested to potentially cause physical or psychological damage. In the 1990s, Groden et al., (1994) further discussed the concept of stress and its close relation to anxiety. Using Selye's original definition of stress, these researchers suggested that the state of anxiety was an indication that the organism was experiencing stress and could be made evident through verbal report or behavior. More recently, other researchers have defined stress in similar ways, related to their various areas of interest. Cohen et al., (2007) for example focused on medical effects and defined stress as the occurrence of environmental events that tax a person's ability to cope, potentially influencing physical health. These researchers suggested that maladaptive coping strategies (e.g., smoking, decreased exercise) and endocrine responses provided key pathways to disease risk. In their chapter on stress related to work, Dewe et al., (2012) focused on the transactional nature of stress, suggesting that stress comes from the appraisal that environmental demands are likely to tax one's individual resources and threaten one's well-being. While these definitions differ to a degree, they all contain a reference to one's psychological resources or ability to cope, as well as

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various environmental demands or events. Stress will result if resources are insufficient to effectively cope with demands whether the resources are too limited or somehow impaired, or the demands are in excess of what even typical resources could handle. The resulting effects of stress can be detrimental psychologically, physically, and behaviorally and can be relatively short-lived or life-long in duration.

Examples of psychological resources that are too limited or somehow impaired abound. A person may have lived a sheltered life, experienced trauma, have low self-esteem, or suffer from depression, which may all negatively affect their ability to cope effectively with positive or negative events or demands. Similarly, the person with autism spectrum disorder (ASD) may have impaired coping resources, because the disorder is marked by elements essential to effective functioning in a social world: impaired social interactions and the ability to communicate using both verbal and non-verbal means. The person with ASD also is apt to demonstrate repetitive, restricted, or stereotyped behaviors, although there is a wide range of both these behaviors and social, affective, cognitive, and behavioral presentations. But these facets of the disorder have been suggested to manifest as problematic in a number of ways. Groden et al., (1994) suggested that these core diagnostic features of ASD and related issues were likely to have negative effects on a person's ability to cope with even what one might consider typical daily events or stressors. Consider how persons with ASD engage with the world with an established difficulty interpreting the emotions and thinking of others, a heightened set of sensory sensitivities, a preference for solitary activities, and/or difficulty being flexible and tolerating any sort of change. These aspects of functioning for the person with ASD put them at an immediate disadvantage, and when the inevitable interactions with the world take place, the typical buffers available to the non-ASD person are also impaired or absent. These might include an ability to effectively communicate wants, needs, and emotions, access to a circle of friends that one can confide in and depend upon, or even engagement in normal social interactions and activities. These facets of functioning that a person with ASD is likely to experience can severely impact the process of coping that is brought to bear on the most typical environmental demands people experience day after day and can be made even more challenging by an intellectual disability. This can result in repeated experiences of high stress and resulting anxiety that may lead to further rejection, social isolation, and an overall sense of failure.

As environmental events and demands are so idiosyncratic and impactful for the person with ASD, it is essential that there be a way to objectively evaluate the level of stress experienced by persons with ASD. To this end, Groden et al., (2001) developed the Stress Survey Schedule (SSS) to better identify stressors so that interventions could be created to improve coping and reduce anxiety and related behavioral challenges. The SSS was designed to measure stressors in a wide range of presentations of persons with ASD, including persons with very limited cognitive capacity who are often omitted from research and the development of intervention strategies. With a better understanding of what stressors were activated in each person, staff supporting a wide range of clients would be better able to target interventions that maximized coping. It is noted that the stressors selected for the SSS sometimes overlapped with those experienced by typically developing persons and sometimes did not, demonstrating the unique and complex relationship between persons with ASD and typically developing persons. The SSS is composed of 49 items and eight subscales which include "Anticipation or Uncertainty," "Changes and Threats," "Unpleasant Events," "Pleasant Events," "Sensory or Personal Contact," "Food-related Activities," "Social/Environmental Interactions," and "Ritual-related." Goodwin et al., (2007) established the validity of the scale, high internal consistency and absence of differences for males and females, and certain differences between age groups. The youngest group of participants indicated lower stress on "Anticipation or Uncertainty" and "Sensory or Personal Contact" compared to older age groups, and the 21 to 30 age group showed lower stress on "Food-related Activities" as compared to the 31 to 40 age group. The relative consistency in age groups up to age 20 and then differences emerging in the 21 to 30 and 31 to 40 age groups was attributed to decreasing levels of available support, routine, and structure as the person aged.

Further research by Woodard et al., (2020) compared the responses of students diagnosed with ASD and intellectual disability to a group of typically developing students and found divergent validity for the scale, as well as confirmed high internal consistency and the absence of differences between males and females in either group. The "Ritual" subscale was the only subscale found to increase with age, and this change was observed when the oldest group assessed (ages 18–21) was compared to the two younger age groups. Woodard et al., (2023) developed normative data for a sample of students ages 6 to 19 with various forms of developmental disabilities. Consistent with previous work by Goodwin et al., (2007) and Woodard et al., (2020), these researchers found general consistency among SSS overall and subscale score among participants under the age of 19. However, selected items frequently rated as low and high stress tended to change for the oldest participants in this study, again suggesting that differences in what is stressful may begin to change for the person with ASD when he or she begins young adulthood.

In the present study, we expand upon the work done by Woodard et al., 2023 and examine an older sample of participants with intellectual disabilities and ASD. The primary aim of this study is to identify the overall and sub-group

stress levels for this adult group and to provide normative data on a population for which there is limited research to create a framework of comparison for SSS scores. Comparisons of stress scores by gender and age, as well as information on commonly high and low-scoring stressors for each age group, will be presented to better understand how stressors change as a person moves through adulthood. A secondary aim of this research is to compare the results for this adult sample with the information previously collected on a group of children participants. This will allow us to compare childhood stress levels and stressors to those reported in adulthood and suggest future research directions for the SSS and the more general topic of stress for persons with autism and intellectual disabilities.

Method

Participants

The sample for the adult normative study was composed of 89 adults who live in two residential facilities located in Rhode Island and Southern Massachusetts. The Groden Center, in addition to providing a continuum of services for children with developmental disabilities and autism in Rhode Island, operates services for adults in Rhode Island and Massachusetts. Clients supported by Groden programs typically have significant behavioral challenges and comorbid diagnoses that cannot be safely managed in less restrictive settings. The organization's focus is on positive psychology principles and the development of effective self-control and coping skills, while maintaining a behavioral psychology orientation. The adults in this study all had a diagnosis of a severe to profound intellectual disability, and additionally, 36 (41.6%) adults also had an autism diagnosis. Adults in the present study were not excluded because of comorbid psychiatric diagnoses, medication use, or active seizure disorder. Table 1 shows the demographic characteristics of this sample. Most were male (87.6%) and lived in a residential group home setting (81.3%). The average age was 44.3 years, with a range of ages of 22 to 66 years. The majority of these adults had some verbal ability ($n = 58$, 65.2%).

The comparative portion of this study examined differences between the present adult sample and the previously collected and analyzed child/adolescent sample (N=155) (Woodard et al., 2023).

Procedures

Staff members familiar with the adults surveyed completed the SSS and provided ratings on their perception of the intensity of the stress response of that person to each of the events listed. These surveys were completed between 2021 and 2023, rated in paper form, and then entered into each person's electronic record. The responses by the rater were used to indicate potential areas for focused behavioral interventions. The SSS was completed as part of a regular/annual assessment process, where the data are used to inform goal development and treatment strategies. All data were de-identified for the purposes of this study.

Table 1 Demographic characteristics of participants

Characteristic, n (%)	N =89
Male	78 (87.6)
Age mean (SD; range)	44.3 (11.2; 22–66)
*Any diagnosis of Autism	37 (41.6)
Residency	
Home with family	8 (10.7)
Independent	1 1.3)
Group home	61 (81.3)
Other	5 (6.7)
Verbal	58 (65.2)

*All participants had a diagnosis of intellectual disability

Measures

The Stress Survey Schedule (SSS) is a 49-item measure of events and experiences that may be associated with stress. Prior recent research by this author's team has detailed the scoring of this measure (Woodard et al., 2023). Items are scored on a five-point Likert-type scale with 1 indicating the individual exposed to the event typically experiences "None to mild" stress and 5 indicating "Severe" stress. Scoring of items are grouped within the 8 subscales: "Anticipation or Uncertainty" (7 items), "Changes and Threats" (11 items), "Unpleasant Events" (9 items), "Pleasant Events" (8 items), "Sensory or Personal Contact" (4 items), "Food-related Activity" (3 items), "Social/Environmental Interactions" (3 items), "Ritual-related" (4 items). Items within each sub-scale are summed and averaged to produce subscale scores between 1 and 5. A total raw stress score was also calculated by summing stress scores, and a total average stress score was calculated from the average across subscales, again fixing an average overall SSS score on a 1 to 5 scale (maximum = 5). The development and validation of the SSS have previously been reported (Goodwin et al., 2007; Woodard et al., 2020). Measures of inter-item consistency and scale reliability were found to be in the acceptable to excellent ranges (Deng & Chan, 2017; Tavakol & Dennick, 2011) using Cronbach's α (Cronbach's $\alpha = 0.69$ to 0.90.0) and McDonald's ω (McDonald's $\omega = 0.68$ to 0.89) for all subscale items except "Social/Environmental Interactions" subscale ($\alpha = 0.48$, $\omega = 0.62$). The SSS allows for the additional collection of limited demographic data including

age at administration, gender, the relationship to the person completing the ratings to the person being rated, primary diagnosis, and living situation.

Data Analyses

Data were analyzed using SAS (version 9.4, Cary, NC). Descriptive analyses were reported as frequencies with 95% confidence intervals (CI) or means with standard deviation (SD) of 95% CI. There were three score types used in these analyses: subscale scores (range 1–5), total average stress score (1–5), and a total raw stress score summing across 49 items (maximum score = 245).

To address the primary research questions on the effect of age and autism diagnosis (none vs. present) on stress scores, the adults' ages were classified into 3 groups based on the available age distribution and developmental stage: young adults 22–35 (n = 25), mid-age 36–50 (n = 35), and older adults ≥ 51 (n = 29). Mean scores with 95% CI for the overall adult sample and by age group and autism diagnosis were calculated for each of the 3 score types (subscales, average total score, raw total score). Additionally, floor and ceiling scores were calculated for each sub-scale and the total average score using the cut-off suggested in prior research (1–2, floor or low stress; 4–5, ceiling or severe stress). For the total raw score where the maximum score = 254, the floor and ceiling values were calculated (98, upper bounds of low stress; >147, lower bounds of severe stress). The percentage (with 95% CI) of individuals by age groups and autism diagnosis in the floor and ceiling categories is reported for each SSS score type. A generalized linear model was used to determine if there were statistically significant differences in the average total and total raw scores by age group or autism diagnosis. To examine differences in the probability of inclusion in the floor or ceiling groups across the scores, a series of Fisher's exact chi-square tests (χ^2) was conducted with the frequency of being classified as ceiling stress levels versus floor as the outcome variables, and age-group and autism diagnosis as predictor variables. Additionally, an item analysis was conducted to determine the five items with the greatest frequency of floor and ceiling scores by age group and autism diagnosis.

We compared the mean (with 95% CI) SSS subscale scores, average stress scores, and total raw scores between the adults in this analytical sample with historical data for children (N = 155) from our prior study (Woodard et al., 2023). This historical sample was originally divided into three age groups representing elementary school (6–10 years), middle school (11–13 years), and high school (≥ 14 years) children. All the participants in the historical child/adolescent sample had a diagnosis of severe to profound intellectual disability, and some also had a diagnosis of ASD.

Results

SSS Scores for Adult Normative Sample

Table 2 shows the overall group mean scores for the eight subscales. The average reported stress score was significantly higher for "Ritual-related" (mean = 3.0, 95% CI: 2.7, 3.2), compared to all other subscale scores. The average "Pleasant Events" (mean = 1.7, 95% CI = 1.6, 1.8) subscale score was significantly lower than all other subscale scores. The overall group average total stress score was 2.3 (95% CI: 2.2, 2.5), and the total raw stress score was 114.0 (95% CI: 107.1, 120.8).

Table 3 shows the mean subscale, average total and raw total scores, standard deviation (SD) and confidence interval (CI) for each age group and autism diagnosis status, and the percentage of reported scores at the floor of the score distribution (score = 1–2 indicating no or low stress) and ceiling (score = 4–5 indicating high stress). There were no significant differences between average subscale scores or total (average or raw) scores by age or autism status, with the exception of the "Pleasant Events" mean subscale score being significantly higher for adults with an autism diagnosis (mean = 1.89) compared to those without this diagnosis (mean = 1.53) (F [1.85] = 5.35, p = 0.02). Generalized linear models found no main effect of age group or autism diagnosis on the average stress or total stress scores. Figure 1 displays graphically the mean scores across the eight subscales and the total average stress score by age group and autism diagnosis.

A review of the percentages of participant responses in the floor range showed relatively high percentages (range = 76 to 85%) for the "Pleasant Events" subscale across age groups, and in the ceiling range showed relatively high percentages for the "Ritual-related" (range = 17 to 36%) subscale across age groups. This pattern was generally present

Table 2 Adult participant stress schedule survey mean subscale and total stress scores

Subscale/score	Mean (95% CI)
Changes and threats	2.6 (2.4, 2.8)
Anticipation and uncertainty	2.3 (2.1, 2.5)
Unpleasant events	2.4 (2.2, 2.6)
Pleasant events	1.7 (1.6, 1.8)
Sensory or personal contact	2.5 (2.3, 2.7)
Food-related activities	2.1 (1.9, 2.3)
Social/environmental interactions	1.9 (1.7, 2.1)
Ritual-related	3.0 (2.7, 3.2)
Average stress	2.3 (2.2, 2.5)
Total stress raw	114.0 (107.1, 120.8)

Table 3 Stress survey scale sub-scores by age group and autism diagnosis

Age group (n)	Performance metric	Changes and threats	Anticipation	Unpleasant	Pleasant	Sensory	Food	Social/environment	Rituals	Average stress	Total stress raw
22–35 (25)	Mean	2.8	2.3	2.4	1.7	2.7	2.1	1.9	3.0	2.4	117.4
	SD	0.9	0.9	0.9	0.9	0.9	1.1	0.6	1.3	0.7	34.6
	95% CI mean	2.4, 3.2	1.9, 2.7	2.0, 2.8	1.4, 2.1	2.3, 3.0	1.7, 2.6	1.6, 2.1	1.7, 3.4	2.1, 2.7	103.1, 131.7
	% floor	24.0	52.0	36.0	76.0	32.0	56.0	76.0	40.0	36.0	32.0
	% ceiling	12.0	4.0	12.0	0	12.0	4.0	0	36.0	0	24.0
36–50 (35)	Mean	2.6`	2.3	2.5	1.6	2.4	2.0	2.1	2.9	2.3	113.6
	SD	0.9	0.8	0.8	0.7	0.9	1.1	1.0	1.1	0.7	34.9
	95% CI mean	2.3, 2.9	2.0, 2.5	2.2, 2.8	1.4, 1.9	2.1, 2.8	1.6, 2.4	1.7, 2.4	2.5, 3.3	2.1, 2.6	101.6, 125.6
	% floor	22.9	45.7	31.4	80.0	37.1	74.3	71.4	22.9	37.1	34.3
	% ceiling	11.4	5.7	5.7	2.6	8.6	11.4	8.6	17.1	2.9	14.3
≥51 (29)	Mean	2.5	2.3	2.3	1.6	2.5	2.1	1.9	3.0	2.3	111.5
	SD	0.6	0.7	0.8	0.6	0.9	0.8	0.7	1.1	0.6	28.5
	95% CI mean	2.3, 2.7	2.1, 2.6	2.0, 2.6	1.4, 1.9	2.2, 2.9	1.8, 2.4	1.6, 2.1	2.5, 3.4	2.1, 2.5	100.7, 122.3
	% floor	20.7	37.9	48.3	75.9	41.4	55.2	69.0	20.7	34.5	41.4
	% ceiling	0	3.5	6.9	0	10.3	3.5	0	27.6	0	17.2
Autism Dx (36)	Mean	2.7	2.5	2.3	1.9*	2.6	2.3	2.0	3.0	2.4	118.2
	SD	1.0	0.9	0.9	0.9	1.0	0.9	0.8	1.12	0.8	38.0
	95% CI mean	2.4, 3.0	2.1, 2.8	2.1, 2.8	1.6, 2.2	2.3, 3.0	2.0, 2.6	1.7, 2.3	2.6, 3.4	2.1, 2.7	105.3, 131.0
	% floor	22.2	33.3	38.9	66.7	38.9	52.8	75.0	25.0	30.6	30.6
	% ceiling	11.1	11.1	8.3	2.8	19.4	5.6	5.6	27.8	2.8	25.0
No autism Dx (53)	Mean	2.5	2.2	2.5	1.5	2.5	2.0	1.9	2.9	2.3	111.1
	SD	0.7	0.7	0.8	0.6	0.8	1.0	0.8	1.1	0.6	28.3
	95% CI mean	2.3, 2.8	2.0, 2.4	2.2, 2.7	1.4, 1.7	2.3, 2.7	1.7, 2.2	1.7, 2.1	2.6, 3.2	2.1, 2.4	103.3, 118.9
	% floor	22.6	52.8	37.7	84.9	35.9	69.8	69.8	28.3	39.6	39.6
	% ceiling	5.7	0	7.6	0	3.8	7.6	1.9	24.5	0	13.2

Dx, diagnosis; *CI*, confidence interval; *SD*, standard deviation, *significant difference $p = 0.02$

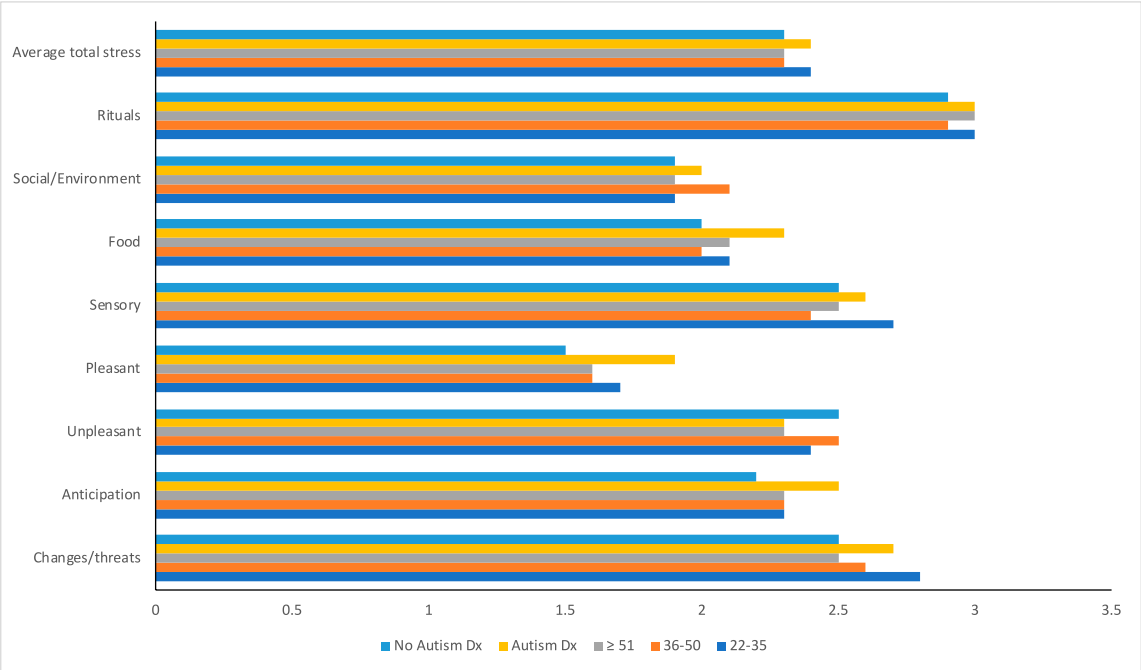

Fig. 1 Average subscales and total average stress scores by adult age group and autism diagnosis

and consistent for participants with or without autism and is consistent with the average subscale score analysis. A series of χ^2 examining the frequency of being in the floor versus ceiling by age groups and autism diagnosis across the subscale scores was conducted. There was no significant association between age groups and being at the ceiling or floor of the eight subscale scores. However, participants with autism were found to have a significantly greater proportion of scores at the ceiling for the "Anticipation or Uncertainty" (11.1% vs. 0%, χ^2 [2] = 8.0, $p = 0.02$), and the "Sensory or Personal Contact" subscales (19.4% vs. 3.8%, χ^2 [2] = 6.6, $p = 0.04$) compared to those without autism.

Item Analysis

Table 4 shows the items with the most frequently low (floor) and high (ceiling) stress scores by age group and autism diagnosis for this adult sample. The one item identified as low stress across all age groups included "Having something marked as correct." The two items that were common to the two age groups included "Receiving tangible reinforcement" and "Receiving a present." Across all age groups, "Having a change in environment from comfortable to uncomfortable" and "Being prevented from carrying out a ritual" were most frequently reported as causing high stress. "Being in the vicinity of noise or disruption by others" was an item most frequently reported as causing high stress for two of the three age groups. Adults with and without an autism diagnosis showed similar patterns of items causing low stress. However, adults with an autism diagnosis were more likely to have endorsed "Having personal objects or materials out of order" as causing the highest stress (47.2%). This item was not endorsed as causing high stress for those without an autism diagnosis.

Comparison of Adult and Younger Student Data

Table 5 shows the mean SSS subscale scores, total average stress score, and total raw scores, and standard deviations for the historical child/adolescent age group from a previous study (Woodard et al., 2023) collapsed across gender and autism diagnosis status and the information from Table 2 in the present study. A series of *t*-test analyses was conducted to test for significant difference between the two samples (adults and historic child sample). These analyses showed significant differences with the adult sample having significantly higher mean stress scores as compared to the historic child/adolescent sample for the average subscale scores for the "Pleasant Events," ($p = 0.02$) "Sensory or Personal Contact," ($p = 0.01$) "Social/Environmental Interactions," ($p = 0.04$) and "Ritual-related" ($p = 0.001$) subscales. The only average subscale score for which the historic child/adolescent sample was higher than the adult sample was for "Food-related Activities" ($p = 0.04$). The overall average stress score and total raw stress score were not significantly different between the adult and historic child sample.

Table 4 Highest and lowest stress items by age group and autism diagnosis

	22-35 years Item (%) $n = 25$	36-50 years Item (%) $n = 35$	≥ 51years Item (%) $n = 29$	Autism diagnosis Item (%) $n = 36$	No autism diagnosis Item (%) $n = 53$
5 items with the lowest stress score (scores = 1, 2)	Q19. Having something marked as correct (88.0) Q28. Having something marked as incorrect (84.0) Q44. Someone else making a mistake (84.0) Q45.Receiving tangible reinforcement (84.0) Q48. Having a conversation (84.0)	Q1. Receiving a present (94.3) Q49. Receiving verbal reinforcement (91.4) Q19. Having something marked as correct (88.6) Q41. Losing at a game (85.7) Q45. Receiving tangible reinforcement (85.7)	Q19. Having something marked as correct (89.5) Q26. Being told "no" (88.3) Q23. Being allowed to attend a party or favored event (86.2) Q1. Receiving a present (86.2) Q18. Receiving activity reinforcement (86.2)	Q19. Having something marked as correct (86.1) Q28. Having something marked as incorrect (83.4) Q1. Receiving a present (83.3) Q48. Having a conversation (83.3) Q41. Q41. Losing at a game (80.7)	Q1. Receiving a present (90.6) Q19. Having something marked as correct (90.5) Q49. Receiving verbal reinforcement (88.7) Q45. Receiving tangible reinforcement (86.8) Q23. Being allowed to attend a party or favored event (86.7)
5 items with the highest stress score (scores = 4, 5)	Q13. Having a change in environment from comfortable to uncomfortable (72.0) Q25. Transitioning from preferred to non-preferred activity (56.0) Q31. Having to engage in not-liked activity (52.0) Q14. Being prevented from carrying out a ritual (48.0) Q12. Being prevented from completing a ritual (48.0)	Q13. Having a change in environment from comfortable to uncomfortable (45.3) Q5. Being in the vicinity of noise or disruption by others (44.7) Q26. Being told "no" (40.0) Q14. Being prevented from carrying out a ritual (40.0) Q10. Having a change in task to a new task with new directions (37.4)	Q13. Having a change in environment from comfortable to uncomfortable (44.8) Q14. Being prevented from carrying out a ritual (37.9) Q2. Having personal objects or materials out of order (37.6) Q5. Being in the vicinity of noise or disruption by others (31.3) Q8. Being touched (31.2)	Q2. Having personal objects or materials out of order (47.2) Q12. Being prevented from completing a ritual (44.5) Q25. Transitioning from preferred to non-preferred activity (44.4) Q5. Being in the vicinity of noise or disruption by others (41.7) Q9. Having personal objects or materials missing (41.7)	Q13. Having a change in environment from comfortable to uncomfortable (54.7) Q14. Being prevented from carrying out a ritual (41.5) Q26. Being told "no" (37.7) Q4. Having a change in schedule or plans (35.9) Q12. Being prevented from completing a ritual (35.8)

Table 5 Adult participant stress schedule survey mean subscale and total stress scores

Subscale/score	(Historic) child mean (SD)	adult Mean (SD)	Statistic (p)
Changes and threats	2.6 (0.80)	2.6 (0.80)	$t(242) = 0$ ($p = 0.50$)
Anticipation and uncertainty	2.3 (0.80)	2.3 (0.80	$t(242) = 0$ ($p = 0.50$)
Unpleasant events	2.3 (0.70)	2.4 (0.90)	$t(242) = 0.97$ (p =0.34)
Pleasant events	1.5 (0.60)	1.7 (0.70)	$t(242) = 2.36$ (p =0.02)*
Sensory or personal contact	2.2 (0.90)	2.5 (0.90)	$t(242) = 2.51$ (p =0.01)*
Food-related activities	2.4 (1.10)	2.1 (1.00)	$t(242) = 2.12$ (p =0.04)*
Social/environmental interactions	1.7 (0.70)	1.9 (0.81)	$t(242) = 2.03$ (p =0.04)*
Ritual-related	2.5 (1.10)	3.0 (1.10)	$t(242) = 3.42$ (p =0.001)***
Average stress	2.2 (0.60)	2.3 (0.70)	$t(242) = 1.18$ (p =0.24)
Total stress raw	108.6 (31.10)	114.0 (32.60)	$t(242) = 1.28$ (p =0.20)

Discussion

Building upon previous research, the primary purpose of the present study was to provide normative data on overall scores and sub-group scores for the Stress Survey Schedule (SSS) for persons with autism and intellectual disability over the age of 22 and to examine trends in the participant sample related to age and gender as participants moved through adulthood. A secondary aim of this research was to compare the results for this adult sample with the information previously collected on a group of children participants. The overall average mean for this adult sample was identical to that for children and indicated moderate levels of stress. However, for this adult sample as a whole, the "Ritual-related" subscale average score was significantly higher than the other adult subscale averages, which was a trend that was not present in the children's group. In comparison, previous research on children ages 6 to 19 (Woodard et al., 2023) found that "Changes and Threats" and "Food-related Activities" were the highest-scoring subscales for this younger sample. In the present adult sample, "Pleasant Events" subscale scores were significantly lower than other subscale scores which is consistent with the children's sample. It is noted that in previous research (Woodard et al., 2020), the "Ritual-related" subscale scores were also found to be significantly higher for the oldest (ages 18 to 21) age group as compared to younger age groups. Furthermore, Goodwin et al., (2007) found differences in subscale scores between participants over and under age 20. Taken as a whole, these results suggest that differences exist between persons in this population that become evident around the typical ages identified for adulthood (ages 18 to 21) in that what is typically reported as high stress is different for those under this age range compared to those over this age range. In contrast, events that are pleasant are identified as low stress across the lifespan for this population.

In the present sample, there was only one significant difference between average subscale scores and total (average or raw) scores by age or autism status. This is consistent with previous research (Woodard et al., 2023) that found no differences between average subscale scores as a function of age, suggesting that there is general consistency of subscale scores within each of the older and younger age groups. In analyzing the percentage of responses in the floor and ceiling for each subscale of the present adult sample, few statistical differences were found. However, as would be expected from the previous discussion, there were comparatively high percentages on the floor for the "Pleasant Events" subscale across age groupings and autism status. There were comparatively high percentages in the ceiling for the "Ritual-related" subscale. This pattern is repeated in an examination of the items most frequently in the floor and ceiling, in that many of the items receiving low-stress scores had to do with pleasant events such as receiving approval, receiving a desired item or message, or doing something that might be considered "fun." Many of the items receiving high-stress scores involved not being able to carry out or finish a ritual, having items out of the preferred order, or changes that could signal an interruption in a person's established (and possibly ritualized) activities. This increased area of ritual-related stress is most distinct, emerges in early adulthood (age 18 to 21), and remains elevated across the adulthood years. This is consistent with what has been termed "late-onset" obsessive-compulsive disorder (OCD) (Raşit Tükel et al., 2005) where similar, ritualized behavior (such as needing items in a certain order or repeating the same behavior over and over) emerges somewhere around age 17 to 18.

Interestingly, there were two items from the "Unpleasant Events" subscale, "Losing at a game" and "Being told 'no'" that were included in the low-stress items for the adult sample, although the latter also showed up as a high-stress item in a different age group. Perhaps, as one grows older, these events either matter less or simply happen less, although "Losing at a game" was also a low-stress item for children in the Woodard et al., (2023) data set. In addition to items from "Ritual-related," high-stress items for adults also came from "Changes and Threats"

with the addition of some "Sensory/Personal Contact" items involving noise or being touched. Some of these items overlap with items frequently scored as high stress for children such as "Changes and Threats" items, likely reflecting the centrality of change as a stressor for the person with ASD regardless of age. There were also differences such as "Being unable to communicate needs" emerging as more of a high-stress item for children but not so for adults. Perhaps, the intensive focus on building communication skills and abilities in younger years helps to ameliorate this area for adulthood. It is interesting to note that "Receiving hugs and affection" was an item frequently scored as low stress for the youngest children, while "Being touched" was an item frequently scored high stress for the oldest adults.

When the younger and older groups are compared to each other, a range of significant differences emerges. Adult average subscale scores were higher for "Pleasant Events," "Sensory or Personal Contact," and "Social/Environmental Interactions," in addition to "Ritual-related." The historical child/adolescent sample average subscale score was higher than the adult sample only for the "Food-related" subscale. This would suggest that as a person in this population enters and moves through adulthood, more areas are identified as more stressful. However, it is noted that even the highest average subscale score would be considered moderate stress. The idea of a shift in stress levels changing as a person in this population enters adulthood is also supported by the trend in raw scores. The children's average total raw score remained constant through age 13 at 111 and then decreased slightly for participants ages 14 to 19, while the average total raw score for the present sample showed a decline across the age groupings. Average total raw scores for the adult sample were highest for young adulthood at 117 and then diminished to 113 and then 111 for the group over age 51. This may suggest that stress remains fairly constant for younger persons with intellectual disability and ASD through the typically consistent and support-rich school-age years that typically extend to age 21 for this group. As supports and services decrease following school-age years and transitions in possibly home and work environments ensue, stress reaches the peak for this population at ages 22 to 35. As the person moves through later adulthood and experiences more and more consistency and stability in one's work and living situation, overall stress levels slowly decrease through this period.

Limitations and Future Research

There are a number of limitations to the present research including a limited number of adult participant survey responses. One of the purposes of the present study was to examine trends across adulthood; however, the number of survey responses was further reduced by dividing the sample into three smaller subgroups. A larger sample may have provided different or more robust findings. This sample was also composed of mainly male participants and would have been improved by a male-to-female ratio that was more representative of the population of persons with intellectual disability and ASD. Another limitation of the present study was the age of the SSS tool in terms of items perhaps not including technological and other world changes and advances that may be relevant areas related to stress. Finally, the SSS tool does not currently contain any guidance or instruction related to what is meant by "stress." This may have led to those administering the SSS giving ratings related to other variables (such as behavioral challenges) that may or may not indicate stress.

These limitations, combined with the findings of the present study, suggest some significant conclusions that inform future research directions. The results of the present study clearly indicate differences between younger and older participants in subscale scores, and differences are also evident in items frequently identified as low and high stress between the child/adolescent and adult sample. Along with the emergence since 2001 of possible new areas of stress, these findings suggest the need for a revision of the survey into child/adolescent and adult formats. This would allow the possible expansion of areas found in this study to be particularly high stress to younger or older groups. It would also allow the inclusion of items such as "Access to my laptop" which reflect technological and world changes, as well as items more relevant to adults such as "Going to workplace or day program" or "Death of a parent." Furthermore, possible revisions to the scale should take into account items or subscales that uniformly show little stress for younger or older groups or those consistently low stress across the lifespan. If there are items that very rarely indicate stress, the scale may be improved by eliminating these items. Finally, respondents may benefit from having guidance on what stress is, how it is defined, or typical behavioral manifestations or indices of stress. This may help respondents provide more accurate information in completing the survey.

The Stress Survey Schedule was developed to better identify stressors for the person with ASD and intellectual disability, based on the idea that needing to function in a social world with limited or impaired social skills is inherently stressful. If we can better understand what is stressful in this population, we are better able as practitioners to create interventions that target these areas and improve coping strategies. This process has the potential to improve lives. This study extended the research on children and adolescents by providing reference points for adults, but it also demonstrated that there are significant differences in what causes high stress for these two groups. Furthermore, the findings of the present study demonstrated that there are areas that are not particularly stressful for the person with

ASD and intellectual disability across the lifespan. These findings suggest that assessing stress in children and adolescents compared to adults needs to be done with tools that are sensitive to different areas and should include items that reflect changes in the world around us.

Author Contributions CW led the project administration and was responsible for the original draft of the manuscript and revisions to the manuscript. JB provided data curation and formal statistical analysis for this project. KA provided investigation support by collecting data and creating/revising the databases. JG provided the conceptualization for this research and ongoing mentorship.

Data Availability The data for this project is maintained at the Groden Center in a secured database. Access to the data can be arranged by contacting the authors.

Declarations

Ethics Statement These data were de-identified and reviewed by the Institutional Review Board (IRB) of the Groden Center. The study was approved and identified as exempt by the IRB.

Conflict of Interest The authors declare no competing interests.

References

Cohen, S., Janicki-Deverts, D., & Miller, G. E. (2007). Psychological stress and disease. *Jama, 298*(14), 1685–1687. https://doi.org/10.1001/jama.298.14.1685

Deng, L., & Chan, W. (2017). Testing the difference between reliability coefficients alpha and omega. *Educational and psychological measurement, 77*(2), 185–203. https://doi.org/10.1177/0013164416658325

Dewe, P. J., O'Driscoll, M. P., & Cooper, C. L. (2012). Theories of psychological stress at work. In R. Gatchel & I. Schultz (Eds.), *Handbook of occupational health and wellness. Handbooks in health, work, and Disability* (pp. 23–38). Springer. https://doi.org/10.1007/978-1-4614-4839-6_2

Goodwin, M. S., Groden, J., Velicer, W. F., & Diller, A. (2007). Brief report: Validating the Stress Survey Schedule for persons with autism and other developmental disabilities. *Focus on Autism and Other Developmental Disabilities, 22*(3), 183–189. https://doi.org/10.1177/10883576070220030501

Groden, J., Cautela, J., Prince, S., & Berryman, J. (1994). The impact of stress and anxiety on individuals with autism and developmental disabilities. In E. Schopler & G. B. Mesibov (Eds.), *Behavioral issues in autism. Current issues in autism* (pp. 177–194). Springer. https://doi.org/10.1007/978-1-4757-9400-7_9

Groden, J., Diller, A., Bausman, M., Velicer, W., Norman, G., & Cautela, J. (2001). The development of a Stress Survey Schedule for persons with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders, 31*(2), 207–217. https://doi.org/10.1023/A:1010755300436

Selye, H. (1974). *Stress without distress*. Lipincott

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education, 27*(2), 53–55. https://doi.org/10.5116/ijme.4dfb.8dfd

Tükel, R., Ertekin, E., Batmaz, S., Alyanak, F., Sözen, A., Aslantaş, B., Atlı, H., & Özyıldırım, I. (2005). Influence of age of onset on clinical features in obsessive–compulsive disorder. *Depression and Anxiety, 21*(3), 112–117. https://doi.org/10.1002/da.20065

Woodard, C. R., Baird, J., Anderson, K., & Groden, J. (2023). The Stress Survey Schedule (SSS): Trends and normative data on a sample of children with severe autism and related developmental disabilities. *Advances in Neurodevelopmental Disorders*. https://doi.org/10.1007/s41252-023-00315-8

Woodard, C. R., Harmony, C., Groden, J., & Audet, K. (2020). A comparison of the Stress Survey Schedule in children with autism and typically developing children: A brief report. *Journal of Autism and Developmental Disorders, 51*, 1375–1384. https://doi.org/10.1007/s10803-020-04616-y