



Parental Perspectives: How Sensory Sensitivities Impact the Transition to Adulthood in Adolescents and Young Adults with Autism Spectrum Disorder

Rachel M. Hantman^{1,2} · Emily B. Johnston¹ · Helen Tager-Flusberg¹

Accepted: 3 November 2022 / Published online: 19 November 2022

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

Sensory sensitivities are common in autism spectrum disorder (ASD) and impact daily life, but research has largely focused on children, neglecting older individuals. Likewise, while there is research regarding parental concerns for their autistic children's transition to adulthood, little is known about the role of sensory sensitivities. To address this gap, 66 parents of autistic adolescents and young adults were interviewed and their responses were qualitatively analyzed. All parents believed their children's sensory sensitivities impacted their transition to adulthood, primary developmentally/psychologically, interpersonally/socially, and managerially. These beliefs did not significantly differ by child characteristics, such as age and ASD severity. Parent perceptions were modality and context specific. Given these findings, transition planning should consider individual's specific sensory sensitivities to optimize independence.

Keywords Sensory sensitivities · Autism spectrum disorder · Adulthood · Parents · Transition · Perspectives

Introduction

Sensory sensitivities are common in autism spectrum disorder (ASD), and they are now included both in the diagnostic criteria (American Psychiatric Association, 2013) and as part of the diagnostic process (e.g., Lord et al., 2012; Rutter et al., 2003) for ASD. Despite being diagnostically intertwined, sensory sensitivities are frequently studied in younger, but not older, individuals with ASD.¹ In an updated meta-analysis of sensory symptoms in ASD, of the 55 studies examined, on average the participants with ASD ranged from 4.6 to 13.6 years old; only 10% included participants who were 25 years old (Ben-Sasson et al., 2019), suggesting that there is a substantial developmental gap in the sensory sensitivities literature. Additionally, seminal papers describing the high prevalence of sensory sensitivities in autistic individuals (69% and 95%) only focused on

children up to the age of six (Baranek et al., 2006; Tomchek & Dunn, 2007). Without a complete understanding of how sensory sensitivities track with development, families with older children are left without resources and with concern for their children's future. To address this gap, in this study, we explored parents' perceptions of sensory sensitivities in their adolescent and young adult children, as well as how these sensory sensitivities impact their transition towards independence and to their next stage in life.

Just as autism symptoms exist on a spectrum, so do sensory sensitivities; some individuals are insensitive to particular sensory stimuli (hyposensitive), while others are overly sensitive (hypersensitive; Dunn, 2001). Sensory behaviors can range from seeking preferred stimuli (e.g., staring at fans) and missing sensory information (e.g., not noticing pain) to avoiding aversive stimuli (e.g., leaving a room when someone is wearing perfume) and heightened sensory awareness (e.g., discriminating differences between food brands). It has been demonstrated that sensory sensitivities impact different areas of daily life for individuals with

✉ Rachel M. Hantman
rhantman@email.sc.edu

¹ Department of Psychological and Brain Sciences, Boston University, Boston, MA, USA

² Present Address: Department of Psychology, University of South Carolina, Columbia, SC, USA

¹ Person-first (e.g., individuals with ASD) and identify-first (i.e., autistic individuals) language will be used interchangeably, as our participants shared their preferences for both.

ASD, such as education (Ashburner et al., 2008; Cai & Richdale, 2016; Howe & Stagg, 2016; Van Hees et al., 2015); participation in community, social, recreational, and familial interactions/activities (Fernández-Andrés et al., 2015; Hochhauser & Engel-Yeger, 2010; Linderman & Stewart, 1999; Little et al., 2015; Pfeiffer et al., 2017; Schaaf et al., 2011); adaptive behaviors (Cermak et al., 2010; Jasmin et al., 2009; Lane et al., 2010; Tomchek et al., 2015; Watson et al., 2011; Zobel-Lachiusa et al., 2015); challenging behaviors (Hattier et al., 2013); mental and physical health; and a combination thereof (Ismael et al., 2018; Kirby et al., 2017; MacLennan et al., 2022; Reynolds et al., 2011; Robertson & Simmons, 2015; Smith & Sharp, 2013). Self-reports from autistic adults also indicate that their sensory sensitivities function in interactive systems, wherein their sensory sensitivities are impacted by and impact internal (e.g., valence, sense of control, mental health), as well as, external factors (e.g., other individuals) that they encounter in their daily lives (MacLennan et al., 2022; Robertson & Simmons, 2015; Smith & Sharp, 2013). Collectively, the literature suggests that sensory sensitivities can negatively impact everyday life experiences by causing overstimulation to the point of distraction, discomfort, decreased participation, and increased challenging behaviors, as well as leading to challenges with adaptive behaviors, interruptions to family functioning, and negative mental health outcomes.

As with the broader sensory sensitivity ASD literature, the studies that explored how sensory sensitivities impact daily living primarily focused on children under 13. In our review of the literature, we identified 15 studies involving children under 13 years of age (Ashburner et al., 2008; Fernández-Andrés et al., 2015; Hattier et al., 2013; Hochhauser & Engel-Yeger, 2010; Jasmin et al., 2009; Kirby et al., 2017; Lane et al., 2010; Linderman & Stewart, 1999; Little et al., 2015; Pfeiffer et al., 2017; Reynolds et al., 2011; Schaaf et al., 2011; Tomchek et al., 2015; Watson et al., 2011; Zobel-Lachiusa et al., 2015), and three studies examined the impact on individuals ages 13–17 (Cermak et al., 2010; Howe & Stagg, 2016; Ismael et al., 2018). Only two studies identified how sensory sensitivities impact daily life in young adults over the age of 18 (Cai & Richdale, 2016; Van Hees et al., 2015); however, sensory sensitivities were not their primary focus, and three studies examined the impact of sensory sensitivities in older adults (MacLennan et al., 2022; Robertson & Simmons, 2015; Smith & Sharp, 2013).

As the people who advocate for and support their children, caregivers have unique perspectives about their children's transition to adulthood. Previous studies examining caregiver perspectives demonstrated that families feel as though their children have progressed towards

independence but are still uncertain about their children's future (Cheak-Zamora et al., 2017; Cribb et al., 2019), citing concerns about their children's unpredictability, lack of experience, and difficulties with newness. Families also discuss the need to balance *their* sense of security for their child's future with their child's own autonomy (Sosnowy et al., 2018); that is, providing their children with the necessary skills to be independent at the expense of parental worries.

Parents' expectations for their children's future also relate to their child's intellectual level (IQ), gender, and symptom severity (Holmes et al., 2016, 2018), such that higher IQ, lower ASD symptom severity, and having a son were associated with higher parental expectations. However, parental expectations have highlighted discrepancies between the importance and the likelihood of meeting adult milestones (e.g., being accepted by the community; Ivey, 2004; Sosnowy et al., 2018), such that the perceived importance of these tasks was greater than their child's likelihood of achievement. Other times, parental expectations were reframed to match their child's individual abilities (Thompson et al., 2018). For example, for future living arrangements, some parents reconceptualized living independently as their child living in a guest house rather than away from their family home. Finally, many parents reported unmet resource needs as their child transitioned (Cheak-Zamora & Teti, 2015; Dudley et al., 2019; Kuo et al., 2018) and a decline in services during and after high school (Laxman et al., 2019). Taken together, many caregivers of autistic children express concerns about their children's transition to adulthood. However, none of these studies focused on the impact of sensory sensitivities; instead, they were contextualized in terms of daily living, social, educational, and/or job/vocational skills (Cai & Richdale, 2016; Cribb et al., 2019; Holmes et al., 2016, 2018; Ivey, 2004; Sosnowy et al., 2018; Thompson et al., 2018), as well as access to services (Dudley et al., 2019; Kuo et al., 2018; Laxman et al., 2019) and navigating the health care system (Cheak-Zamora & Teti, 2015; Cheak-Zamora et al., 2017). No one has yet asked caregivers how they think their children's sensory sensitivities impact their child's transition.

In the current study, in order to address these research gaps, we took a qualitative approach, asking parents of young adults with ASD about the impact of their children's sensory sensitivities on this developmental period through semi-structured interviews. Due to the lack of research at the intersection of sensory sensitivities and the transition to adulthood, we did not have any a priori hypotheses. We did, however, have a priori research questions:

1. To establish context, we first asked, what sensory sensitivities do parents report in their interviews? Do they differ by child characteristics, such as gender or age?
2. As our main research questions, we then asked:
 - a. How do parents believe that their child’s sensory sensitivities impact or will impact their child’s transition to adulthood?
 - b. How do these beliefs differ by child characteristics, such as age, gender, independence level, sensory (i.e., auditory and tactile) hypersensitivity, anxiety, adaptive ability, language ability, and ASD symptom severity?

Methods

Participants

This research was approved by the Boston University Institutional Review Board. All participants were eligible to participate in our study if they were caregivers of a child with ASD, who was transitioning to adulthood (16;0–25;11 years old), who had sensory sensitivities (past or present), and who lived at home with their caregiver. Participants were conversationally fluent in English. Participants were recruited through convenience sampling from the Center for Autism Research Excellence’s participant registry at Boston University, online community platforms, social media posts, and through participant referrals. The study was carried out remotely during the Covid-19 pandemic and included participants from across North America.

126 parents expressed interest in the study by completing an online screener, 35 of whom were ineligible (e.g., child did not have ASD). Of the 91 eligible parents, 77 parents completed the consenting process via Zoom, a video conferencing platform. Four parents then withdrew from the study, one citing that she did not have enough time to participate, and three parents did not respond after four interview scheduling requests. Seven of the remaining 73 parents were excluded from analyses because their children received an autism severity score below the ASD cut-off on the Social Responsiveness Scale-2 (SRS-2; Constantino & Gruber, 2012), leaving a final sample size of 66 parents. Four parents had more than one child (two or three) who met criteria for the study (e.g., 17-year-old twins, each with different sensory sensitivities) and completed all components of the study for each child. Because their perspectives were unique for each child, for the purposes of analyses, these parents were re-counted each time they participated.

Table 1 Parental and child demographic information

| Characteristics | Parents | | Children | |
|--|---------|-------|----------|-------|
| | # | % | # | % |
| Mother/daughter ^a | 64 | 96.97 | 11 | 16.67 |
| Non-Hispanic/Latino | 61 | 92.42 | 63 | 95.45 |
| Race | | | | |
| Asian | 3 | 4.55 | 1 | 1.52 |
| Black/African American | 4 | 6.06 | 4 | 6.06 |
| White | 54 | 81.82 | 52 | 78.79 |
| Multiple | 2 | 3.03 | 6 | 9.09 |
| Unknown/decline | 3 | 4.55 | 3 | 4.55 |
| Highest level of education | | | | |
| < 8th grade | 0 | 0 | 3 | 4.55 |
| 9–11th grade | 0 | 0 | 31 | 46.97 |
| High school or GED | 1 | 1.52 | 17 | 25.76 |
| Vocational or trade degree | 1 | 1.52 | 0 | 0 |
| Associate’s/2-year degree | 10 | 15.15 | 1 | 1.52 |
| Courses towards a college degree | 3 | 4.55 | 5 | 7.58 |
| College degree | 22 | 33.33 | 2 | 3.03 |
| Master’s degree | 21 | 31.82 | 0 | 0 |
| Professional degree | 8 | 12.12 | 0 | 0 |
| Unknown/decline/other | 0 | 0 | 7 | 10.61 |
| Combined household income | | | | |
| < \$50,000 | 8 | 12.12 | – | – |
| \$50,000–\$99,999 | 10 | 15.15 | – | – |
| \$100,000–\$149,999 | 17 | 25.76 | – | – |
| \$150,000–\$199,999 | 9 | 13.64 | – | – |
| \$200,000–\$249,999 | 7 | 10.61 | – | – |
| ≥ 250,000 | 6 | 9.09 | – | – |
| Decline | 9 | 13.64 | – | – |
| Relationship status | | | | |
| Married, remarried, or living with partner | 54 | 81.82 | – | – |
| Divorced, separated, single, or widowed | 12 | 18.18 | – | – |
| Language abilities | | | | |
| Verbal | – | – | 42 | 63.64 |
| Minimally/non-verbal | – | – | 24 | 36.36 |
| Comorbid diagnosis ^b | – | – | 53 | 80.00 |
| Intellectual disability ^b | – | – | 28 | 42.42 |

Percentages are out of 66 participants

^aOne parent was a stepmother and one child identified as gender fluid

^bAs per parent report

All parents indicated that they were their child’s primary caregiver. The parents were primarily mothers (97%), and their children were primarily sons (83%). At the time of the interview, their children were, on average 19.42 years old ($SD = 2.54$ years), ranging from 16.03 to 25.47 years. See Tables 1 and 2 for parental and child characteristics.

Table 2 Children's scores on questionnaires

| Variables of interest | Mean | Median | SD | Minimum | Maximum |
|--|-------|--------|-------|---------|---------|
| VABS-3 | | | | | |
| Adaptive behavior composite ^a Standard Score ^a | 66.58 | 69 | 19.02 | 20 | 105 |
| Daily Living Skills Standard Score ^a | 69.35 | 74 | 23.44 | 20 | 120 |
| PRAS-ASD ^a | 23.20 | 22 | 14.10 | 1 | 62 |
| ABC-2 | | | | | |
| Irritability ^a | 8.64 | 8 | 8.38 | 0 | 35 |
| Hyperactivity/noncompliance ^a | 10.24 | 8 | 9.08 | 0 | 41 |
| Demographic form | | | | | |
| Age at interview ^a | 19.42 | 18.79 | 2.54 | 16.03 | 25.47 |
| Independent Composite Score ^a | 4.94 | 4.31 | 3.62 | − 1.64 | 13.18 |
| AASP | | | | | |
| Touch hypersensitivity Z-Score | 0.72 | 0.17 | 0.98 | − 2.53 | 2.45 |
| Sound hypersensitivity Z-Score ^a | 0.11 | 0.09 | 1.0 | − 3.26 | 1.58 |
| | | # | | | % |
| SRS-2 Severity^b | | | | | |
| Severe | | 32 | | | 48.48 |
| Moderate | | 25 | | | 37.88 |
| Mild | | 9 | | | 13.64 |

^aUsing the Shapiro–Wilk test, the variables were not normally distributed

^bNot tested for normality

Procedure

After completing the consenting process, participants were invited to complete online questionnaires and were then scheduled to participate in a recorded semi-structured interview.

Parent Questionnaires

Vineland Adaptive Behavior Scales, Third Edition (VABS-3; Sparrow et al., 2016)

The VABS-3 is a standardized, normed parent survey used to measure adaptive behavior and support diagnosis of intellectual and developmental disabilities. Parents completed the domain-level parent-caregiver form. Per domain, scores range from 20–140 ($M = 100$, $SD = 15$), with higher scores indicating better adaptive skills. We used two standard scores from the VABS-3: the Adaptive Behavior Composite (ABC) Standard Score and the Daily Living Skills Standard Score.

Parent Rated Anxiety Scale for ASD (PRAS-ASD; Scahill et al., 2019)

The PRAS-ASD assesses anxiety severity in youth with ASD. It was specifically designed to not rely on children's

verbal ability. Scores range from 0–75, with higher scores indicating more anxiety.

Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012)

The SRS-2 assesses social impairments in ASD. It relies on t-scores to establish ASD severity, where t-score < 60 is the cut-off for ASD. T-scores 60–65, 66–75, and > 75 refer to mild, moderate, and severe ASD symptom severity respectively. As our study was remote, we used the SRS-2 to verify that the children met criteria for ASD.

Aberrant Behavior Checklist, Second Edition (ABC-2; Aman & Singh, 2017)

The ABC-2 assesses challenging behaviors in a variety of daily settings, such as home, school, and work. Two of the five subscales, Irritability and Hyperactivity/Noncompliance were used in our analyses; for both subscales, higher scores indicate more challenging behaviors. For Irritability, scores range from 0 to 45. For Hyperactivity/Noncompliance, scores range from 0 to 48.

Demographic Information

This questionnaire was adapted from previous studies examining this transition period (Holmes et al., 2018; Ivey, 2004; Laxman et al., 2019; Rehm et al., 2012; Thompson et al., 2018). It contained questions about family and child background, child medical history, intervention history, level of independence, and caregiver expectations for how their child will progress into adulthood.

Independent Composite Score

This composite variable was calculated to determine child level of independence based upon highest level of completed education, high school graduation plan, employment, and driver's license status from the demographic questionnaire, as well as z-score transformed Daily Living Skills standard score from the VABS-3. Individual items were summed; higher total scores indicated greater independence.

Adolescent/Adult Sensory Profile (AASP; Brown & Dunn, 2002)

The AASP was used to measure sensory processing patterns. Although designed as a self-report measure, to account for the variability in cognitive and language abilities of participants' children, we instructed all parents to complete the questionnaire *with* their children. The AASP generates scores based upon how similar an individual's sensory behavior is compared to others. Respondents describe the frequency of their behavior across different sensory modalities (e.g., touch), in which higher scores indicate higher frequencies. These behaviors are mapped onto two continua, neurological threshold (low versus high) and behavioral response (passive versus active). Low threshold, which describes requiring only a small amount of sensory stimuli, can also be called hypersensitivity (Dunn, 2001; Pfeiffer et al., 2017). For our quantitative analyses, we focused on hypersensitivity behaviors specifically because the literature suggests that hypersensitivity is negatively related to participation in daily tasks, family functioning, schooling, and interactions with others (Kirby et al., 2017; Little et al., 2015; Pfeiffer et al., 2017; Reynolds et al., 2011; Robertson & Simmons, 2015; Schaaf et al., 2011) and can lead to stressful daily experiences (MacLennan et al., 2022; Smith & Sharp, 2013). Quantitatively, we also focused on touch and sound hypersensitivity because they were the most frequently endorsed sensory modalities in our interviews (see Table 5).

Touch Hypersensitivity Z-Score

From the AASP, we calculated a z-score for responses describing touch hypersensitivity (i.e., questions 27, 29, 31, 33, and 34). We did not include questions 35 ("I move away when others get too close to me") or 38 ("I avoid standing in lines or standing close to other people because I don't like to get too close to others") because we did not want to risk conflating touch hypersensitivity with social anxiety.

Sound Hypersensitivity Z-Score

From the AASP, we calculated a z-score for responses describing sound hypersensitivity (i.e., questions 51, 53, 54, 56, 57 and 60).

Interview

The interview script was created by the first author, borrowing questions from Thompson et al. (2018) and Cribb et al. (2019). It contained five main questions, eliciting information about children's sensory sensitivities, community acceptance, children's level of independence, how sensory sensitivities intersect with this transition, and what this transition means to parents. While the interviewer, the first author, followed a script (see Supplementary Online Resource 1), she asked follow-up questions given participants' unique answers and rephrased questions if participants did not understand them. The interviews took place over Zoom and were, on average, 75 minutes in length. Completed interviews were transcribed by an outside vendor (Academic Language Experts (ALE)). Upon receipt, 44% of the transcripts were verified to ensure accuracy and all identifiable information was redacted.

Analysis Plan

Qualitative Data

We used content analysis, a form of qualitative data analysis, to identify parent perceptions expressed in the interviews (Elo & Kyngäs, 2008; Elo et al., 2014; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). In doing so, we used clauses (i.e., complete thoughts) as our unit of analysis, coded at the manifest level (i.e., *what* the participants are saying, as opposed to the meaning *underneath* what they are saying), took an inductive approach (i.e., building our coding scheme based upon participant responses, not preexisting literature), and coded clauses mutually exclusively. As answers to our research questions were bounded by specific sections of the interview, we analyzed Question 1 and portions of

Questions 4 and 5 of the interview script (4, 4i, 4ii, 4iv, and 5iii; see Supplementary Online Resource 1).

The interview coding scheme was developed by the first author. Upon data analysis, she was already familiar with the data, having conducted all the interviews and reviewed the transcripts upon receipt from ALE. To further increase her familiarity, the first author then read all relevant portions of the transcripts and made notes on her initial impressions (Henninger & Taylor, 2014; Hsieh & Shannon, 2005). These observations were then grouped into preliminary categories and applied to nine transcripts (i.e., clauses were coded with preliminary categories). In doing so, new categories were developed and revised when clauses did not fit into a category or fit into multiple categories. This process led to the development of a draft coding scheme that included clear definitions for each category.

The draft coding scheme was then discussed with the second author. Both coders applied it to 2–4 transcripts, met to discuss coding, and modified the draft coding scheme to resolve discrepancies. They iteratively repeated this process until the coding scheme did not change when applied to transcripts; 24 transcripts were tested during development. At this point, the coding scheme and the codebook were considered finalized. The final scheme had eight sensory sensitivity categories (see Table 3) and 11 categories describing the ways in which parents believed their children’s sensory sensitivities impacted their transition to adulthood (“impact categories”; see Table 4). Two impact categories, “Sensory management” and “Interference of tasks or opportunities”, were considered vague categories. Clauses were coded mutually exclusively, so if a clause referenced a vague and a more specific category (e.g., “Living environment”), the more specific category was used.

Once the codebook was finalized, the interviews were randomly ordered to remove potential order effects on coding. During the coding process, the first two authors then applied the coding scheme to the transcripts by identifying categories that mapped onto participants’ clauses. That is, clause by clause, the first two authors determined which categories aligned with the participants’ clauses. All transcripts tested during coding scheme development were re-coded using the final scheme and were coded using NVivo 12 (QSR International Pty Ltd, 2018). The first and second author both coded the first three interviews using the finalized codebook to ensure high inter-rater reliability (IRR = 89.99%). Throughout the coding process, they randomly coded 11 more interviews for reliability; their final IRR was 90.31% across the 14 interviews (21.21% of the sample). Coding discrepancies were resolved through discussion. The first author independently coded 47 interviews (71.21%) and the second author coded five interviews (7.58%).

Quantitative Data

In line with Henninger and Taylor (2014), from the coding process, we first established the frequencies of endorsed sensory sensitivities (e.g., 37/66 participants endorsed taste) and the ways in which sensory sensitivities impact the transition to adulthood (e.g., 34/66 participants endorsed “Living environment”). Then, queries were run in NVivo to determine how many participants endorsed particular sensory sensitivities and impacts by their child’s characteristics (e.g., four daughters versus 33 sons for taste sensitivities). Using the values extracted from the NVivo queries, to assess if sensory sensitivities or impacts differed by child characteristics (i.e., age, gender, independence level, sensory hypersensitivity, anxiety, adaptive ability, language ability, and ASD symptom severity), we employed chi-square analyses. In the chi-square tests, we used median splits for continuous variables (e.g., age, VABS-3 ABC score) and categories for categorical variables (e.g., gender, language ability). Chi-square tests were run in R version 4.0.5 (R Core Team, 2021). To account for Type I errors, we employed the Benjamini–Hochberg correction method (Benjamini & Hochberg, 1995; Thissen et al., 2002) for each set of chi-square tests.

Results

Research Question 1: Parent Reported Sensory Sensitivities

During the interviews participants endorsed, on average, 4.06 sensory sensitivities, ranging from 1 to 7 sensory sensitivities with a mode of 4 and 5 (see Table 3 for definitions and Table 5 for frequencies).

Parents most frequently endorsed touch and sound (83%), followed by sight (58%), taste (56%), smell (55%), unclear/other (52%), food texture/temperature (38%), and bodily states (33%). Parents described sensory seeking behavior for preferred stimuli, as well as sensory avoidance of aversive stimuli. One parent explained, “He puts crushed red on everything... I’m afraid what his stomach’s going to look like as he gets older because of the spice... he always say[s] it has no flavor... unless it’s a pow flavor, to him it’s nothing.” While another parent recounted, “He doesn’t [do] certain textures in his mouth... Sticky, gooey stuff. He won’t go anywhere near oatmeal or anything that has a similar texture to oatmeal.” Similarly, parents discussed both hypersensitivity and hyposensitivity. One parent reflected on how she began to understand her son’s touch sensitivities, “... [my child] said [this] one day that just blew my mind... [my child] said, ‘Dad, the water is too wet.’” Conversely, another parent described the opposite scenario, “And on one side of the

Table 3 Codebook for endorsed sensory sensitivities

| Category | Definition | Exemplar quotes |
|--------------------------|---|---|
| Touch | Includes descriptions about touch, putting things in one's mouth, fabric/clothing, light/heavy pressure, (e.g., stomping, jumping), what can be on the skin/body, and toothbrushing | “He has tactile issues, so if he's eating in front of people and he picks up like a piece of toast for example, he doesn't like getting the fine grains on his fingers, so he'll kind of immediately wipe it on himself... he can't tolerate it being on his fingers for two seconds and he just has to do whatever, he has to get it off right away.” |
| Sound | Includes descriptions about sound, auditory, noise, hearing, and pitch. Includes hyperacusis and misophonia | “So, basically most of the sensory issues seem to revolve around audio. So, like, loud noises, especially if they're startling noises, even from the time she was a baby, that has always been something that I've been aware that she had an issue with.” |
| Sight | Includes descriptions about vision, sight, lightness, and darkness | “Oh, it could be light at home, it could be light on her...on my phone and that she would turn it down, on my iPad that she would turn it down, all the television or you know, of course daylight. And if it's on a very sunny day she will have a problem... She wears glasses. So we had it so that she have these transitional lens, so whenever she goes out, it just automatically is much easier for her to manage than to have to put a clip on or whatever. It's a big issue when she drives...” |
| Taste | Includes descriptions about taste, food, flavor, diet, and palate, as it relates to eating | “He likes, popcorn chicken, he likes tacos, but a certain kind of tacos. He likes some kind of quesadilla from Taco Bell... I have been trying to mimic that at home but it's not the same. He knows that it's not from Taco Bell, so it's not the same.” |
| Food texture/temperature | Includes descriptions about food textures (e.g., crunchy, slimy, slick, goopy) or food temperatures (e.g., hot or cold items), as it relates to eating | “He dislikes anything gushy, mushy, gritty, oatmeal or cream of wheat or something like that but he loves smooth and creamy, he likes yogurt or like a pudding texture, he'll eat that.” |
| Smell | Includes descriptions about smells and odors. Includes lack of smell | “Perfume, perfume. If she gets somebody that has a lot of perfume on she will, 'I've got to move, I've got to move, I need to move now because they've got a lot of perfume on,' and I can't even smell it.” |
| Bodily states | Includes inability to sense pain, interoception, proprioception, and vestibular sensations. Also includes inability to sense hot/cold external temperature and hot/cold water | “This is a sensitivity he doesn't have, he's impervious to the weather. So, it doesn't matter to him if it's 90, 95, 100 degrees, it doesn't matter to him if it's 25, 30, 35 degrees...He doesn't notice [those temperatures], he's impervious to it, it doesn't faze him in the least. So, there's no for him to say, 'oh, it's cold, I should put on a jacket,' or anything. I mean, it's me just saying, 'no, [son's name], you need to wear a jacket or something.” |
| Unclear/other | Includes descriptions where the sensory sensitivity is unclear (e.g., uncertainty regarding its presence or what is driving the sensitivity) or not included in our codebook | “He's not sensory deprived, but he looks for sensory input elsewhere, you know, because he doesn't have the awareness kind of, you know, on his own to ... to or input. I don't know how to explain it.” |

These codes describe any current sensory sensitivities, sensory insensitivities, and/or sensory interests

Table 4 Codebook for endorsed impacts of sensory sensitivities on the transition to adulthood

| Category | Definition | Exemplar quotes |
|--|--|--|
| Lack of Impact | Includes statements about how parents do not believe that their children's sensory sensitivities impact their transition to adulthood. Includes descriptions of uncertainty and the sensitivity being integral to their child | "I don't think his sensory stuff really limits that much because he, you know, he can tolerate a lot... he doesn't tear up clothing in a store or, you know, damage things, you know, public stuff or whatever. So, you know, I don't think it will prevent him from doing something." |
| Interpersonal, community, or social situations | Includes descriptions about social situations, socially acceptable (or expected) behaviors, the child's ability to go out into the community and participate, relationships, navigating the environments in which behaviors are socially appropriate or inappropriate | "Beaches are not good... bright sunlight, loud crashing waves, and the sand, it's just a perfect storm, a sensory nightmare, and we do live in Maryland and so we're on the coast, and so going to the beach is definitely something that people do socially here. So, I think it's going to these social events, so, going to concerts, that's out, going to movies, probably out, going to the beach, right out. So, there are a lot of activities that he's just not going to be able to participate in, and it does have social repercussions, absolutely." |
| Living environment | Includes descriptions about how their current or future home/living | "When you lived in an apartment usually there are the noises of the other people in the other units, and that's part of apartment living, right? So, I could imagine that being a challenge for him." |
| Developmental or psychological | Includes descriptions about skill development (e.g., gaining new skills/more independence, personal motivation, overcoming challenges, using sensory preferences as a reinforcer). Includes developmental descriptions about how a child's sensory sensitivities alter parents' expectations for their child's future. Includes descriptions about mental/emotional health (e.g., sensory sensitivities causing stress, interfering with happiness, leading to pleasure) | "...independence, perfect example, who wants to bake and cook and use a mixer if you have to go like this [mimics hands covering ears tightly] the whole time, right? So now, you know, she can work the...she can make herself a smoothie, she can, you know. So yeah, I mean, I would say that they are, you know, directly related." |
| Parental, caregiver, or staff support/involve-ment | Includes descriptions about how a parent/caregiver supports their child and does additional planning related to their sensory sensitivities | "Having an assistant with him would be necessary if his sensory was not under control. Things can happen, things can happen out there that you haven't anticipated noise-wise." |
| Physical safety, physical health, and hygiene | Includes descriptions about physical safety, physical health, and hygiene in relation to themselves and others | "I mean, I worry about it. If he doesn't brush his teeth, his teeth are gonna rot out of his head, or he's gonna get bleeding gums, and it's gonna lead to root canals and all kinds of other stuff, you know. And I just don't want that stuff to happen." |
| Profession—school, job, or vocational training | Includes descriptions about how sensory sensitivities impact schooling, their job, or vocational training | "It's going to be very hard for him to get a job, even if he went to a supermarket, he would not be able to even bag groceries because if one person yelled at him, it would be the whole sensory overload or if he had to put something in the bag and it was wet or if he had to put something in the bag and it was hard or it was meat, something like that and something that touched his hand that would be gushy, it would end up being all over the place, the bag would go on the floor and he would just walk into the corner and go 'Ah, ah, ah.' So, that's going to be a big problem for him, even just finding a job because of his sensory issues." |
| Self-advocacy or lack thereof | Includes descriptions about (in)ability to use language to communicate needs, the need for self-advocacy, or the need to ask for accommodations | "... to me the biggest piece is self-advocacy, because that I think ultimately is the hallmark, well, at least one of the hallmarks of adulthood, is to be able to speak up for yourself and what you need, to be able to ask for help when you need it." |

Table 4 (continued)

| Category | Definition | Exemplar quotes |
|--|--|--|
| Sensory management | Includes descriptions about self-regulation, trust in child's ability to manage sensory needs, managing reactions to sensory situations, adapting, shaping behavior, or increasing tolerance to aversive stimuli | "I think kind of her being able to sort of integrate her sensory needs into her daily life to understand that there are things that she needs and absolutely has a right to, while at the same time understanding, again, how to behave appropriately..." |
| Interference of tasks or opportunities | Includes descriptions about sensory sensitivities leading to their child missing information, losing track of tasks, lack of productivity, preoccupation with sensory sensitivities, and sensory sensitivities restricting new experiences/opportunities | "Because he already has a lot of resistance to change to new situations, to trying things, just because that comes with the whole package of autism. And then you add on top of it and aversion to smell, an aversion to the way that looks, the way that sounds, the way that tastes, the way that feels, and it's just going to be a roadblock to new experiences, to new people, to new things, to new places." |
| Unclear/other | Includes descriptions where the impact is unclear or not included in our codebook | "But I think you should just put trust you know, in your kids." |

These codes describe how parents believe their children's sensory sensitivities (will) impact their transition to adulthood

Table 5 Frequencies of endorsed sensory sensitivities

| Category | # | % |
|-------------------------------------|----|-------|
| 1. Touch | 55 | 83.33 |
| 2. Sound | 55 | 83.33 |
| 3. Sight | 38 | 57.58 |
| 4. Taste | 37 | 56.06 |
| 5. Smell | 36 | 54.55 |
| 6. Unclear/Other | 34 | 51.52 |
| 7. Food texture or food temperature | 25 | 37.88 |
| 8. Bodily states | 22 | 33.33 |

Percentages are out of 66 participants

Table 6 Frequencies of endorsed impacts of sensory sensitivities on the transition to adulthood

| Category | # | % |
|--|----|-------|
| 1. Developmental or psychological | 59 | 89.39 |
| 2. Interpersonal, community, or social situations | 55 | 83.33 |
| 3. Sensory management | 54 | 81.82 |
| 4. Profession—school, job, or vocational training | 46 | 69.70 |
| 5. Interference of tasks or opportunities | 45 | 68.18 |
| 6. Parental, caregiver, or staff support/involvement | 44 | 66.67 |
| 7. Lack of impact | 37 | 56.06 |
| 8. Physical safety, physical health, and hygiene | 37 | 56.06 |
| 9. Living environment | 34 | 51.52 |
| 10. Self-advocacy or lack thereof | 33 | 50.00 |
| 11. Unclear/other | 8 | 12.12 |

Percentages are out of 66 participants

spectrum is not feeling things. And that's going on with [my son]... not feeling how clothes are on properly or not, not feeling whether your hands are messy or your face is messy."

None of the frequencies reported in Table 5 differed significantly by age or gender when using median splits.

Research Question 2a: The Impact of Sensory Sensitivities on the Transition to Adulthood

On average participants endorsed 6.85 impacts, ranging from 4 to 10 impacts with a mode of 8 (see Table 4 for definitions and Table 6 for frequencies).

Developmental or Psychological

Nearly all the parents (89%) described how their children's sensory sensitivities impacted them developmentally or psychologically as they transitioned. Parents discussed how their children's sensory sensitivities impacted their

expectations for their children achieving independence. In doing so, parents evoked this idea of a trajectory *towards* adulthood and independence. Their descriptions ranged from that trajectory being truncated, obscured, or slowed. Parents also described hopes that their children's sensory sensitivities would not be limiting and that the sensitivities would improve. However, some parents felt that the sensory sensitivities were not insurmountable. For example:

And, as I watched him work through these sensitivities and work through the challenges in his life, I saw... that he could overcome certain things and he could be a productive member of society. So why can't he continue on that track and live independently and, you know, transition to adulthood? ... it's going to take longer so, you know, I got to keep that perspective. But he can do it eventually, in his time.

Other parents then described sensory sensitivities as facilitating skill development, in that a preferred sensory activity would be used as reinforcers (e.g., swinging as a reward for verbally identifying an object) and the desire to learn an independent skill helped build tolerance to aversive stimuli (e.g., using a hand mixer to make cookies despite the unpleasant sounds).

Within this category, parents also discussed how sensory sensitivities impacted their children psychologically positively, such as providing a source of leisure, and negatively, such as causing stress or anxiety and interfering with happiness. Some parents used common language, discussing how their children's sensory sensitivities impeded their ability to "feel comfortable in their own skin." Other parents discussed their children's sense of self and self-awareness in relation to their sensory sensitivities, describing the ways in which their children knew about their sensory sensitivities and the challenges it presented. However, some parents talked about how their children were not able to recognize their sensory sensitivities and how this lack of awareness was something they hoped would dissipate over time. Some parents explicitly discussed what type of self-awareness their children needed to develop in order to be successful, focusing on understanding *how much* the sensory stimuli were bothersome. Finally, parents also described how they hoped that their children did not think less of themselves for having their sensory sensitivities, emphasizing that everyone has their own quirks and preferences.

Interpersonal, Community, or Social Situations

A majority of parents (83%) expressed beliefs that their children's sensory sensitivities impacted or would impact them socially. At the community level, many parents talked about other people's perceptions of their children's sensory

behaviors and what others viewed as socially acceptable. They discussed how their children's sensory behaviors caused unwanted attention because their behaviors were unexpected, such as being unusual actions for young adults (e.g., plugging their ears) or because their children otherwise presented "typically." Some parents described that they were not bothered by the negative attention, while others were. Some parents worried that their children's unexpected behavior would elicit negative behaviors in others. One parent questioned:

And how do you make sure you're controlling your environment in a way that's acceptable...? ...unfortunately, people... if they don't get that expected behavior, they do sort of get agitated, because it's unexpected. And people don't really like change or unexpected. So, really, giving him that toolset to, like, transition, not just to transition but, like, to survive it. Because, like, realistically, he's trying to operate in a world that he doesn't understand or belong to because it's not his world.

Driven by worries of stigmatization, parents helped their children understand socially appropriate behaviors (e.g., requesting that someone stop making a particular noise rather than yelling). Similarly, some parents described how their children learned to mask their behaviors in public, such that they did not receive negative attention. Many parents expressed frustration at the conflict between wanting their children to embrace who they are and the realities of social expectations and other people's judgement. At the interpersonal level, some parents believed that their children's sensory sensitivities would impact their abilities to form connections (e.g., romantically due to challenges with physical touch, platonically due to avoiding environments with aversive auditory stimuli) and participate in social gatherings (e.g., inability to go to restaurants due to taste aversions).

Sensory Management

Many parents (82%) described how their children's sensory sensitivities impacted their transition to adulthood through their (in)ability to manage them. Many parents described their strategies as "coping", as well as learning to "tolerate", "overcome", or "deal" with aversive stimuli; others talked about "controlling" or "managing" sensory behaviors. While some parents broadly talked about sensory management, others were specific regarding the management strategies their children do or do not use (e.g., wearing headphones).

Some parents felt that their children's ability to transition was impeded because they did not know when or how to manage their sensitivities. However, other parents felt confident that their children could access management tactics when needed. Further, some parents explained that while their

children knew which strategies to rely on once in a sensory situation (e.g., locating sunglasses after going outside), their child's next step towards independence was *anticipating* and *preparing* for those scenarios (e.g., packing sunglasses in a bag beforehand). Like with other categories, other's perceptions of their children's sensory management strategies were common in parents' responses. One parent predicted, "That's probably gonna be... a life-long challenge probably for him because he's got this issue and he deals with it the way he knows how which is great but others may not understand what he's doing."

Profession—School, Job, or Vocational Training

70% of parents discussed their child's sensory sensitivities impacting their profession. Because of the age range of the participants' children (16;0–25;11), professions encompassed schooling, jobs, and vocational training. Parents felt that their children's sensory sensitivities impacted the type of profession they could have, their ability to perform it, and their interactions.

Children's sensory sensitivities both facilitated and limited job opportunities. Some parents felt that their children's sensory sensitivities could be harnessed into a career. One parent hoped, "... audio engineering... is an example of a job where being sensitive to the audio is an enhancement... So, if he could find something like that... it would be a gift to him." Parents also discussed that their children needed to find jobs in environments that met their sensory needs (e.g., a shortened work week to compensate for being overwhelmed by sensory stimuli). Conversely, some parents worried that their children's sensory sensitivities would make it difficult for them to find or maintain a job (e.g., touch sensitivities to clothes eliminating jobs with dress codes). Other parents expressed concern that their children's sensory sensitivities compounded the existing challenges of finding a job given their skill level. For example, a parent explained, "...the noise, so you know, when you have low job skills... Some might be like assembly line, or they might be in a store, and that, you can't always control the noise volume."

Similarly, some parents felt that their children's sensory sensitivities would enhance their work performance (e.g., using perfect pitch in audio editing positions), while others feared it would hinder them (e.g., aversive auditory input derailing success). Parents also emphasized that their children's sensory sensitivities would impact their work interactions, such as reacting negatively to a handshake during an interview. For schooling, some parents believed that their children's sensory sensitivities created barriers, such as noises being distracting or engaging in visual stimulatory behavior at the expense of attention. Conversely, other parents explained that their children masked their sensory sensitivities at school and were able to "hold it together."

Interference of Tasks or Opportunities

68% of parents described how their children's sensory sensitivities impeded their success as they transitioned, narrowing their options in terms of what they can do and where they can go. Parents felt that their children's sensory sensitivities prohibited their children from moving forward and from learning new skills. One parent explained:

I'd have to go back to that chain... it disallows him from being able to do the next thing... a lot of stuff he can't do... has to start from the sensory, the sounds, the touch...tasting, he can't cook because he can't taste the food and he can't pour the things because he can't touch the things... it all connects back to sensory.

For other parents, this concern went a step further; they believed that their children's sensory sensitivities prohibited task completion, "...he'll start becoming so bothered... that he then focuses on that... the task he can do then becomes extremely compromised because now his body and his emotions and everything is very focused on that sensory... then that productivity stops..." Parents also discussed that their children were missing information due to sensory behaviors distracting from (e.g., seeking oral input) or blocking (e.g., wearing headphones) their environment. Some parents believed that their children's distress about potentially aversive sensory situation minimized their ability to have new experiences and to identify new sources of happiness. One parent said, "...it keeps her from doing things...there's always that fear or anxiety or the feeling of that scratchy fabric... it's almost like you're traumatized, right?" Some parents worried that this avoidance would even lead to social isolation later in life.

A subset of parents talked about how auditory sensitivities limited the ways in which their children could travel or the places they could go. For example, if their children were averse to the sound of crying babies, they could not fly because they would be trapped in a plane, thereby limiting future opportunities. For other families, their children's negative behaviors to aversive stimuli were so negative that they stopped visiting particular environments where the stimuli might be present, again limiting the child's future opportunities.

Parental, Caregiver, or Staff Support/Involvement

Two thirds of parents (67%) discussed ways in which they, other caregivers, and staff support their children navigate their sensory sensitivities as they have aged. Parents often described plans they implement to help their children, such as mentally preparing their children for loud events, minimizing aversive stimuli in their home to eliminate sensory distress, finding resources for their child, and planning for

the future by establishing guardianship, trusts, and familial responsibilities. In doing so, parents demonstrated the extent to which they would go to help their children with their sensory sensitivities. To make community spaces more understanding of her child's sensory needs, one parent described, "it puts more pressure on me as a parent and a legal guardian, because I feel the need to clear a path, pre-teach any public place he's going to." Parents also described including the sensory sensitivities in their children's IEP goals and talking to their supervisors on their children's behalf.

Additionally, some parents believed that in order for their children to transition, they needed support from additional staff. Some parents discussed how a behavioral therapist in the community would be beneficial to manage challenging behaviors due to aversive stimuli. Other parents described how a psychologist would be helpful, providing tools for their child to implement when overwhelmed by sensory situations. For children that struggled with self-awareness, parents believed that they or other staff could help their child build introspection and the ability to recognize when a sensory environment was becoming overwhelming. Finally, a subset of parents also felt that, in order for their children to lead fulfilling lives, they needed to be surrounded by people who knew and understood their sensory sensitivities. For example:

... if [my daughter] was out shopping with someone who doesn't know her as well as we do, who may not be picking up with all of her nonverbal cues. I think it would be an obstacle for sure because they wouldn't be able to recognize and respond to it in the same way or right away.

Lack of Impact

All parents identified at least one sensory sensitivity that would impact their child's transition to adulthood. However, 56% of parents also discussed at least one sensory sensitivity that would *not* be impactful, suggesting that the impact of the sensory sensitivity was sensory modality specific and situation dependent. For example, one parent explained the impact of sound in relation to her son's profession and living environment, while also noting how food textures and visual stimuli would likely not impact him professionally or socially:

I don't think the food textures and things like that are going to be a deal breaker for him. ... from a noise perspective, I could see it affecting... he would have to be in a quiet office and it's going to affect where he lives to a point 'cause seeing when we were in Ireland

how agitated he was with that street sound and stuff. He doesn't like the light, but he'll go ahead into the light if something is pushing him. He will go to work; he will get on that schedule and he will meet up with friends in the daytime and stuff. So I don't see visually that being an issue.

In these moments, some parents also articulated that they did not view their children's sensory sensitivities as problematic and sometimes related the sensitivities to themselves, "Of course there's the tags, I mean you know if he doesn't like them then that's fine, I don't like them either... I get it... that's not going to affect him I think in the long run." Generally, parents felt that some sensory sensitivities were benign because they could be avoided and were within their child's control (e.g., not eating particular foods).

Many parents discussed how their children's sensory sensitivities were integral to who their child was or were masked by more pressing challenges (e.g., anger management), making it difficult to articulate (at that particular point in the interview) how the sensory sensitivities impacted the transition to adulthood. Other times, parents were not sure how their children's sensory sensitivities impacted their transition, sometimes because they had not considered it before or sometimes because they did not have the opportunity to observe it. One parent explained, "I would hope not, I would hope not. But there's only so much that I can see when I'm not with him. I don't know what happened when he was at his internship, I don't know."

Physical Safety, Physical Health, and Hygiene

Just over half of parents (56%) also believed that their children's sensory sensitivity impacted their or others physical safety, their health, and/or their hygiene. Regarding physical safety, parents focused on if other people perceived their children's sensory behaviors as threatening or dangerous (e.g., screaming due to aversive stimuli, engaging in self-injurious behavior). In doing so, several parents mentioned the police. For example:

I don't want him to act non-autistic or anything, I don't care about that, but it's really more about not scaring people or just being safe. You'll scare someone if you walk up to a stranger and smell their hair, you know, they could call the police on you.

Parents also described how their children would engage in potentially harmful behavior to themselves if faced with aversive stimuli, such as jumping out of a moving car due to

unpleasant odors, and to others, such as strangling someone for making them eat a particular food. Many parents felt that these safety risks, real or perceived, limited their children's opportunities (e.g., jobs, group homes, community acceptance).

For health, regarding touch and bodily states, parents described how their children would wear clothes inappropriate for their climate, making them susceptible to heat stroke or frostbite. For taste, parents expressed concerns that their children's restricted diets could lead to diabetes and heart disease, as well as high cholesterol and blood pressure. In the context of Covid-19, some parents discussed how their children found face masks aversive and, in an effort to keep their children safe, parents had to restrict their activities. Finally, parents believed that their children's sensory sensitivities negatively impacted their hygiene. For touch, parents talked about their children's sensitivity to toothbrushing leading to root canals and gum disease, as well as their aversion to the feeling of soap causing a lack of cleanliness and sanitation.

Living Environment

About half of parents (52%) discussed their children's sensory sensitivities in relation to where they are living or might live in the future. These discussion points related to their children living within a family context (e.g., in their family's home, carriage house, or second property), residentially (e.g., in a group home), and independently (e.g., in their own house, or apartment). In a family context, some parents explained that because of their sensory sensitivities, their children would never be able to live alone, without their family, or without people who were highly familiar with their child's needs. Other parents discussed modifying their home or their children's room to meet their sensory needs.

Regarding group homes, parents explained that their children's sensory sensitivities created additional parameters for selecting the right environment, "I mean that's part of that major concern... 'cause as far as I know, there are not very many or any programs that are dealing with sensory things like kids who are low functioning sensory kids." This became challenging for parents when the availability of group homes was limited geographically and/or through years long wait lists.

In terms of living independently, parents explained how they were teaching their children to identify optimal living environments for their individual needs, such as selecting a corner unit in an apartment building to minimize noise. Some parents spoke more generally, explaining the sensory difficulties that could arise in living independently, such as

noisy neighbors or loud traffic patterns; others described specific sensory solutions, such as suggesting that their children only use paper plates to avoid the feeling of food while washing dishes. Parents also talked about how their children modified their own living environments due to their sensory sensitivities, such as keeping their blinds drawn in their room, and expected their children would maintain those habits in the future. Other parents described their children's desire to live independently and their confidence in their children to do so. A subset of parents mentioned climate as well, explaining that their children found long clothing aversive, so warmer climates would be better. Some parents also expressed general sadness, worry, and fear about where their children will live in the future, acknowledging that they themselves will not be around forever and that residential homes in their geographical area could not meet their child's needs.

Self-advocacy or Lack Thereof

Half of the parents (50%) discussed how their children's sensory sensitivities related to self-advocacy in their transition. Parents' comments ranged from *hoping* that their children would learn to advocate for their sensory needs to examples of their children self-advocating or being unable to do so. Further, many parents explained that self-advocacy laid the transition's foundation, for better (e.g., "...the key to independence is self-advocacy. I think the key to her sensory is self-advocacy, right, to get her sensory needs met, to get her independence needs met") or for worse (e.g., "I think more just communication about it to others so that it doesn't isolate him... if he was able to do that regularly... it would make it much easier for him going forward to be an independent adult"). In the context of aversive stimuli, several parents explained that their children's lack of self-advocacy was going to impede their independence because parents were left guessing what was causing their children distress; they felt like they could not help or understand their children. For the children that were not already self-advocating for themselves, some parents discussed how they were teaching their children this skill and the nuances of appropriately advocating given a particular social context. Notably, some parents explained that their child's ability to advocate for their sensory needs was tied to their language and cognitive level. When describing interoception and pain, one parent said:

... when you don't have the language, I mean, how do you teach a child what hurts and what doesn't? I mean in order to say, "oh yeah, this hurts!" you have to hurt her. Who's going to do that? ... So it's very difficult

Table 7 Impacts of sensory sensitivities on the transition to adulthood by child characteristics

| Category | Independence level | | | ABC-2 Hyperactivity/Noncompliance | | | VABS-3 ABC | | | Sound Hypersensitivity Z-Score | | |
|--|--------------------|----------------|----------------|-----------------------------------|----------------|----------------|----------------|----------------|----------------|--------------------------------|----------------|----------------|
| | <4.31 | ≥4.31 | X ² | ≤8 | >8 | X ² | ≤69 | >69 | X ² | ≤0.09 | >0.09 | X ² |
| | % ^a | % ^a | | % ^b | % ^c | | % ^d | % ^e | | % ^b | % ^c | |
| 1. Developmental or psychological | 87.88 | 90.91 | 0.00 | 91.18 | 87.50 | 0.01 | 80.00 | 100.00 | 4.99 | 85.29 | 93.75 | 0.51 |
| 2. Interpersonal, community, or social situations | 78.79 | 87.88 | 0.44 | 82.35 | 84.38 | 0.00 | 85.71 | 80.65 | 0.05 | 91.18 | 75.00 | 2.05 |
| 3. Sensory management | 75.76 | 87.88 | 0.92 | 82.35 | 81.25 | 0.00 | 74.29 | 90.32 | 1.87 | 70.59 | 93.75 | 4.49 |
| 4. Profession—school, job, or vocational training | 63.64 | 75.76 | 0.65 | 73.53 | 65.63 | 0.19 | 57.14 | 83.87 | 4.37 | 67.65 | 71.88 | 0.01 |
| 5. Interference of tasks or opportunities | 72.73 | 63.64 | 0.28 | 64.71 | 71.88 | 0.13 | 62.86 | 74.19 | 0.52 | 52.94 | 84.38 | 6.13 |
| 6. Parental, caregiver, or staff support/involvement | 69.70 | 63.64 | 0.07 | 58.82 | 75.00 | 1.28 | 62.86 | 70.97 | 0.19 | 76.47 | 56.25 | 2.19 |
| 7. Lack of impact | 45.45 | 66.67 | 2.21 | 61.76 | 50.00 | 0.51 | 54.29 | 58.06 | 0.00 | 61.76 | 50.00 | 0.51 |
| 8. Physical safety, physical health, and hygiene | 72.73 | 39.39 | 6.15 | 38.24 | 75.00 | 7.61 | 71.43 | 38.71 | 5.88 | 50.00 | 62.50 | 0.60 |
| 9. Living environment | 51.52 | 51.52 | 0.00 | 47.06 | 56.25 | 0.25 | 57.14 | 45.16 | 0.53 | 50.00 | 53.13 | 0.00 |
| 10. Self-advocacy or lack thereof | 42.42 | 57.58 | 0.97 | 58.82 | 40.63 | 1.52 | 42.86 | 58.06 | 0.97 | 41.18 | 59.38 | 1.52 |
| 11. Unclear/Other | 12.12 | 12.12 | 0.00 | 11.76 | 12.50 | 0.00 | 11.43 | 12.90 | 0.00 | 17.65 | 6.25 | 1.08 |

^aPercentages are out of 33

^bPercentages are out of 34

^cPercentages are out of 32

^dPercentages are out of 35

^ePercentages are out of 31

when you don't have the cognitive ability to be able to articulate exactly what's going on in your body.

Research Question 2b: The Impact of Sensory Sensitivities on the Transition to Adulthood by Child Characteristics

The frequencies of the endorsed impacts did not differ by age, anxiety, irritability, or touch hypersensitivity when using median splits. Likewise, the frequencies of the endorsed impacts did not differ by gender, ASD severity, or language level.

Before correcting for multiple comparisons using the Benjamini–Hochberg method, the frequencies of endorsed impacts did differ by independence level ($X^2 = 6.15$, $p = 0.013$), hyperactivity/noncompliance ($X^2 = 7.61$, $p = 0.006$), and overall adaptive skills (VABS-3 ABC; $X^2 = 5.88$, $p = 0.015$) for “Physical safety, physical health, and hygiene”. Impact frequencies also differed by overall adaptive skills for “Developmental or psychological” ($X^2 = 4.99$, $p = 0.026$) and “Profession—school, job, or vocational training” ($X^2 = 4.37$, $p = 0.037$). Likewise, impact frequencies differed by sound hypersensitivity for “Sensory management” ($X^2 = 4.49$, $p = 0.034$) and “Interference of tasks or opportunities” ($X^2 = 6.13$, $p = 0.013$; see Table 7). However, upon correcting for multiple comparisons, no group differences survived.

Discussion

The main goal of our study was to address a gap in the ASD literature by asking parents how they believed their children's sensory sensitivities impacted or will impact their transition to independence. To contextualize their responses, we first established that, across all ages and in both daughters and sons, their children most frequently had auditory and tactile sensitivities. In their responses to key interview questions, parents discussed how their children's sensory sensitivities impact their ability to gain independence to varying degrees, primarily regarding developmental trajectories and psychological influences, social situations, and sensory management. After correcting for multiple comparisons, there were no significant group differences regarding the endorsed impacts, suggesting that, in our sample, *all* parents, regardless of their child's profile, had similar concerns for how their child's sensory sensitivities would impact their transition to adulthood. Previous studies have demonstrated that child characteristics, such as ASD symptom severity, predict parental expectations (Holmes et al., 2016, 2018), so it was surprising that we did not find group differences. However, as the first study to exclusively examine the connection between sensory sensitivities and impending independence, this null result emphasizes the importance of this intersection. Despite the heterogeneity of their children, *all* parents in our sample had similar concerns, suggesting that this is an area worth investigating more deeply.

Our findings also converge with the extant literature. In terms of the category “**Profession—school, job, or vocational training**,” findings from our study track with findings from the ASD sensory sensitivity literature. Howe and Stagg (2016) found that autistic adolescents felt that their sensory sensitivities led to classroom distractions and therefore them missing critical information. From the perspective of caregivers, Cai and Richdale (2016) also reported sensory sensitivities as distracting in educational contexts for their adult children. The category “**Parental, caregiver, or staff support/involvement**” can be seen in the extant literature as well. Schaaf et al. (2011) discussed the many ways in which parents alter their family’s routine to accommodate their young children’s sensory needs, just as the parents in our study describe supporting their children. Combined, these findings triangulate the perspectives our participants shared, suggesting that sensory sensitivities’ negative educational impact, as well as parental support in relation to sensory sensitivities, may be constant throughout development.

Moreover, another salient theme between the extant literature and our results revolves around the interconnectedness of sensory sensitivities. From interviews with autistic adults, Smith and Sharp (2013), Robertson and Simmons (2015), and MacLennan et al. (2022) have proposed bidirectional models in which sensory experiences interact with, moderate, and impact many aspects of lived experiences. Our results similarly illustrate a “chain reaction”, in which because of their children’s sensory sensitivities, parents report interference with tasks, physical and mental health consequences, and social isolation or avoidance. Likewise, our results also demonstrate moderating factors, which can be most clearly seen in the “**Lack of impact**” category. In our study, the degree to which parents report that sensory sensitivities impact the transition to adulthood appears to depend on context and sensory modality. Again, this speaks to a potential developmental trend, in which sensory sensitivities appear to be tightly connected to many daily experiences through adolescence, young adulthood, and even into later adulthood.

When exploring the perspectives of caregivers and autistic young adults learning to navigate the health care system, Cheak-Zamora et al. (2017) found that parents worried that their child’s developmental age lagged behind the responsibilities associated with their chronological age. Similarly, our parents discussed how their children’s trajectory towards independence was dampened due to their sensory sensitivities. Likewise, Cheak-Zamora et al. (2017) discussed parental concerns regarding their children’s behavioral unpredictability. However, rather than in the context of unexpected social behaviors as discussed by our participants, this was reported in the context of social situation efficacy. Cribb et al. (2019) broadly examined parental and child perspectives at this

transition period and found that parents believed that their children’s transition was hindered by their challenges with newness. This perspective maps onto the category “**Interference of tasks or opportunities**” that we identified in our interviews. Some parents in our study shared that their children would not try new opportunities due to fear of aversive stimuli. For the category “**Living environment**”, just as in our findings, other caregiver perspective studies describe parents’ fears regarding maintaining their children’s current living situation and fears about what will happen to their children after they pass away (Cheak-Zamora et al., 2017; Cribb et al., 2019; Sosnowy et al., 2018). Collectively, the similarities between the findings in our work and those in the sensory sensitivity and transition literature speak to the importance of considering antecedents in order to achieve a more nuanced understanding of lived experiences. Although these studies share the same parental perspectives, what differentiates our findings is the context for parental expectations. In their opinion, our participants have their perspectives *because* their children have sensory sensitivities.

Limitations

Although it was a critical first step to establish that parents believe their children’s sensory sensitivities impact their transition to adulthood, this study is not without its limitations.

Our participants were limited to individuals with reliable internet access, as well as access to a smart phone, tablet, or computer to complete the questionnaires and interview. Participants were also limited to those who were at least conversationally fluent in English due to the language abilities of the researchers. Finally, participants were restricted to those who had the availability to join; while this is always a limitation of any study, it is particularly notable because this study took place during Covid-19. It raises questions about who was able to balance working at home with caregiving and who had the mental bandwidth to add obligations to their existing responsibilities. Further, we excluded parents whose children did not live at home; it is possible that our results do not generalize to children who live in a residential facility or group home.

In terms of study design, we did not involve stakeholders (i.e., parents, autistic individuals) in the interview script development; doing so could have increased our study’s trustworthiness (Elo et al., 2014) by ensuring that the participants understood the interview questions as they were intended. Additionally, the parental beliefs reported in this study are only from *one* parent. 82% of participants indicated that they were not single; we do not know if these perspectives would be upheld by their partners. We also do not know if other family members

or individuals in their child's care team (e.g., therapists) would share these parental beliefs or if they would provide new insights. Some parents of minimally/non-verbal children shared that the AASP was challenging to complete because many questions relied on their child being able to explain the antecedent for their behaviors, so parents reported making assumptions.

Contributions

Despite these limitations, this study demonstrates noteworthy implications. It is clear, from our sample of parents, that sensory sensitivities have a sustained impact through childhood and into the transition to adulthood. In order to best support individuals with ASD and their families, our practices must start considering how sensory sensitivities directly impact young adults' level of independence. As many parents noted, the vocational training that we provide some autistic young adults, such as bagging or stocking groceries, may be at odds with their sensory sensitivities. We must think creatively to provide more diverse vocational training that works *with* their strengths, not against their sensitivities. Additionally, some parents described challenges locating residential or group homes suited to their children's full set of needs, as many facilities did not have the expertise to support sensory sensitivities. Again, we must expand the available options and change our practices, increasing awareness of how to support individuals with sensory sensitivities, such that families do not experience additional barriers beyond those that already exist (e.g., geographic limitations, long waitlists). Holistically, this study calls for a shift in practices; for some autistic individuals, sensory sensitivities do not dissipate, and parents are in need of resources as their children age. This need should be not taken lightly; throughout the interviews, parents expressed genuine concerns and fears for their children's future due to their sensory sensitivities and the field should strive to address their deep, not unfounded worries. One parent summarized the feelings of many:

I just never thought I'd be here [at] 24, still fighting him over these crying babies. I just thought he would outgrow that [auditory sensitivity]... I'm living with this ticking time bomb all the time... I think examining the fact that this still exists in adults is really important... we spend a lot of time thinking about sensitivities in kids and teaching them skills of how to deal with all these and then for those that just never outgrow them, it's like "What? Are they just supposed to live like this?"

Future Directions

It is important to reemphasize that the results of this study only speak to *parent perceptions*; these beliefs are not necessarily reality or the true experiences of their children, so a critical next step would be to interview young adults themselves. Previous work has demonstrated the feasibility of interviewing verbal autistic children and adolescents about their sensory sensitivities (Kirby et al., 2015), as well as autistic adults themselves (MacLennan et al., 2022; Robertson & Simmons, 2015; Smith & Sharp, 2013), which helps to establish methodological precedent. Comparing the young adult perspectives against the beliefs of their parents would facilitate a more nuanced understanding of how the sensory sensitivities of autistic individuals impact their transition to adulthood. Further, having established that parents do believe that their children's sensory sensitivities impact their independence, a logical next step would be to determine *what* parents think would help at this intersection. Identifying beneficial supports would then lay the groundwork for developing such services. Moving forward, it may also be beneficial for sensory sensitivities to be actively considered in transition planning between service providers and parents, such as by systematically discussing the young adult's sensory sensitivities by each modality and in specific contexts to ensure that the transition plans (e.g., job training) are truly optimizing independence and not exacerbating sensory sensitivities.

Conclusions

Our study used qualitative content analysis to interview parents of young adults with ASD to determine how their children's sensory sensitivities impact their transition to adulthood. From our interviews, the overwhelming response was affirmative: sensory sensitivities do impact the transition to independence. While this impact was not child characteristic dependent, it was sensory modality and context specific. Moreover, for some families, the impact of their child's sensory sensitivities was defining:

I think [his sensory sensitivities] are the sky that we walk under all the time. Sometimes it's cloudy and awful and uncomfortable and then sometimes it's sunny and warm, but it's the sky we walk under all the time. And sometimes it's dark and sometimes it's light, sometimes it's stormy, sometimes it's beautiful, but it's the sky.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10803-022-05815-5>.

Acknowledgements The authors would like to acknowledge Matthieu Sherwood for his memory and spirit during this study. We would also like to thank Jenna Sandler Eilenberg for her qualitative analysis advice, as well as Katia Bulekova, Meredith Pecukonis, and Karen Chenausky for their statistical guidance. Most importantly, the authors would like to thank the families for their valuable time and invaluable insight.

Author Contributions RMH designed and implemented the study, developed the coding scheme, coded and analyzed the data, and drafted the manuscript. EBJ was involved in developing the coding scheme, coding the data, and revising the manuscript. HTF was the principal investigator of the Attention Training for Listening in Autism Study and critically revised the manuscript.

Funding This work was supported by the Department of Defense [W81XWH-18-1-0241].

Declarations

Conflict of interest The authors declare that they have no conflict of interests.

Ethical Approval All procedures performed in the current study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Institutional Review Board at Boston University.

Informed Consent Informed consent was obtained from all individual participants included in the study.

References

- Aman, M. G., & Singh, N. N. (2017). *Aberrant behavior checklist, second edition (ABC-2)*. Slosson Educational Publications.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). American Psychiatric Publishing.
- Ashburner, J., Ziviani, J., & Rodger, S. (2008). Sensory processing and classroom emotional, behavioral, and educational outcomes in children with autism spectrum disorder. *American Journal of Occupational Therapy, 62*(5), 564–573. <https://doi.org/10.5014/ajot.62.5.564>
- Baranek, G., David, F., Poe, M., Stone, W., & Watson, L. (2006). Sensory experiences questionnaire: discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 47*, 591–601. <https://doi.org/10.1111/j.1469-7610.2005.01546.x>
- Benjamini, Y., & Hochberg, Y. (1995). Controlling the false discovery rate—A practical and powerful approach to multiple testing. *Journal of Royal Statistical Society Series B, 57*, 289–300. <https://doi.org/10.2307/2346101>
- Ben-Sasson, A., Gal, E., Fluss, R., Katz-Zetler, N., & Cermak, S. A. (2019). Update of a meta-analysis of sensory symptoms in ASD: A new decade of research. *Journal of Autism and Developmental Disorders, 49*(12), 4974–4996. <https://doi.org/10.1007/s10803-019-04180-0>
- Brown, C., & Dunn, W. (2002). *Adolescent/Adult sensory profile (AASP)*. Pearson Assessments.
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(1), 31–41. <https://doi.org/10.1007/s10803-015-2535-1>
- Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food selectivity and sensory sensitivity in children with autism spectrum disorders. *Journal of the American Dietetic Association, 110*(2), 238–246. <https://doi.org/10.1016/j.jada.2009.10.032>
- Cheak-Zamora, N. C., & Teti, M. (2015). “You think it’s hard now ... It gets much harder for our children”: Youth with autism and their caregiver’s perspectives of health care transition services. *Autism, 19*(8), 992–1001. <https://doi.org/10.1177/1362361314558279>
- Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & Koegler, E. (2017). Exploration and comparison of adolescents with autism spectrum disorder and their caregiver’s perspectives on transitioning to adult health care and adulthood. *Journal of Pediatric Psychology, 42*(9), 1028–1039. <https://doi.org/10.1093/jpepsy/jsx075>
- Constantino, J. N., & Gruber, C. P. (2012). *Social responsiveness scale, second edition (SRS-2)*. Western Psychological Services.
- Cribb, S., Kenny, L., & Pellicano, E. (2019). ‘I definitely feel more in control of my life’: The perspectives of young autistic people and their parents on emerging adulthood. *Autism, 23*(7), 1765–1781. <https://doi.org/10.1177/1362361319830029>
- Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders, 49*(2), 556–568. <https://doi.org/10.1007/s10803-018-3729-0>
- Dunn, W. (2001). The sensations of everyday life: Empirical, theoretical, and pragmatic considerations. *American Journal of Occupational Therapy, 55*(6), 608–620. <https://doi.org/10.5014/ajot.55.6.608>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open, 4*(1), 2158244014522633. <https://doi.org/10.1177/2158244014522633>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Fernández-Andrés, M. I., Pastor-Cerezuela, G., Sanz-Cervera, P., & Tárraga-Mínguez, R. (2015). A comparative study of sensory processing in children with and without Autism Spectrum Disorder in the home and classroom environments. *Research in Developmental Disabilities, 38*, 202–212. <https://doi.org/10.1016/j.ridd.2014.12.034>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Hattier, M. A., Matson, J. L., Macmillan, K., & Williams, L. (2013). Stereotyped behaviours in children with autism spectrum disorders and atypical development as measured by the BPI-01. *Developmental Neurorehabilitation, 16*(5), 291–300. <https://doi.org/10.3109/17518423.2012.727107>
- Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities, 52*(2), 98–111. <https://doi.org/10.1352/1934-9556-52.2.98>
- Hochhauser, M., & Engel-Yeger, B. (2010). Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder (HFASD). *Research in Autism Spectrum Disorders, 4*(4), 746–754. <https://doi.org/10.1016/j.rasd.2010.01.015>
- Holmes, L. G., Himle, M. B., & Strassberg, D. S. (2016). Parental romantic expectations and parent–child sexuality communication

- in autism spectrum disorders. *Autism*, 20(6), 687–699. <https://doi.org/10.1177/1362361315602371>
- Holmes, L. G., Kirby, A. V., Strassberg, D. S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders*, 48(9), 2925–2937. <https://doi.org/10.1007/s10803-018-3545-6>
- Howe, F. E. J., & Stagg, S. D. (2016). How sensory experiences affect adolescents with an autistic spectrum condition within the classroom. *Journal of Autism and Developmental Disorders*, 46(5), 1656–1668. <https://doi.org/10.1007/s10803-015-2693-1>
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Ismael, N., Lawson, L. M., & Hartwell, J. (2018). Relationship between sensory processing and participation in daily occupations for children with autism spectrum disorder: A systematic review of studies that used Dunn's sensory processing framework. *The American Journal of Occupational Therapy*, 72(3), 1–9. <https://doi.org/10.5014/ajot.2018.024075>
- Ivey, J. K. (2004). What do parents expect?: A study of likelihood and importance issues for children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19(1), 27–33. <https://doi.org/10.1177/10883576040190010401>
- Jasmin, E., Couture, M., McKinley, P., Reid, G., Fombonne, E., & Gisell, E. (2009). Sensori-motor and daily living skills of preschool children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(2), 231–241. <https://doi.org/10.1007/s10803-008-0617-z>
- Kirby, A. V., Boyd, B. A., Williams, K., Faldowski, R. A., & Baranek, G. T. (2017). Sensory and repetitive behaviors among children with autism spectrum disorder at home. *Autism: THE International Journal of Research and Practice*, 21(2), 142–154. <https://doi.org/10.1177/1362361316632710>
- Kirby, A. V., Dickie, V. A., & Baranek, G. T. (2015). Sensory experiences of children with autism spectrum disorder: In their own words. *Autism: THE International Journal of Research and Practice*, 19(3), 316–326. <https://doi.org/10.1177/1362361314520756>
- Kuo, A. A., Crapnell, T., Lau, L., Anderson, K. A., & Shattuck, P. (2018). Stakeholder perspectives on research and practice in autism and transition. *Pediatrics*, 141(Supplement 4), S293–S299. <https://doi.org/10.1542/peds.2016-4300F>
- Lane, A. E., Young, R. L., Baker, A. E. Z., & Angley, M. T. (2010). Sensory processing subtypes in autism: Association with adaptive behavior. *Journal of Autism and Developmental Disorders*, 40(1), 112–122. <https://doi.org/10.1007/s10803-009-0840-2>
- Laxman, D. J., Taylor, J. L., DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2019). Loss in services precedes high school exit for teens with ASD: A longitudinal study. *Autism Research*, 12(6), 911–921. <https://doi.org/10.1002/aur.2113>
- Linderman, T. M., & Stewart, K. (1999). Sensory integrative-based occupational therapy and functional outcomes in young children with pervasive developmental disorders: A single-subject study. *The American Journal of Occupational Therapy*. <https://doi.org/10.5014/AJOT.53.2.207>
- Little, L. M., Ausderau, K., Sideris, J., & Baranek, G. T. (2015). Activity participation and sensory features among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45(9), 2981–2990. <https://doi.org/10.1007/s10803-015-2460-3>
- Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule, second edition (ADOS-2) manual (Part I): Modules 1–4*. Western Psychological Services.
- MacLennan, K., O'Brien, S., & Tavassoli, T. (2022). In our own words: The complex sensory experiences of autistic adults. *Journal of Autism and Developmental Disorders*, 52(7), 3061–3075. <https://doi.org/10.1007/s10803-021-05186-3>
- Pfeiffer, B., Coster, W., Snethen, G., Derstine, M., Piller, A., & Tucker, C. (2017). Caregivers' perspectives on the sensory environment and participation in daily activities of children with autism spectrum disorder. *The American Journal of Occupational Therapy*, 71(4), 1–9. <https://doi.org/10.5014/ajot.2017.021360>
- QSR International Pty Ltd. (2018). NVivo (Version 12). https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?_ga=2.240597895.543818462.1626810483-646238476.1626810483
- R Core Team. (2021). *R: A language and environment for statistical computing* (4.0.5). R Foundation for Statistical Computing. <https://www.R-project.org/>
- Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., & Chesla, C. A. (2012). Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *ANS. Advances in Nursing Science*, 35(3), E57-72. <https://doi.org/10.1097/ANS.0b013e3182626180>
- Reynolds, S., Bendixen, R. M., Lawrence, T., & Lane, S. J. (2011). A pilot study examining activity participation, sensory responsiveness, and competence in children with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 41(11), 1496–1506. <https://doi.org/10.1007/s10803-010-1173-x>
- Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception*, 44(5), 569–586. <https://doi.org/10.1068/p7833>
- Rutter, M., Le Couteur, A., & Lord, C. (2003). *ADI-R. Autism diagnostic interview revised*. Manual.
- Scahill, L., Lecavalier, L., Schultz, R. T., Evans, A. N., Maddox, B., Pritchett, J., Herrington, J., Gillespie, S., Miller, J., Amoss, R. T., Aman, M. G., Bearss, K., Gadow, K., & Edwards, M. C. (2019). Development of the Parent-Rated Anxiety Scale for youth with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 58(9), 887–896.e2. <https://doi.org/10.1016/j.jaac.2018.10.016>
- Schaaf, R., Toth-Cohen, S., Johnson, S., Outten, G., & Benevides, T. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism: THE International Journal of Research and Practice*, 15, 373–389. <https://doi.org/10.1177/1362361310386505>
- Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *Journal of Autism and Developmental Disorders*, 43(4), 891–910. <https://doi.org/10.1007/s10803-012-1633-6>
- Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, 22(1), 29–39. <https://doi.org/10.1177/1362361317699585>
- Sparrow, S. S., Saulnier, C. A., Cicchetti, D. V., & Doll, E. A. (2016). *Vineland adaptive behavior scales: Third edition (Vineland III)*. Pearson Assessments.
- Thissen, D., Steinberg, L., & Kuang, D. (2002). Quick and easy implementation of the Benjamini-Hochberg procedure for controlling the false positive rate in multiple comparisons. *Journal of Educational and Behavioral Statistics*, 27(1), 77–83. <https://doi.org/10.3102/10769986027001077>
- Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PLoS ONE*, 13(3), e0194758. <https://doi.org/10.1371/journal.pone.0194758>
- Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy*, 61(2), 190–200. <https://doi.org/10.5014/ajot.61.2.190>

- Tomchek, S. D., Little, L., & Dunn, W. (2015). Sensory pattern contributions to developmental performance in children with autism spectrum disorder. *The American Journal of Occupational Therapy*. <https://doi.org/10.5014/ajot.2015.018044>
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45(6), 1673–1688. <https://doi.org/10.1007/s10803-014-2324-2>
- Watson, L. R., Patten, E., Baranek, G. T., Poe, M., Boyd, B. A., Freuler, A., & Lorenzi, J. (2011). Differential associations between sensory response patterns and language, social, and communication measures in children with autism or other developmental disabilities. *Journal of Speech, Language, and Hearing Research*, 54(6), 1562–1576. [https://doi.org/10.1044/1092-4388\(2011/10-0029\)](https://doi.org/10.1044/1092-4388(2011/10-0029))
- Zobel-Lachiusa, J., Andrianopoulos, M. V., Mailloux, Z., & Cermak, S. A. (2015). Sensory differences and mealtime behavior in children with autism. *The American Journal of Occupational Therapy*, 69(5), 6905185050p1-6905185050p8. <https://doi.org/10.5014/ajot.2015.016790>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.