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Social/Sexual Awareness of Persons with Autism: A Parental Perspective

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A parental survey that addressed the social sexual awareness, sex education, and sex behaviors of persons with autism, a developmental disability is provided. Questionnaires from 100 caregivers of persons with autism 9 years of age and older and with the DSM-III-R diagnosis were analyzed. Eighty-five percent of respondents were mothers, 8% both parents, 5% fathers, and 2% others; 32% of the persons with autism were female and 68% male with an age range of 9.1 to 38.9 years. The verbal level of the person with autism related to parents' beliefs about the relevance of sex relations ($\chi^2 = 6.99$, $p < 0.05$) and sex education ($\chi^2 = 22.91$, $p < 0.001$). No relationship between parents' report of the verbal level of the individual and the display of inappropriate sexual behaviors was found ($\chi^2 = 2.56$, ns). Parents of males were more concerned about their son being taken advantage of by a same-sex person ($\chi^2 = 15.90$, $p < 0.001$); parents of females were worried about an opposite-sex person ($\chi^2 = 4.06$, $p < 0.05$). Parental concerns and beliefs regarding sexuality varied and could not be generalized. The nonsignificant finding regarding verbal level and display of inappropriate sexual behaviors suggests that the need for sex education is best determined by the behaviors of the person rather than the functioning or verbal levels.

KEY WORDS: autism; developmental disability; social/sexual awareness; parental concerns; sex behaviors.

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INTRODUCTION

In the research literature on autism, information regarding sexuality is scarce (Mesibov, 1983; Ford, 1987). Sexuality of persons with autism is a major concern for parents (DeMyer, 1979) and community service providers (Mesibov, 1983), yet few resources addressing problems and questions regarding sex education, parental concerns, and behaviors related to sexuality are available.

In DeMyer's survey of parents (1979), she found that parents of boys with autism believe that their child is not interested in intercourse and parents of girls worry that their daughter may engage "passively" in intercourse. They were also concerned about their male child exhibiting inappropriate behavior such as rubbing genitals against others in public. More recently parents have expressed the desire to help their child on an individual basis learn appropriate sexual behaviors (Torisky and Torisky, 1985) and be taught normal social interactions and preferences based on their values (Akerley, 1984). A decade has passed since DeMyer's survey, and more people with autism are living in the community.

Typically the caregiver is responsible for determining if information is needed and what type of training should be provided for the individual with autism. Dewey and Everard (1974), parents of persons with autism, say that the absence of expressed concerns about sexuality does not mean that the individual is experiencing satisfaction with his/her sexual life and that the problems caused by sexual expression lead the person to decide that sexual fulfillment is not worth the trouble. Ford (1987) stated that issues regarding sexuality are taught retroactively once inappropriate behaviors are exhibited that call for the need for education (e.g., masturbation) and when the intervention leads to a behavior change considered meaningful by others (e.g., menstrual hygiene).

The onset of adolescence may further complicate the caregiver's understanding about the individual with autism. Physically and sexually the person typically matures normally (DeMyer, 1979; Adams and Sheslow, 1983; Cairns, 1986). However, parents may experience confusion raising a child who develops normally in some aspects yet continues to display impairments in social behavior (DeMyer, 1979; Cairns, 1986).

A priori beliefs about sexuality and autism are reflected in the literature. Some authors discourage sexuality for these people (Lieberman and Melone, 1979) or state that it is irrelevant due to the characteristics of autism (Elgar, 1985). However, Ford (1987) advocated that programs should be established with the assumption that the individual can learn relationship skills. The polarized viewpoints are surely confusing for caregivers.

The lack of attention to sexuality and autism can be explained by many reasons. Only in the past 20 years have persons with mental retardation become recognized as having sexual rights (Craft, 1987). This has yet to be realized for individuals with autism. In the past, most persons with autism lived in segregated settings (Sullivan, 1977), and sexuality was probably ignored.

METHOD

Subjects

The sample was drawn from a population of all parents who had children 9 years of age or older with autism in a data base at the Indiana Resource Center for Autism. The diagnostic criteria used by agencies in Indiana are the same as those in the DSM-III-R (American Psychiatric Association, 1987) and include qualitative impairment: (i) in reciprocal social interaction, and (ii) in verbal and nonverbal communication and imaginative activity, (iii) markedly restricted repertoire of activities and interests, and (iv) onset during infancy or childhood. Three-hundred fifteen questionnaires were mailed with an explanation of the study, 116 were returned anonymously, and 16 were discarded due to incomplete data or incorrect age. Thus, 100 surveys were compiled and analyzed. Almost one third of the original sample was utilized. Because the returned surveys were anonymous, a comparison of the sample to the dropout group could not be performed. Eighty-five percent of the respondents were mothers, 8% both parents, 5% fathers, and 2% others, including grandparents; 97% of the children of the sample lived in community living arrangements or the parents' home. They consisted of 32 females and 68 males between the ages of 9.1 and 38.9 years ($\bar{x}$ = 19.5 years). Although autism occurs about four times more often in males than in females (Rutter, 1985), this sample of 2 males to 1 female may reflect that parents of females had a higher probability of responding than parents of males because the original sample represented about a 3.4 to 1 male–female ratio. As measured by parental reports, verbal and cognition level related significantly ($r = -.33, p < 0.01$) confirming previous studies (Rutter, 1966; Hermelin and O'Connor, 1970; DeMyer *et al.*, 1981). Validity of the parental reports of functioning level are indicated because the percentage of persons with mental retardation in this study, 84%, is within the range of epidemiology studies of 76 to 89% (Gillberg, 1990). Gender and cognitive and verbal levels did not relate significantly; the mean age of diagnosis, 5.08 years, did not relate to demographic information.

The Clinical Picture of Autism

Because people with autism have varying cognitive and verbal abilities, the clinical picture of the disability differs in each individual. For example, a person with mild mental retardation may be minimally verbal with a vocabulary of 20 words and need a picture communication system; whereas an individual with normal intelligence may have difficulty understanding concepts, problems answering questions, and conversing through several exchanges. Both of these persons may lack ability to understand emotions and social cues, and to make peer friendships.

Development of the Survey Instrument

The Sexuality Awareness Survey (SAS) was developed using a sample of 10 parents. Extended interviews were conducted with parents of children between the ages of 12 and 24, including 2 females and 8 males with varying cognitive levels to discover the issues to be addressed by the survey. The SAS consisted of 15 open-ended questions involving: (i) social/sexual awareness, (ii) sex education, (iii) sexual behaviors, (iv) parental concerns, and (v) interest in receiving more information regarding sexuality. Feedback from parents was used to design the final questionnaire consisting of 13 primary questions with some divided for specificity. Cognitive functioning levels reported by parents from a choice of five categories included severe/profound, moderate, mild, average, and gifted; verbal levels included verbal, minimally verbal, and nonverbal. The levels were derived from experience with two statewide needs assessment surveys and the interview study. Because of the correlation between verbal and cognitive levels and similarity of findings, only the statistics concerning verbal levels are reported in this study. The sample was divided by a median split on age of the child in order to indirectly determine any influence of parental age (this was unknown) on their responses. An alpha coefficient of internal consistency calculated for the SAS yielded .86.

RESULTS

Social/Sexual Awareness

Items regarding the parents' view of social/sexual awareness are broken down by verbal level and listed in Table I. A significant relationship was found between the verbal level and all five items. Individuals with more

Table I. Social/Sexual Awareness and Sex Education by Verbal Level[a]

	Total sample (N = 100)		Verbal level[b]						χ^2 test of significance
			Nonverbal (N = 33)		Minimally verbal (N = 29)		Verbal (N = 38)		
	%	N	%	N	%	N	%	N	
Knowledge of body parts/functions	47	87	14	29	41	22	78	36	26.85[e]
Respect others' privacy	50	88	23	31	50	26	77	31	18.65[e]
Want own privacy respected	61	93	39	31	50	26	89	36	19.61[e]
Understand public/private behavior	51	88	17	29	60	25	74	34	20.94[e]
Taught rules of private behavior	90	97	77	30	90	29	100	38	9.87[d]
Received sex education	45	94	20	30	46	28	64	36	12.80[d]
Effective for son/daughter	71	21	33	3	88	8	70	10	3.16
Could benefit from sex education	56	86	23	30	60	25	84	31	22.91[e]

[a]N = sample size. Variation is due to missing information.
[b]Percentage of subjects who answered yes.
[c]$p < 0.05$.
[d]$p < 0.01$.
[e]$p < 0.001$.

verbal skills were more likely to have knowledge and understanding about sexuality and to be taught rules.

Seventy-four percent of parents reported the greatest perceived need for privacy was during toileting, 65% while being alone, 56% during bathing, 35% while dressing, 33% when masturbating, and 5% at other times such as eating, and listening to music. Persons who were more verbal were reported to more likely want privacy.

Ninety percent of the sample reported that their child has been taught specific rules governing private behaviors. Of those who answered in the affirmative, 76% reported that their son or daughter has been taught to undress in the bedroom/bathroom, 75% to touch own private body areas only in private places, 71% to close the bathroom door, 71% to not walk around nude, 64% to undo pants only in bedroom/bathroom, and 8% other rules such as no one else touches private body parts, knocking on closed doors, and asking to enter a room.

Rules about privacy and appropriate behaviors were taught by several methods: 68% by repeating, 55% by redirecting, 49% by reinforcing ap-

propriate behavior, 44% by modeling, 24% by scolding, and 8% by other means. Males were more likely to be taught rules than females ($\chi^2 = 7.42$, $p < 0.05$).

Sex Education

Parents of more verbal individuals were more likely to report that their child received sex education and thought the person could benefit from it (see Table I). Of those who received sex education, 45% did so in private from an individual, 36% by group discussion, 33% by reading, pictures, and videotape, and 33% as part of a daily program plan; 55% received education at school, 52% at home, 21% at a group home, and 17% at other places like workshops, and adult day treatment centers.

Sexual Behaviors

Questions pertaining to the sexual behaviors of the person with autism are listed in Table II. No significant associations were found between verbal level and exhibition of sexual behaviors (see Table II) and between gender and sexual behaviors ($\chi^2 = 0.68$, ns).

Individuals with autism engage in a wide range of sexual behaviors. Sixty-five percent have touched their private parts in public, 28% removed clothing in public, 23% masturbated in public, and 18% touched the opposite-sex inappropriately; 18% mentioned other things such as talking about inappropriate subjects, looking up shorts and down shirts, and touching parents inappropriately. Fourteen percent have masturbated with unusual objects such as a pair of socks, 4% display private pictures in public, and 2% refuse to touch their penis.

Several of these behaviors have been particularly problematic for parents: 46% of those who answered in the affirmative are concerned about their children touching private parts in public, 26% refusing to touch their penis while urinating, 26% removing clothing in public, 20% masturbating in public, 11% masturbating with unusual objects, 3% touching the opposite-sex improperly, and 3% displaying private pictures in public.

When asked whether males worried about certain physiological reactions, one parent reported that her son apologized for wetting the bed when he ejaculated. Several parents stated that they were not sure if their son was worried or confused. However, one individual expressed confusion and fright when his penis was stiff, and another parent stated that her child thought his penis was broken. About 50% of the parents of females reported that their daughter worried about menstruation or sensations of sex

Table II. Sexual Behaviors by Verbal Levels[a]

	Total sample (N = 100)		Verbal level[b]						χ^2 test of significance[c]
			Nonverbal (N = 33)		Minimally verbal (N = 29)		Verbal (N = 38)		
	%	N	%	N	%	N	%	N	
Exhibit inappropriate sexual behaviors	57	99	47	33	55	29	66	38	2.56
Behaviors have been a problem	35	99	25	33	38	29	42	38	2.34
Females worried									
Menstruation	44	27	33	9	56	9	44	9	0.90
Sensations of sex organs	58	26	57	7	60	10	56	9	2.76
Males worried									
Ejaculation	24	41	20	15	8	12	43	14	4.42
Stiff penis	39	46	47	17	23	13	44	16	2.00
Increased heart rate when aroused	20	35	31	13	0	10	25	12	3.63

[a]N = sample size. Variation is due to missing information.
[b]Percentage of subjects who answered yes.
[c]All $p > 0.05$, ns.

organs. One parent reported that her daughter had trouble with emotional ups and downs around the time of menstruation, and another parent was uncertain whether the daughter experienced worry.

Parental Concerns Regarding Sexuality

Parents' major concern was about their child's behavior being misinterpreted as sexual, followed by sexual behaviors being misunderstood. These concerns did not relate to the gender of the child (see Table III). Sixty-one percent of the parents of females were concerned that their daughter would get pregnant, whereas only 19% of the parents of males worried that their son would get someone pregnant. Although verbal level did not relate significantly to parental concerns, gender of child associated significantly to parent's concern of molestation by a same-sex person or opposite-sex person (see Table III). Parents of males were more likely to report concern that their son would be abused by a same-sex person; parents of females were more likely to worry that a daughter would be taken advantage of by an opposite-sex person. Seven percent of the parents reported other concerns such as how to teach information to a nonverbal child and fear of a son having a sexual relationship.

Table III. Parental Concerns and Information Wanted by Verbal Levels and Gender[a]

Parental concerns	Total sample (n = 100)		Verbal level[b]							Gender				
			Nonverbal (n = 33)		Minimally verbal (n = 29)		verbal (n = 38)		χ^2Test of significance	Male (n = 68)		Female (n = 32)		χ^2Test of significance
	%	N	%	N	%	N	%	N		%	N	%	N	
Taken advantage by same sex	67	90	70	30	62	26	68	34	0.47	80	61	38	29	15.90[h]
Taken advantage by opposite sex	66	80	65	26	72	25	62	29	0.61	58	50	80	30	4.06[f]
No opportunity to enjoy sex relations	59	81	61	23	43	23	69	35	3.65	64	56	48	25	1.90
Daughter get pregnant	61	28	56	9	70	10	56	9	0.56	—[e]				
Son impregnate	19	47	19	16	17	12	21	19	0.09	—[e]				
Contract VD	45	73	52	23	48	21	38	29	1.12	43	49	50	24	0.33
Contract AIDS	44	72	52	23	45	20	38	29	1.06	42	48	50	24	0.45
Sex behaviors be misunderstood	76	83	65	23	74	23	84	37	2.74	76	58	72	25	0.30

Behavior mistakenly thought sexual	81	81	81	26	75	24	87	31	1.32	84	56	76	25	0.72
Should BC be practiced	35	54	19	16	33	18	50	20	3.85	22	32	55	22	6.10[f]
What BC best for females[c]	50	20	20	5	71	7	50	8	3.09	—[e]				
Should condom use be taught[d]	28	32	0	11	30	10	55	11	8.12[f]	—[e]				
How relevant is sex for person	78	81	64	22	71	24	91	35	6.99[f]	82	56	68	25	2.00
Can masturbation be controlled	68	59	61	18	69	16	72	25	0.58	81	42	35	17	11.56[g]
Do people with autism have kids	68	62	50	16	60	20	85	26	6.24[f]	73	41	57	21	1.63

[a]N = sample size. Variation is due to missing information.
[b]Percentage of subjects who answered yes.
[c]Answered by parents of females.
[d]Answered by parents of males.
[e]Not applicable.
[f]$p < 0.05$.
[g]$p < 0.01$.
[h]$p < 0.001$.

Information Wanted

The most frequent request for further information was the relevance of sexual relations for people with autism. Many wanted information about whether touching self or masturbation can be controlled. A significant relationship between gender and controlling masturbation was found (see Table III). Parents of males were more likely to want this information. Parents of females were more likely to wonder about whether birth control should be practiced. Verbal level related significantly to 3 of the 6 items (see Table III). Parents of more verbal persons were more likely to want information.

Parental/Child Age

The age factor of the persons with autism influenced the following 7 items and were significant at $p < 0.05$ with parents of the older group more likely to answer in the affirmative: (i) concern about their child's sexual behaviors being misunderstood, (ii) behaviors being interpreted as sexual when they were not, (iii) whether birth control should be practiced, (iv) information about whether people with autism have children, (v) could masturbation be controlled, (vi) how relevant are sexual relations, and (vii) that their child would benefit from sex education. Parents of females in the older group were concerned more about their daughter becoming pregnant, while parents of males in the older group were more likely to wonder if condom use should be taught. The only item that parents in the younger group were more likely to report was that a son had been confused by an erection.

DISCUSSION

The verbal level of the individual with autism is associated with parents' belief about the relevance of sex relations and whether these individuals received sex education. Hence, rules are more likely taught to the more verbal individual. Ironically, these beliefs exist despite the finding of no relationship between the verbal level and the display of inappropriate sexual behaviors. This finding suggests that an autistic individual of normal intelligence is just as likely as an autistic person with mental retardation to display inappropriate behaviors, emphasizing that the need for sex education is best determined by the behaviors of the person rather than by the functioning or verbal levels.

Although no relationship was found between exhibiting inappropriate behaviors and gender or concern about child's behavior being misinterpreted and gender, parents of males were more likely to want information about controlling masturbation and teaching rules. Research summarized in Basow (1986) explains that parents in the United States expect sons, not daughters, to engage in overt sexual activity, and parents as well as teachers provide more rules to males. This may reflect the attitudes of parents of children with autism as well.

Parents think that individuals with higher verbal levels were more likely to benefit from education. Perhaps the difficulty in teaching persons who are nonverbal and knowing what to teach influenced this response. Sex education is most likely received in schools; thus, schools need to consider how to teach sex education to those who are nonverbal. Possibly, information is not reaching these students because of a lack of appropriate sex educational programs geared for those who are not verbal.

Many parents are unsure about the worries of their son or daughter. However, parental concerns were identified and did not relate to the verbal level of the child. Parents are concerned about their child's vulnerability to AIDS and venereal disease and to being misunderstood and misinterpreted by others. Some parents expressed further concern for the child *not* having the opportunity for a sexual relationship. Similar to parents of children with other developmental disabilities (Fischer *et al.*, 1973) parents were worried about their child being molested. However, one interesting finding is that parent's concerns are related to the gender of the individual. Parents of males were more worried about their son being taken advantage of by a same-sex person; conversely, parents of females were worried about their daughter being molested by an opposite-sex person.

Parental attitudes toward sexuality vary; thus, their beliefs cannot be generalized. The relevancy of sexual relations for people with autism was the question asked by most parents suggesting their confusion. The age of the person influenced all of the items concerning information parents wanted and some regarding concerns parents expressed. Parents appear more likely to want information about sexuality as their child becomes an adult.

Many issues concerning sexuality for the person with autism include: (i) How do individuals with autism learn best about relationships and intimacy skills? (ii) what is the relationship between behaviors and sexual development? (iii) to what degree does teaching alleviate the effects of autism on sexuality and intimacy? (iv) how can sex behaviors be distinguished by need-for-intimacy behaviors? (v) to what extent do gender role biases of parents influence the training of persons with autism about sexuality?

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