Sexual and Reproductive Health Service Utilization and Sexuality for Teens on the Autism Spectrum

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ABSTRACT: ***Objectives:*** **Health care providers and educators play critical roles in supporting healthy sexuality development for youth with autism spectrum disorder. There is limited information about the sexual behavior of these youth, especially girls, and about their access to sexuality education or health care services.** ***Methods:*** **This study addressed these gaps by surveying parents of youth with autism aged 12–18 years (N = 298, 52.7% boys) with a range of intellectual functioning.** ***Results:*** **According to parent report, most youth experienced sexual attraction and were interested in relationships, including same-sex attraction or relationships (13.2%). Girls were more likely than boys to have had a romantic relationship and less likely to have experienced school or legal consequences for sexual behavior. Around one-fifth of youth had engaged in a socially inappropriate sexual behavior, whereas 6.4% had a known sexual abuse history and 14.5% were bullied by peers for lack of sexual knowledge. Almost 40% received no sex education in school or in the community, including 60.9% of youth with parent-reported intelligence quotient under 70. Some parents consulted with school personnel (36.4%) or health care providers (55.9%) about sexuality issues, whereas 19.5% reported taking no action aside from talking to their child about sexuality. Utilization models including predisposing, enabling, and needs-related factors were applied to parent consultation with providers and use of school-based sexuality education programming.** ***Conclusion:*** **The results suggest unmet needs for sexual and reproductive health services, particularly among youth who are younger, those who have co-occurring intellectual disability, or those who are homeschooled or who attend private, charter, or therapeutic versus public schools.**

(*J Dev Behav Pediatr* 41:667–679, 2020) **Index terms:** autism spectrum disorder, adolescence, sexuality and puberty, sexual and reproductive health, service utilization, sexuality education.

An estimated 1 in 59 youth is diagnosed with autism spectrum disorder, meaning that 707,000 to 1,116,000 will transition to adulthood over the next decade.[1,2] Autism is associated with heterogeneity in intellectual, communication, and social abilities[2] and social motivation.[3] Similar to their neurotypical peers, many teens with autism experience sexual attraction and will engage in partnered sexual behavior and relationships during adolescence and adulthood.[4] The United Nations Convention on the Rights of Persons with Disabilities states that youth with disabilities have the right to the same range and quality of sexual and reproductive health services as their peers without disabilities.[5] Youth with autism often have complex medical and educational support needs that may affect puberty, sexuality development, autonomy, and personal identity.[6,7] Because of factors including social communication impairments and lack of information or understanding about sexuality,[8,9] youth with autism experience heightened sexual health risks, including sexual abuse or exploitation[10,11] and socially inappropriate sexual behavior (SISB).[12] People with autism who participate in surveys are more likely to be sexual and sex minorities (i.e., lesbian, gay, bisexual, pansexual, transgender, genderqueer, queer, intersexed, agender, asexual, and ally) than controls,[13] placing them at risk for family rejection, discrimination, and violence.[14] Thus, lack of access to developmentally

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appropriate school-based sexuality education (SBSE) and sexual and reproductive health services during adolescence threatens health and well-being across the lifespan. Currently, evidence on sexual and reproductive health outcomes and service utilization in autism is limited. Addressing this gap can help inform coordination and communication between families, schools, and health care professionals and thereby improve support for healthy sexuality development.

In the United States, students with disabilities are afforded the same rights to education as their peers without disabilities.[15] Laws governing SBSE vary by state, with 33 requiring information about HIV, 18 about contraception, and 13 mandating medical accuracy.[16] Currently, the best information on SBSE for students served by the special education system comes from the National Longitudinal Transition Study-2. In 2000, only 28% of students with autism received SBSE, with school staff reporting that an additional 30.9% of nonparticipants could have benefitted.[17] This represented the lowest SBSE rate of any disability; for comparison, 43.2% of students in the intellectual disability (ID) category participated. Across disability categories, students with moderate to profound ID (vs mild or none) and lower expressive language ability had lower odds of participating in SBSE or being categorized by school staff as nonparticipants who could benefit.[18] Barnard-Brak et al.[18] argued that every student can benefit from sex education "as long as instructional trials are matched to the individual student's strengths and weaknesses" as in other content areas (pg. 93). Adolescence is a critical timeframe for learning healthy behaviors, and lack of access to preventative health education may contribute to the "cascade" of health disparities experienced by people with ID across the life course.[19]

The need for comprehensive sexual and reproductive health care for youth with intellectual and developmental disabilities has been highlighted by the American Academy of Pediatrics and the Society for Adolescent Health and Medicine.[20,21] In a national survey of pediatricians caring for youth and young adults with autism, many reported addressing sexual health topics primarily on an "as-needed" basis rather than proactively.[22] Asked about topics raised routinely with all families, around half reported discussing risk for sexual abuse, sexuality/sexual behavior, or SISB, which affects an estimated one-third of youth with autism.[12] Only 25% routinely provided families with information specific to sexuality within the context of autism. Given that parents may not be aware of youth's sexual behavior, may underreport some behaviors (e.g., masturbation),[23] and can be ambivalent about SBSE,[24] it is important for pediatric providers to initiate conversations with families, encourage SBSE, and talk to youth without parents' presence when possible.[20] Over 90% of pediatricians perceived sexual health care as an important part of their role but reported that lack of training in sexual health and autism and the limited availability of accurate information to share with families were significant barriers. This study addresses the latter barrier by providing information on sexual behaviors by sex, age, and estimated level of intellectual functioning (IF).

Identification of autism in youth continues to increase,[2] meaning that health care providers will increasingly encounter teens with autism. Providing appropriate sexual and reproductive health care is critical for supporting lifespan health and well-being.[25] The goal of this study was to describe selected sexual behaviors and family utilization of SBSE and other services to inform educators and health care providers and contribute toward the development of standards of care for education and anticipatory guidance. Parent report was used for this study to include youth with ID and to provide stratified estimates of behaviors across the range of IF. Andersen's behavioral model of health services utilization was used to examine factors affecting parent engagement with professionals. The model incorporates individual and contextual determinants of service utilization, organized into predisposing (e.g., age, gender, race/ethnicity, and education), enabling (e.g., socioeconomic indicators, and location), and need-related factors (e.g., symptom severity).[26]

The aims for this project are as follows:

1. Examine parent-reported sexual interests, behaviors, and abuse experiences by sex and IF for 12- to 18-year-old youth with autism.
2. Describe parent actions in support of healthy sexuality development or to address sexuality-related problems (e.g., consulting with individualized education plan team or health care provider, formal social skills training, and providing sex education at home).
3. Identify parent-reported predisposing, enabling, and need-related factors in sexual and reproductive health service utilization (i.e., consulting with a health care provider, school personnel, or receipt of SBSE)

METHODS

Participants

We recruited 323 parents of adolescents with autism across 2 phases. Phase 1 occurred in 2012 to 2013, and phase 2 occurred in 2015 to 2016. Of the 323 enrolled in the study, we excluded from analyses those who did not provide adequate data (n = 11), failed data validity checks (n = 2), or rated their youth as below threshold on a measure of autism symptoms (n = 12; Social Responsiveness Scale, second edition [SRS-2]; Total Score; see below).[27] The final sample consisted of 298 parents of youth between the ages of 12 to 18 at the time of data collection. Phase 1 participants included the parents of 157 boys and 25 girls recruited via US autism support groups. Phase 2 participants included the parents of 116 girls recruited via research registries at the Children's Hospital of Philadelphia Center for Autism Research and the Interactive Autism Network Research Registry and Database (Johns Hopkins Medicine Institutional Review Board #NA_00002750; PI: Dr. Paul H. Lipkin), an online platform developed by the Kennedy Krieger Institute and

the Simons Foundation.[28] Autism diagnosis has a 4:1 sex ratio, leading to small samples of girls and women in research and gaps in understanding of sex differences.[29] Thus, phase 2 was specifically undertaken to recruit more parents of adolescent girls with autism to have a sample large enough to allow for investigation of sex differences at all levels of intellectual functioning (IF). Some demographics and data on family sexuality communication and parent activities to prepare youth for vocation and independent living are described elsewhere.[30–32] Parents were eligible to participate if they reported that their adolescent had a formal medical diagnosis of autism spectrum disorder. There were no specific exclusion criteria.

Procedures

This study was approved by the authors' institutional review board, and informed consent was obtained for all participants. Participants completed an anonymous online survey about autism and sexuality. Phase 1 participants were entered into a raffle for 10 $40 gift cards and received a list of relevant resources. Phase 2 participants received a $10 gift card and a list of resources.

Measures

Parents completed a 50-item web-based survey with demographics and an inventory of family sexuality communication topics,[30] sexuality-related concerns and expectations,[33,34] and questions about supports used to meet their child's sexual and reproductive health needs (see Supplemental materials for survey, Supplemental Digital Content 1, http://links.lww.com/JDBP/A261). Parents reported their child's measured intelligence quotient (IQ) (if known, 85.9%, n = 256) or provided an estimated IQ (n = 46) based on official descriptive guidelines.[35] Parents reported whether, to their knowledge, their child had participated in family-based, school-based, or community-based sexuality and relationships education. Survey questions were developed based on relevant studies with general population youth[36] and youth with autism.[24,37–40] All questionnaires created for this study were pilot tested and refined through feedback from parents of youth with and without autism.

Sexual Behavior Inventory

Parents were presented with the following normalizing statement: "Parents of youth with autism/Asperger's have reported a variety of romantic and sexual behaviors (listed below). Some behaviors are healthy and others may cause problems even though the child doesn't mean to hurt anyone." They were then asked whether, to their knowledge, their child had ever engaged in a list of behaviors or had experienced victimization ("yes," "no," or "not sure"). Responses indicating "no" and "not sure" were combined for analyses (see the Appendix for full questionnaire, Supplemental Digital Content 1, http://links.lww.com/JDBP/A261). Table 2 includes a selected list of these behaviors.

Parent Action Inventory

Parents were presented with the following statement: "Of the following, which actions have you taken to support healthy sexual development and opportunities for relationships, or to address sexuality-related problems that you've encountered?" Parents selected from a list (e.g., consulted with teachers or school personnel and spoke to other parents) or wrote in actions (Table 3). Parents were asked a separate question about whether they had consulted with an individualized education plan team about sexuality (yes/no), and this question was combined with the list item on consultation with teachers or school personnel. Parents could also respond by selecting 1 of 3 items, indicating that they had not taken any action. Respondents who indicated that they had not yet needed to take action, that they did not know what to do, or that they would take action later and who did not indicate taking any other actions were combined into a group for analytic purposes. Table 3 includes a selected list of these behaviors.

Social Responsiveness Scale—Second Edition (Parent Report)

The SRS-2 is a 65-item parent-report rating scale of autism symptoms, with items falling into the domains of social motivation, cognition, awareness, communication, and restricted or repetitive behavior. The measure has well-established psychometric properties.[27] SRS-2 Total Standard Scores (T-scores) were calculated based on male and female norms, and as noted, youth scoring below 60 were excluded from analyses. Thus, scores ranged from 60 to 107 (mean = 80.90, SD = 10.02) and were consistent with a diagnosis of autism spectrum disorder. The SRS-2 showed excellent reliability in this sample (Cronbach $\alpha = 0.926$).

Data Analysis

Analyses were conducted using SPSS Version 24 and G*Power.[41] The prevalence of youth behaviors and parent activities was calculated by youth sex, IF level, and age. Pearson χ^2 and Fisher exact tests were used to test associations between sex, IF, and age categories by behaviors and parent actions. To detect medium effects with χ^2 ($\alpha = 0.01$; N = 298), (1) for sex analyses ($df = 1$), we had 99% power; (2) for IF analyses ($df = 3$), we had 97% power; and (3) for age analyses ($df = 2$), we had 98% power. Cramer V is presented to indicate effect size for chi-squares. Cramer V (range = 0–1) is the same as phi for a 2×2 contingency table and is preferred for tables larger than 2×2. For analyses with minimum columns/rows = 2, small effects are 0.10 to 0.29, medium effects are 0.30 to 0.49, and large effects are ≥ 0.50.[42] Standardized residuals (mean = 0, SD = 1) are the square root of each cell's contribution to the χ^2 value. Adjusted standardized residuals are adjusted for row and column totals, with values of ± 1.96, suggesting that a cell is a significantly large contributor to the effect. Positive values indicate that significantly more cases are observed in the cell than expected, while negative values indicate significantly fewer cases than expected. Multivariate binary logistic regression models were conducted to determine whether youth and family characteristics were related to service access. For model 1, which predicted whether parents

Table 1. Demographics for Full Sample (N = 298)

	n (%) or Mean (SD)
Youth demographics	
Age, yrs, mean (SD); range	14.27 (1.78); 12–18
Male	157 (52.7)
Identifies as White/non-Hispanic[a]	247 (84.0)
IF below 70	64 (21.5)
IF borderline range (70–84)	38 (12.8)
IF average range (85–115)	100 (33.6)
IF above average (115+)	96 (32.2)
SRS-2 T-score, mean (SD); range	80.90 (10.02); 60–107
School setting	
Public	190 (65.5)
Private, charter, or therapeutic	68 (23.4)
Homeschool or online	32 (11.0)
Has individualized education plan	253 (85.2)
Parent demographics	
Age, yrs, mean (SD); range	46.92 (6.29); 30–66
Female	272 (92.2)
Identifies as White/non-Hispanic[b]	260 (87.2)
Urbanicity	
Suburban	206 (69.8)
Urban	48 (16.3)
Rural	41 (13.9)
Highest level of parent education is bachelor's or higher	208 (70.0)
Household income higher than US median ($59,000)	197 (68.2)
Married or cohabiting	236 (79.8)
Moderately or very religious	155 (53.1)

[a]Race was parent-reported. [b]Race was self-reported. IF, intellectual functioning (parent-reported); SRS-2, Social Responsiveness Scale, Second Edition.

consulted with a health care provider about sexuality, school setting was not included as an enabling factor because it was not expected to influence parent discussions with health care providers. Power analyses for N = 298 and $\alpha = 0.05$ indicated that (1) for model 1 (rate = 55.9%), an odds ratio of 2.0 could be detected with 0.81 power; (2) for model 2 (rate = 36.4%), it could be 0.84 power; and for model 3 (rate = 63.5%), it could be 0.77 power. To control for the effects of multiple comparisons, a priori α for significance was set to 0.01 for χ^2 and logistic regression models, with 95% confidence intervals (equating to $\alpha = 0.05$) used within logistic regression models.

RESULTS

Parent and youth demographic information is provided in Table 1. There were no demographic differences by sex or intellectual functioning (IF), and IF (above average, average, borderline, below average; see below) was evenly distributed across males and females (χ^2 [3, N = 298] = 3.768, $p = 0.288$). Parents of boys reported that 33.1% had above average IF, 35.7% had average IF, 14.0% had borderline IF, and 17.2% had IF < 70. Parents of girls reported that 31.5% had above average IF, 31.2% had average IF, 11.3% had borderline IF, and 26.2% had IF < 70.

Most parents in this study (85.2%) reported that youth had an individualized education plan, indicating that they were served by the US special education system. To examine how this sample compares with the broader population of youth with autism in the United States served by the special education system, we compared demographics with the National Longitudinal Transition Study-2012 (NLTS2012), a national representative sample of youth receiving special education services between 2012 to 2013.[43] In the NLTS2012, 12% of youth with autism were Black and 16% Hispanic. In the present study, 16% of youth identified as racial/ethnic minorities, including Black (0.7%), Hispanic (2.0%), Asian (1.7%), Native American or Alaskan (3.1%), or Multiracial (8.4%). In the NLTS2012, 37% of youth with autism lived in low-income households below the federal poverty level (e.g., $42,643 for a household of 4 in 2012). We are unable to make a perfect comparison with the NLTS2012 data because federal poverty level requires income and number of people in the household. However, 45% of participants in this study lived in households earning less than $50,000. Fewer NLTS2012 youth with autism (43%) had a parent with a 4-year degree or higher compared with youth in this study (70%). In the NLTS2012, 72% of parents were married or cohabitating, which is slightly less than in this study (79.8%). Compared with the NLTS2012, far more youth in this study lived in a suburban area (69.8% vs 39.0%), and fewer lived in urban (13.9% vs 28.0%) or rural areas (13.9% vs 33.0%). Finally, compared with US population-based autism data, this sample included a lower proportion of youth whom parents reported to be in the borderline range of IF (12.8% vs 25.0%) or IF < 70 (21.5% vs 31.0%).[2]

Youth Sexual Interests, Behaviors, and Abuse History

According to parents, most youth had expressed sexual attraction (68.5%) or the desire for relationships (58.4%; Table 2), with expressions of attraction (χ^2 [2, N = 298] = 17.892, $p < 0.001$, V = 0.245), desire for relationships (χ^2 [2, N = 298] = 14.828, $p = 0.001$, V = 0.223), and romantic relationships increasing with age (χ^2(2, N = 298) = 14.704, $p = 0.007$, V = 0.157). Few significant sex differences emerged. Parents of girls were more likely than parents of boys (19% vs 6.5%) to report that their youth had a romantic relationship (χ^2 [1, N = 296] = 10.883, $p = 0.001$, V = 0.192) and were less likely to report that their youth touched someone inappropriately (3.5% vs 12.1%; χ^2 [1, N = 298] = 7.343, $p = 0.007$, V = 0.157) or experienced school consequences for sexual behavior (0.0% vs 6.4%; χ^2 [1, N = 298] = 9.293, $p = 0.002$, V = 0.177). Parents of youth with IF < 70 were less likely to report that their child expressed sexual attraction (χ^2 [3, N = 298] = 20.853, $p < 0.001$, V = 0.265) or interest in relationships (χ^2 [3, N = 298] = 66.018, $p < 0.001$, V = 0.471) compared with other youth and more

Table 2. Parent Report on Youth Sexual Interests, Behaviors, and Abuse Experiences by Youth Sex, IF, and Age: Results of χ^2 Analyses

	% (95% CI)									
Variable	**Total Sample (N = 298)**	**Parents of Boys (n = 157)**	**Parents of Girls (n = 141)**	**IF < 70 (n = 64)**	**Borderline IF (n = 38)**	**Average IF (n = 100)**	**Above Average IF (n = 96)**	**12–13 yrs (n = 107)**	**14–15 yrs (n = 105)**	**16–18 yrs (n = 86)**
Expressed the desire for a relationship	58.4 (52.7–63.8)	57.3 (49.5–64.8)	59.6 (51.3–67.3)	15.6 (−) (8.7–26.4)	60.5 (44.7–74.4)	66.0 (56.3–74.5)	78.1 (+) (68.9–85.2)***	45.8 (−) (36.1–55.7)	59.0 (49.0–68.5)	73.3 (+) (62.6–82.2)**
Showed or expressed attraction to person of same or other sex	68.5 (63.0–73.5)	72.0 (64.5–78.4)	64.5 (56.4–72.0)	45.3 (−) (33.7–57.4)	76.3 (60.8–87.0)	72.0 (62.5–79.9)	77.1 (+) (67.7–84.4)***	53.3 (−) (43.4–63.0)	76.2 (+) (66.9–84.0)	77.9 (+) (67.7–86.1)***
Showed or expressed attraction to person of same sex	12.4 (8.9–16.7)	8.9 (5.0–14.5)	16.3 (10.6–23.5)	6.3 (1.7–15.2)	13.2 (4.4–28.1)	10.0 (4.9–17.6)	18.8 (11.5–28.0)	8.4 (3.9–15.4)	14.3 (8.2–22.5)	15.1 (8.3–24.5)
Showed or expressed attraction to person of other sex	66.8 (61.1–72.1)	71.3 (63.6–78.3)	61.7 (53.1–69.8)	43.8 (−) (31.4–56.7)	76.3 (59.8–88.6)	71.0 (61.1–79.6)	74.0 (64.0–82.4)***	51.4 (−) (41.5–61.2)	73.3 (63.8–81.5)	77.9 (+) (67.7–86.1)***
Had romantic or sexual relationship with peer of same or other sex	12.5 (9.2–16.8)	6.5 (3.5–11.5)	19.1 (13.5–26.4)**	1.6 (0.3–8.5)	18.9 (9.5–34.2)	12.0 (7.0–19.8)	17.7 (11.4–26.5)	3.8 (−) (1.0–9.3)	13.5 (7.5–21.4)	22.1 (+) (13.9–32.3)***
Same-sex romantic or sexual relationship (s)	3.0 (1.4–5.7)	1.3 (0.2–4.6)	5.0 (2.0–10.0)	0.0 (0.0–5.7)	2.7 (0.1–14.2)	1.0 (0.0–5.4)	7.3 (3.0–14.4)	1.9 (0.2–6.6)	1.9 (0.2–6.7)	5.8 (1.9–13.0)
Other-sex romantic or sexual relationship (s)	12.1 (8.6–16.3)	6.4 (3.1–11.4)	18.4 (12.4–25.8)**	1.6 (11.5–28.0)	18.4 (7.7–34.3)	12.0 (6.4–20.0)	16.7 (9.8–25.6)	2.8 (−) (0.6–8.0)	13.3 (7.5–21.4)	22.1 (+) (13.9–32.3)***
Masturbated privately in an appropriate setting	35.2 (30.0–40.8)	41.4 (34.0–49.2)	28.4 (21.6–36.3)	48.4 (36.6–60.4)	44.7 (30.2–60.3)	27.0 (19.3–36.4)	31.3 (22.9–41.1)	30.8 (22.3–40.5)	35.2 (26.2–45.2)	40.7 (30.2–51.8)
Had sexual intercourse[a]	2.0 (0.7–4.3)	1.3 (0.02–4.5)	2.8 (0.1–7.1)	0.0 (0.0–5.6)	2.6 (0.1–13.8)	3.0 (0.6–8.5)	2.1 (0.3–7.3)	0.0 (0.0–3.4)	0.0 (0.0–3.5)	7.0 (2.6–14.6)
Known sexual abuse history	6.4 (4.2–9.8)	3.8 (1.8–8.1)	9.3 (5.5–15.2)	1.6 (0.3–8.3)	5.3 (1.5–17.3)	5.0 (2.2–11.2)	11.7 (6.7–19.8)	3.8 (1.0–9.3)	6.7 (2.7–13.3)	9.3 (4.1–17.5)
Bullied by peers because does not know sexual slang or social norms	14.5 (10.9–18.9)	16.7 (11.6–23.3)	12.1 (7.7–18.5)	7.8 (3.4–17.0)	21.6 (11.4–37.2)	15.0 (9.3–23.9)	15.6 (9.7–24.2)	7.5 (−) (3.3–14.2)	18.1 (11.3–26.8)	18.6 (11.0–28.4)
Talked about private sexual topics while in public	19.1 (15.1–24.0)	17.2 (12.1–23.9)	21.3 (15.3–28.8)	4.7 (−) (1.6–12.9)	23.7 (13.0–39.2)	18.0 (11.7–26.7)	28.1 (+) (20.1–37.8)**	17.8 (11.0–26.3)	21.0 (13.6–30.0)	11.0–28.4
Undressed in public inappropriately	20.8 (16.6–25.8)	17.2 (12.1–23.9)	24.8 (18.4–32.6)	43.8 (+) (32.3–55.9)	23.7 (13.0–39.2)	12.0 (−) (7.0–19.8)	13.5 (−) (8.1–21.8)***	27.1 (19.0–36.6)	20.0 (12.8–28.9)	14.0 (7.4–23.1)
Stared inappropriately at people	21.1 (16.9–26.1)	23.6 (17.6–30.8)	18.4 (12.9–25.7)	28.1 (18.6–40.1)	26.3 (15.0–42.0)	18.0 (11.7–26.7)	17.7 (11.4–26.5)	21.5 (14.1–30.5)	21.9 (14.4–31.0)	19.8 (12.0–29.8)
Masturbated in public or in the presence of others	13.4 (10.1–17.8)	12.1 (7.9–18.1)	14.9 (10.0–21.7)	35.9 (+) (25.6–49.0)	13.2 (5.8–27.3)	6.0 (−) (2.8–12.5)	6.3 (−) (2.9–13.0)***	18.7 (11.8–27.4)	12.4 (6.8–20.2)	8.1 (3.3–16.1)
Looked at someone nude without their knowledge/consent	13.1 (9.7–17.4)	12.7 (8.4–18.9)	13.5 (8.8–20.1)	15.6 (8.7–26.4)	18.4 (9.2–33.4)	14.0 (8.5–22.1)	8.3 (4.3–15.6)	16.8 (10.3–25.3)	13.3 (7.5–21.4)	8.1 (3.3–16.1)

(*Table continues*)

Table 2. Continued

Variable	% (95% CI)									
	Total Sample (N = 298)	Parents of Boys (n = 157)	Parents of Girls (n = 141)	IF < 70 (n = 64)	Borderline IF (n = 38)	Average IF (n = 100)	Above Average IF (n = 96)	12–13 yrs (n = 107)	14–15 yrs (n = 105)	16–18 yrs (n = 86)
Touched someone sexually when not wanted	8.1 (5.5–11.7)	12.1 (7.9–18.1)	3.5 (1.5–8.0)**	12.5 (6.5–22.8)	10.5 (4.2–24.1)	8.0 (4.1–15.0)	4.2 (1.6–10.2)	7.5 (3.3–14.2)	9.5 (4.7–16.8)	7.0 (2.6–14.6)
School or legal consequences for sexual behavior	3.7 (2.1–6.5)	6.4 (3.5–11.3)	0.7 (0.04–4.5)	6.3 (2.5–15.0)	2.6 (0.5–13.5)	2.0 (0.6–7.0)	4.2 (1.6–10.2)	0.9 (0.0–5.1)	5.7 (2.1–12.0)	4.7 (1.3–11.5)
School consequences for sexual behavior	3.4 (1.6–6.1)	6.4 (3.1–11.4)	0.0 (0.0–2.6)*	4.7 (1.0–13.1)	2.6 (0.1–13.8)	2.0 (0.2–7.0)	4.2 (1.1–10.3)	0.9 (0.0–5.1)	4.8 (1.6–10.8)	4.7 (1.3–11.5)
Legal consequences for sexual behavior[a]	1.0 (0.2–2.9)	1.3 (0.2–4.5)	0.7 (0.0–3.9)	1.6 (0.0–8.4)	0.0 (0.0–9.3)	2.0 (0.2–7.0)	0.0 (0.0–3.8)	0.0 (0.0–3.4)	2.9 (0.6–8.1)	0.0 (0.0–4.2)

+/− subscripts indicate significant contributions to offset based on adjusted standardized residuals, with (−) indicating that fewer cases were observed than expected for the group and (+) indicating more observed than expected for the group. [a]Chi-square analyses were not conducted because of 0 cell counts. *$p = 0.01$, **$p < 0.01$, and ***$p < .001$. IF, intellectual functioning.

likely to report some socially inappropriate sexual behaviors (SISBs) including undressing in public inappropriately (χ^2 [3, N = 298] = 28.420, $p < 0.001$, V = 0.309) and public masturbation (χ^2 [3, N = 298] = 36.910, $p < 0.001$, V = 0.352). Approximately 6.4% of youth in this sample had a known history of being sexually abused, with no significant differences by sex (χ^2 [1, N = 298] = 3.634, $p = 0.057$, V = 0.111) or IF (χ^2 [3, N = 298] = 7.300, $p = 0.063$, V = 0.157). Parents reported that 14.5% of youth experienced peer bullying because of youth's lack of knowledge about sexual slang or social norms around sexuality and relationships. See Supplemental Tables 1 and 2 (see Supplemental Digital Content 2, http://links.lww.com/JDBP/A264), which contain the responses from the full sample and statistics for comparisons by sex, intellectual functioning, and age.

We created an index of SISB by summing whether parents reported that youth had ever engaged in looking at nude people without their consent, inappropriate touching, or public masturbation. Of those who engaged in at least 1 SISB behavior (n = 81), 76.5% engaged in 1 behavior, 19.8% engaged in 2 behaviors, and 3.7% engaged in all 3 behaviors. Within this group, there were no differences in number of behaviors by sex (χ^2 [2, N = 81] = 0.166, $p = 0.920$, V = 0.045), IF (χ^2 [6, N = 81] = 5.962, $p = 0.427$, V = 0.192), or age χ^2 [4, N = 81] = 2.564, $p = 0.633$, V = 0.178). Around one-fifth of youth in the total sample engaged in 1 SISB behavior (21.7% male patients and 19.9% female patients), 1 in 20 engaged in 2 SISB behaviors (5.7% male patients and 5.0% female patients), and engagement in all 3 was rare (1.3% male patients and 0.7% female patients).

Parent Actions and Service Utilization

According to parents, almost 40% of youth did not receive sexuality education at school or in the community, including 61% of youth in the IF < 70 category (Table 3). The proportion of youth who participated in school-based sexuality education (SBSE) increased with age (i.e., 49.5% of 12- to 13-year-olds vs 76.7% of 16- to 18-year-olds; χ^2 [4, N = 298] = 16.059, $p < 0.001$, V = 0.233). Youth with IF < 70 were also less likely than others to have received family-based sex education (χ^2 [3, N = 296] = 38.413, $p < 0.001$, V = 0.360). For youth who had participated in SBSE (n = 188), half of parents (48.9%) had to opt their child in, whereas 51% reported that that SBSE was provided to all students unless parents opted out. Only 36.4% of parents reported having consulted with their individualized education plan team, teacher, or school about sexuality development, with parents of youth with IF < 70 being more likely to have done so (63% vs 27% of youth with average IF; χ^2 [3, N = 297] = 28.937, $p < 0.001$, V = 0.312). Around half (55.9%) of parents reported having consulted with a health care provider (36.7% to physician or nurse and 39.7% to psychologist or psychiatrist) about sexuality development, with no significant sex ($p = 0.039$), IF ($p = 0.254$), or age ($p = 0.871$) differences. Few parents provided "formal social

Table 3. Parent Actions to Support Healthy Sexuality Development by Youth Sex and IF: Results of χ^2 Analyses

	% (95% CI)									
Variable	**Total Sample (N = 298)**	**Parents of Boys (n = 157)**	**Parents of Girls (n = 141)**	**IF < 70 (n = 64)**	**Borderline IF (n = 38)**	**Average IF (n = 100)**	**Above Average IF (n = 96)**	**12–13 yrs (n = 107)**	**14–15 yrs (n = 105)**	**16–18 yrs (n = 86)**
Parent consulted IEP team, teacher, or school about sexuality	36.4 (31.1–42.0)	41.7 (34.2–49.5)	30.5 (23.5–38.5)	62.5 (+) (50.3–73.3)	44.7 (30.2–60.3)	27.3 (−) (19.5–36.8)	25.0 (−) (17.4–34.5)***	38.3 (29.1–48.2)	35.2 (26.2–45.2)	35.3 (25.2–46.4)
Received sex education at school (parent report)	63.5 (57.9–68.8)	64.5 (56.7–71.6)	62.4 (54.2–70.0)	39.1 (−) (28.1–51.3)	63.2 (47.3–76.6)	67.7 (58.0–76.1)	75.8 (+) (66.3–83.3)***	49.5 (−) (39.7–59.4)	67.0 (55.8–74.7)	76.7 (+) (67.3–86.0)***
Received sex education in the community	2.0 (0.9–4.3)	1.3 (0.4–4.5)	2.8 (1.1–7.1)	4.7 (1.6–12.9)	5.3 (1.5–17.3)	1.0 (0.2–5.5)	0.0 (0.0–4.8)	0.0 (0.0–3.4)	3.8 (1.0–9.5)	2.3 (0.3–8.2)
Received NO sex education at school or in community (parent report)	36.5 (31.2–42.1)	35.5 (28.4–43.3)	37.6 (30.0–45.8)	60.9 (+) (48.7–72.0)	36.8 (23.4–52.7)	32.3 (23.9–42.0)	24.2 (−) (16.7–33.7)***	50.5 (+) (40.6–60.3)	33.0 (23.6–42.2)	23.3 (−) (15.0–34.0)***
Received sex education at home with family	78.0 (72.9–82.6)	76.1 (68.6–82.6)	80.1 (72.6–86.4)	50.8 (−) (37.9–63.6)	81.6 (65.7–92.3)	80.8 (71.7–88.0)	91.7 (+) (84.2–96.3)***	68.6 (−) (57.5–76.0)	84.8 (+) (76.4–91.0)	81.4 (72.6–89.8)
Parent consulted health care provider about sexuality development	55.9 (50.2–61.4)	61.5 (53.7–68.8)	49.6 (41.5–57.8)	60.9 (48.7–72.0)	63.2 (47.3–76.6)	57.6 (47.2–66.3)	47.9 (38.2–57.8)	54.2 (44.3–63.9)	60.0 (50.0–69.4)	52.9 (41.8–63.9)
Physician or nurse	36.7 (31.4–42.3)	34.0 (27.0–41.7)	39.7 (32.0–48.0)	50.0 (+) (38.1–61.9)	55.3 (+) (39.7–69.9)	31.3 (23.0–41.0)	26.0 (−) (18.3–35.6)**	41.4 (31.7–51.0)	37.1 (27.9–47.1)	30.6 (21.0–41.5)
Psychologist or psychiatrist	39.7 (34.3–45.4)	46.2 (38.5–54.0)	32.6 (25.4–40.7)	39.1 (28.1–51.3)	34.2 (21.2–50.1)	43.4 (34.1–53.3)	38.5 (29.4–48.5)	34.6 (25.6–44.4)	43.8 (34.1–53.8)	41.2 (30.6–52.4)
Parent spoke to other parents about sexuality development	35.0 (29.8–40.6)	41.0 (33.6–48.9)	28.4 (21.6–36.3)	34.4 (23.9–46.6)	52.6 (37.3–67.5)	35.4 (26.6–45.2)	28.1 (20.1–37.8)	30.8 (22.3–40.5)	36.2 (27.0–46.1)	38.8 (28.4–50.0)
Parent researched sexuality development using research journals or the internet	46.1 (40.6–51.8)	51.3 (43.5–59.0)	40.4 (32.7–48.7)	42.2 (30.9–54.4)	42.1 (27.9–57–8)	47.5 (37.9–57.2)	49.0 (39.2–58.8)	45.8 (36.1–55.7)	45.7 (36.0–55.7)	47.1 (36.1–58.2)
Parent provided formal social skills training to support sexuality development	25.9 (21.3–31.2)	26.3 (20.0–33.7)	25.5 (19.1–33.3)	23.4 (14.8–35.1)	26.3 (15.0–42.0)	28.3 (20.4–37.8)	25.0 (17.4–34.5)	21.5 (14.1–30.5)	29.5 (21.0–39.2)	27.1 (18.0–37.8)
Parent provided condoms or birth control	6.4 (4.1–9.8)	1.9 (0.7–5.5)	11.3 (7.1–17.6)**	7.8 (3.4–17.0)	5.3 (1.5–17.3)	4.0 (1.6–9.9)	8.3 (4.3–15.6)	3.7 (1.0–9.3)	7.6 (3.3–14.5)	8.2 (3.4–16.2)
Parent took no actions aside from talking to child	19.5 (25.4–24.4)	14.1 (9.5–20.4)	25.5 (19.1–33.3)	18.8 (11.1–30.0)	10.5 (4.2–24.1)	19.2 (12.6–28.0)	24.0 (16.5–33.3)	23.4 (15.7–32.5)	17.1 (10.5–25.7)	17.6 (10.2–27.4)

± subscripts indicate significant contributions to affect based on adjusted standardized residuals, with (−) indicating that fewer cases were observed than expected for the group and (+) indicating more observed than expected for the group. *$p = 0.01$, **$p < 0.01$, and ***$p < 0.001$. IEP, individualized education plan; IF, intellectual functioning.

skills training" (e.g., a manualized curriculum delivered by educators or health care providers) to support sexuality and relationships development (25.9%) or provided their teen with condoms or birth control (6.4%). For parent actions, the only significant sex difference was that parents of girls were more likely to provide their teen with condoms or birth control than parents of boys (11.3% vs 1.9%; χ^2 [3, N = 297] = 10.985, $p < 0.001$, V = 0.192). Almost 20% (n = 58) of parents reported taking no action except talking to their child about sex. Of these, 37.9% endorsed not yet needing to take action, 20.7% endorsed that they would take action in the future, and 13.8% endorsed that they do not know what action to take.

Predictors of Service Utilization

Using Andersen's service utilization framework,[26] model 1 examined factors predicting parent consultation with a health care provider about sexuality development, model 2 parent consultation with school personnel, and model 3 examined youth receipt of SBSE (Table 4). Model 1 did not significantly predict factors involved in parents having consulted with a health care provider about sexuality development ($p = 0.034$). In model 2 ($p < 0.001$), parents who consulted with school personnel had youth who were more likely to be male (odds ratio [OR] = 1.97; 95% confidence interval [CI], 1.12–3.45), less likely to be homeschooled (OR = 0.14; CI, 0.03–0.62), and more likely to attend private, charter, or therapeutic than public schools (OR = 2.07; 95% CI, 1.09–3.95) and to have borderline IF (OR = 2.52; 95% CI, 1.10–5.81) or IF < 70 (OR = 3.77; 95% CI, 1.74–8.18). In model 3 ($p < 0.001$), youth who received SBSE were older (OR = 1.32; 95% CI, 1.09–1.60), less likely to attend private, charter, or therapeutic schools (OR = 0.35; 95% CI, 0.18–0.70) or be homeschooled (OR = 0.04; 95% CI, 0.01–0.12), and were less likely to have IF < 70 (OR = 0.23; 95% CI, 0.10–0.54). Parent race, urbanicity, parent education, household income, autism symptom severity, youth interest in relationships, and history of SISB did not significantly predict service utilization or receipt of SBSE.

DISCUSSION

Health care providers and educators play critical roles in supporting healthy sexuality development for youth and have cited a need for accurate information about sexuality and autism.[22] Furthermore, information on school- and community-based sex education and sexual health service utilization patterns and access disparities is critical for efforts to develop targeted resources and innovative delivery mechanisms. This study addresses these needs by providing parent-report information on youth's sexual interests and behaviors and family utilization of health care and school-based sexuality education (SBSE). Parents reported that most youth experienced sexual feelings and were interested in romantic relationships, and some were engaging in solo or partnered sexual behavior. Although parents reported that relatively few teens with autism had romantic or sexual relationships at the time of this study, the young mean age of youth in the sample (around 14 years) is an important consideration. Many people with developmental disabilities have sexual relationships in later adolescence and adulthood.[44] Around half of families had spoken to a health care provider (physician, nurse, psychologist, or psychiatrist) about sexuality development, and fewer than half of them had consulted their child's education team. Furthermore, a substantial number of parents reported that teens had not participated in SBSE.

The results of this study show that young people with autism have relationships and engage in a variety of sexual behaviors, indicating that high-quality, accessible, and inclusive sexual and reproductive health services are important for these teens. Their interest in relationships and experiences of sexual attraction suggest that sexuality and dating should be important (and potentially motivating) components of social skills interventions for this age group. In addition, sex education may help prevent bullying (reported by almost 1 in 7 parents reported for youth in this sample) by teaching terminology, social norms, consent, and self-esteem.[45] Consistent with other literature,[13] 13.2% of youth (that parents knew about) had experienced same-sex attraction or had a relationship with a same-sex peer. Services should therefore prioritize inclusivity for sexual minorities. Educators and providers are encouraged to choose language and content that does not assume heterosexuality or the desire for sexual contact (e.g., "if you decide to be sexual with a partner, it is important to talk to your partner about barrier methods such as condoms and dental dams").[46] Finally, professionals should be aware of existing sex education programs and other resources targeted to autism.[47,48]

The World Health Organization states that sexual health is based on a foundation of freedom from coercion.[25] Sexual abuse in youth with autism has been linked with running away from home, sexual acting out or offending, and suicide.[49] Parents reported that 6.4% of youth in this study had known sexual abuse histories, and an additional 3.0% of parents endorsed being "unsure" of whether their child had been sexually abused. This is similar to US general population estimates (6.1%)[50] and to national self-report data that included an autism/learning disabilities group (9.0%).[51] However, one study using parent report for a community mental health sample found a higher rate (16.6%).[49] Among adults who can respond to written surveys, retrospective self-report indicates that autism diagnosis[10] and traits[9] are associated with higher odds of childhood sexual abuse for women. Adults may also be at higher risk of victimization, as 78% of respondents in one online survey reported unwanted sexual contact at age 14 or older (vs 47.4% of controls)[8] and college students with autism report higher rates of unwanted sexual contact on campus (8.2%) than students without disabilities (4.6%).[11] Together, these studies indicate that providers and educators should be prepared to hear reports of sexual abuse and to assess, refer, or treat based on their scope of practice.[52] Consultation on preventing sexual abuse may also be useful for families.[53]

Table 4. Logistic Regression Models for Parent Consultation with Health care or School Personnel and Parent-Reported Access to School-Based Sexuality Education

	OR (95% CI)					
	Model 1		Model 2		Model 3	
	Consulted Health Care Provider	*p*	Consulted with School Personnel[a]	*p*	Accessed SBSE (Parent Report)	*p*
Predisposing factors						
Youth age	1.02 (0.88–1.18)	0.844	1.04 (0.90–1.21)	0.581	1.32 (1.09–1.60)	**0.005**
Male sex	1.87 (1.13–3.08)	0.014	1.97 (1.12–3.45)	**0.019**	0.68 (0.38–1.22)	0.195
Parent race						
White	1.0		1.0		1.0	
Non-white	1.14 (0.51–2.55)	0.745	0.73 (0.30–1.73)	0.469	1.02 (0.40–2.62)	0.957
Parent education						
Bachelor's or higher	1.0		1.0		1.0	
Associate's or lower	1.42 (0.80–2.52)	0.232	1.12 (0.61–2.06)	0.722	1.26 (0.62–2.58)	0.519
Enabling factors						
Urbanicity						
Suburban	1.0		1.0		1.0	
Urban	0.61 (0.30–1.25)	0.175	0.75 (0.33–1.69)	0.483	0.88 (0.39–1.99)	0.766
Rural	1.04 (0.49–2.20)	0.925	1.17 (0.53–2.59)	0.693	0.82 (0.35–1.88)	0.634
Household income						
At/above US median	1.0		1.0		1.0	
Below US median	0.85 (0.47–1.54)	0.592	1.27 (0.65–2.45)	0.484	0.99 (0.50–1.99)	0.984
School setting						
Public	—		1.0		1.0	
Private, charter, or therapeutic	—		2.07 (1.09–3.95)	**0.027**	0.35 (0.18–0.70)	**0.003**
Homeschooled or cybercharter	—		0.14 (0.03–0.62)	**0.010**	0.04 (0.01–0.12)	**<0.001**
Need-related factors						
Intellectual functioning						
Average	1.0		1.0		1.0	
Above average	0.69 (0.37–1.27)	0.229	1.16 (0.58–2.35)	0.673	1.70 (0.79–3.68)	0.177
Borderline	1.07 (0.48–2.41)	0.862	2.52 (1.10–5.81)	**0.031**	0.66 (0.26–1.70)	0.393
Below 70	1.13 (0.53–2.37)	0.757	3.77 (1.74–8.18)	**0.001**	0.23 (0.10–0.54)	**0.001**
SRS-2 total T-score	1.04 (1.01–1.07)	0.005	1.0 (0.98–1.04)	0.645	0.99 (0.96–1.03)	0.620
Interest in sexual or romantic relationships						
Youth is interested	1.0		1.0		1.0	
Youth is NOT interested	0.57 (0.30–1.09)	0.087	1.25 (0.63–2.48)	0.520	0.61 (0.30–1.26)	0.183
Youth sexual problems						
NO history of SISB	1.0		1.0		1.0	
History of SISB	1.26 (0.70–2.27)	0.452	1.72 (0.93–3.17)	0.082	0.88 (0.45–1.73)	0.710
χ^2 (*df*, N)	23.720 (13, 285)	0.034	55.187 (15, 284)	**<0.001**	87.781 (15, 282)	**<0.001**

Variables marked "—" were not included in model. Bold indicates a significant *p* value. [a]School personnel = individualized education plan team, teacher, or other school personnel. CI, confidence interval; OR, odds ratio; SBSE, school-based sexuality education; SISB, socially inappropriate sexual behavior; SRS-2, Social Responsiveness Scale, Second Edition.

Our results showed no significant differences between IF groups on incidence of parent-reported sexual abuse but showed an apparent trend toward higher prevalence among youth with average or above IF versus those with IF < 70. This contrasts with the literature showing higher risk for youth with intellectual disability as compared with other youth with or without disabilities.[54] Limited verbal ability may impede some youth from reporting abuse, although factors such as youth's level of inclusion in activities with peers and unsupervised time with peers or adults may also affect rates of abuse for youth with average or above IF. Although it is unclear why rates of abuse

were lower in this study than in previous studies,[49] it is possible that this study underreports abuse, particularly for youth with lower IF. Research on prevalence, prevention, methods to facilitate screening and reporting, and treatment of sexual abuse and trauma for youth with autism who are less verbal or who have intellectual disability is needed,[55] and it is critical that these youth be taught principles of bodily autonomy, consent, and how to report abuse.

Sexual exploration and behaviors are developmentally normative during childhood and adolescence. Socially inappropriate sexual behaviors (SISBs) are those that occur in public, without the consent of others, are aggressive, or interfere with activities of daily living.[56] The severity and consequences for SISB vary dramatically depending on context (e.g., asking an inappropriate question of a parent vs a schoolmate) and whether the behavior causes discomfort or harm to others (e.g., occurs in public or is directed toward others). In this sample, around 1 in 4 youth (27%) had ever engaged in person-oriented or public SISB, and 6.4% in multiple different SISBs. Consistent with research on adults, parents reported that teens with IF < 70 had higher rates than others of behaviors suggesting a limited understanding of public versus private contexts (e.g., public masturbation or disrobing).[12] Parents may want to prepare a response for potential SISB in advance and teach children about the importance of privacy from an early age. Boys were more likely to have faced school or legal consequences for SISB despite few sex differences in parent report of the prevalence of behaviors. Future research would benefit from having a validated tool shown to differentiate between socially appropriate and inappropriate behavior across populations and to include frequency or intensity of SISB in addition to lifetime presence.

The history of SISB was not a significant predictor of parent consultation with health care or school professionals, yet parents could likely benefit from guidance about what constitutes SISB and how to prevent these behaviors or intervene when indicated. Similar to any challenging behavior, SISB has many potential causes, including physical health issues such as infections, boredom, lack of privacy, medication side effects, expression of interest in sexuality, escape or avoidance, or attention.[57] Both research and clinical services in this area focus on intervention rather than prevention, but providing sexuality education and opportunities to express sexuality appropriately (e.g., privacy) are recommended for prevention.[58] After behaviors have occurred, a developmental assessment including a sexual history, a physical examination, and a functional behavior assessment are important for conceptualization and intervention.[57] Existing evidence is limited, but positive behavioral support and cognitive behavioral therapy may increase socially appropriate replacement behaviors and decrease or prevent the reoccurrence of SISB.[56,57] Youth with SISB can be adjudicated to the juvenile justice system where their specific cognitive needs and limits are not always recognized or accommodated. Research on pathways and barriers to preventative and intervention services for SISB is needed.

According to parents, almost 1 in 5 youth in this sample did not receive any sexuality education outside of their families. We found that youth with IF < 70 were particularly underserved, with over 60% of parents reporting no school- or community-based sexuality education at the time of this survey. Parents of older youth had higher odds of reporting SBSE participation than those of younger youth. In other studies, parents of older general population youth report that their teens have more sexuality knowledge than younger teens, but this is not the case for young people with autism,[45,59] who report that they learn less about sexuality and relationships from both formal and informal sources.[8,60,61] Learning about sexuality and relationships is an ongoing process, and beginning earlier may allow for greater gains throughout adolescence. Advocating for comprehensive sexuality education is part of a health care provider's role,[20] and this advocacy may be especially important for youth with intellectual disability (ID), younger teens, and for youth attending private, charter, or therapeutic schools or who are homeschooled. Only 2% of families in this sample were able to access sexuality education outside of school settings, suggesting a need for access to community-based programs run by mental health professionals, parent or self-advocate support groups, or faith-based organizations (e.g., the Unitarian Universalist Our Whole Lives Curriculum).

Health care and service utilization are influenced not only by need but also by beliefs and by the structure of health care, education, and other systems. Although we do not have evidence for why SBSE is often not provided to youth with autism and other disabilities, persistent stigmatizing beliefs about the sexuality of people with disabilities[62,63] and beliefs that sexuality education will cause teenagers to have sex (rather than delaying sexual debut)[64] may contribute. Some parents of youth with autism believe that withholding information about sexuality protects youth from rejection, SISB, or victimization,[24] indicating psychoeducation may help. Alternatively, providers using a developmental age equivalent for education and treatment planning may delay providing sexuality education or health care to youth with ID until later adolescence. However, pediatricians are encouraged to introduce issues of sexuality in early childhood for all youth,[65] and many youth with ID will physically mature on time, meaning that they must learn age-appropriate facts about puberty and sexuality in a manner that accounts for their learning needs. On a positive note, many families reported consulting with health care providers and school personnel about sexuality. The number of parents who rely on these sources for accurate information and guidance indicates that training on sexuality and the sexuality of people with disabilities is an important component of professional education for educators and health care providers.[22]

Limitations

Several limitations warrant attention. First, this sample is not population-based, and that limits generalization, particularly to Black and Hispanic youth, those in urban or rural locales, and those with parents who did not earn 4-year degrees. Given the sample characteristics, the results likely overestimate access to services and, based on racial disparities, may underestimate rates of school or legal disciplinary consequences related to SISB. Second, this survey used parent report, and results were not validated by external sources. Previous research suggests that parents of youth with autism may not be aware of their child's sexual behavior (particularly masturbation).[23] These findings may therefore underestimate sexual behavior and SBSE among youth with autism. Next, parents were not asked whether they completed the survey alone or with input from the youth's other parent, so we are unable to estimate the extent to which parents may have underreported utilization of services by a coparent on behalf of their child. In addition, intelligence quotient (IQ) was based on parent report. IQ testing is not provided to all youth, and access may differ (e.g., by racial/ethnic or socioeconomic background). Furthermore, youth with autism often have discrepancies (e.g., between verbal and nonverbal abilities) that render a full-scale IQ score invalid. Given these results and their implications for public health, studies using population-based sampling and well-characterized samples are indicated. Next, our service utilization models were not comprehensive, and factors such as insurance status affect access to sexual and reproductive services for people with disabilities. Other professionals who could play an important role in providing these services, such as social workers, should be included in future research. Finally, the survey did not include a comprehensive slate of sexual interests and behaviors and focused more on SISB behaviors than on developmentally normative sexual behaviors (e.g., kissing and oral sex). This has the potential to stigmatize autistic sexuality, and it is important to state that many youth with autism engage in normative sexual behaviors.[66]

CONCLUSION

Sexual and reproductive health services contribute to health and quality of life across the lifespan for autistic people. This study provides preliminary information about parents' views of the sexuality development of their children and parent actions in support of sexual and reproductive health for girls and boys across the autism spectrum. Talking about sexuality is often challenging for parents, educators, and health care providers, regardless of youth abilities. There are likely many barriers to providing sexual and reproductive health care and education for youth with autism that have not yet been identified and addressed. Research on access disparities and barriers, pathways to care, teaching nuanced social behaviors, and how existing policies affect sexual and reproductive health service use is needed to better support educators, providers, families, and individuals with autism in achieving optimal health and well-being.

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