Foreword

Questions related to sexuality and autism spectrum disorders have been the elephant in the room for quite a while. For years parents and professionals have been aware that youngsters on the autism spectrum develop biologically at a much faster rate than they do socially, emotionally, and interpersonally, and this knowledge has led to many questions about how to help this group deal with their biological needs and handle their own sexuality. The topic is a very sensitive one because it requires knowledge of their social and emotional limitations as they pertain to this area. The need of individuals with ASD for very concrete and specific instructions also challenges many parents and professionals who are not accustomed to discussing these kinds of issues using the concrete, specific, and visual strategies that work well in so many other areas of education.

After years of experts in sex education addressing this problem without an understanding of autism and experts in autism addressing these issues without being knowledgeable about or comfortable with many aspects of sexuality, we finally have a book that combines the best and most current information on both sexuality and autism. Parents and professionals will welcome this clear, direct, specific, and autism-friendly treatment of the full range of issues relating to sexuality – from the concrete descriptions and pictures of biological body parts and their functions to discussions of the more nuanced social and interpersonal relationships that intimacy involves. The book also includes numerous references to materials, websites, and illustrations that will help teachers formulate lessons for groups of children and young adults as well as individual instruction.

The authors are very explicit in explaining things and in offering teaching and content suggestions. It is hard to imagine a more thorough and detailed presentation on this topic. The authors even present helpful suggestions for teachers and presenters using this volume on how to manage their own discomfort with talking about these issues while discussing them in the kind of concrete, detailed, and visual ways that individuals with ASD require.

The book will be most welcome for those parents and professionals concerned about people with ASD functioning at a normal or near-normal intellectual level. It is unique in terms of its comprehensive treatment of the area, its concrete, specific, and detailed style, and the many helpful resources, teaching strategies, and suggestions it offers. Parents and professionals teaching youngsters with ASD about sexuality will find this book very handy as will anyone involved with a person with ASD who has the skills to understand these issues and who is dealing with sexuality questions and issues. Reading this book will help anyone trying to guide these youngsters through their many confusing and perplexing concerns.

The authors are to be congratulated for meeting such a compelling need in the field and doing it with such skill, attention to detail, and comprehensiveness. The field is now much richer for this remarkable contribution.

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Chapter 1: Introduction

This book provides a structured curriculum for teaching human sexuality and relationships to young adults and adolescents with high-functioning autism spectrum disorders (ASD). Throughout the book, we refer to these learners as "students with ASD." Specifically, we include any learner who has an autism spectrum diagnosis with average to high cognitive abilities, including diagnoses of Asperger Syndrome, high-functioning autism, pervasive developmental disorder, or any related condition that includes a social deficit. (See *Participants and Size of Class* for more information.)

Historically, what has been labeled "sex education" has been the focus of much controversy, both in the terms of the content of the curriculum and whether this is a suitable topic for educators to teach. Common objections to sex education have centered on fears that it may condone or encourage adolescent/premarital/unsafe sex. The best available evidence suggests that such fears have been largely exaggerated.

For example, Goldman (2008) notes that the evidence of the last 50 years clearly indicates that denying access to knowledge is not an effective way to deal with adolescent sexual activity. Rather, the vast majority of the available academic evidence across multiple countries shows that comprehensive sexuality education is an effective strategy for helping young people delay initiation of sexual intercourse, reduce the frequency and number of sexual partners, reduce the number of coerced teen marriages, reduce the rates of sexually transmitted infections, and increase the use of condoms and effective contraception. Goldman notes that most Western European countries now have mandatory, comprehensive sexuality education, and consequently have lowered their adolescent pregnancy rates to fewer than 40 per 1,000. By comparison, the United States, Russia, Bulgaria, Belarus, and Romania (all of which restrict or delay sexuality education) have rates of more than 70 per 1,000.

A few studies (e.g., Jemmott, Jemmott, & Fong, 2010) have claimed that abstinence-only education programs are effective. In a broader study, Kirby (2008) assessed the impact of 56 programs on adolescent sexual behavior, comparing abstinence-only and comprehensive sex education programs. He found that most abstinence programs did not delay initiation of sex, provided inaccurate medical information to adolescents, including false or misleading statements about the effectiveness and safety of condoms, and inflated the actual failure rate of condoms.

Further, as Smith, Steen, Spaulding Givens, and Schwendinger (2003) note, significant methodological problems exist in the vast majority of studies that have attempted to evaluate abstinence-only programs, not the least of which is reliance on self-report data on program outcomes. These are commonly subject to false reporting of abstinence by adolescents who know that abstinence is the socially desirable outcome.

In many respects, individuals with ASD are similar to their typically developing peers with regard to sexual health. They undergo normal physical body changes during puberty (Henault, 2006; Nichols & Blakeley-Smith, 2010). Also, research shows that individuals with ASD are aware of and interested in sexuality issues and engage in a variety of sexual behaviors (Gabriels & Van Bourgondien, 2007). However, due to the nature of their social impairment, communication deficits, executive functioning challenges, restricted areas of interests and behaviors, and sensory sensitivities, the intricacies of emotional/romantic relationships are likely to be more difficult for individuals with ASD to learn about, understand, and navigate than the general population. Indeed, Stokes, Newton, and Kaur (2007) found that adolescents and adults with ASD differed significantly in their social (e.g., friendship skills) and romantic functioning (e.g., skills to initiate and pursue romantic relationships, using appropriate behaviors like refraining from calling someone who asks you not to) compared with typically developing peers.

The same authors also noted that individuals with ASD obtained less romantic knowledge from their peers and the media than typically developing peers; in particular, their lack of peers/friends largely prevents them from accessing this learning. This "disconnect" between physical maturation and social relationship skills/understanding can lead to significant problems, both in terms of depression or anxiety linked to unmet needs and sometimes inappropriate sexual behaviors towards others (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Ray, Marks, & Bray-Garretson, 2004; Stokes et al., 2007; Sullivan & Caterino, 2008). In addition, as Sullivan and Caterino note, the social-communication impairments of individuals with ASD together with their lack of exposure to appropriate peer interactions leave them at great risk of misinterpretation of social cues and sexual behaviors of predators.

In short, there is a wealth of evidence to support the use of a curriculum that teaches both about the technical details of sex and the relationship factors involved to individuals with

ASD. As the landmark study by Kinsey, Pomeroy, and Martin (1948) stated, sexual expression is essential to an individual's well-being. The notion that individuals with ASD have the same rights to sexual health as typically developing individuals is, therefore, central to this book. The World Health Organization's definition (2006, as described in Hirst, 2008) is key when considering important factors in teaching this topic:

> Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. (p. 401)

Key to Icons

Throughout the book, icons are used to highlight key features as follows:


Note to instructor


Time needed (either to prepare or to carry out an activity)


Student objectives


Agenda


Warning to the instructor


Reproducible student handout


Reminder to explain student assignment

Reminder to instruct or tell students to put material into binders

List of where to look for the Internet resources listed if a specific URL no longer works (as happens frequently when websites are reorganized)

Activity

Teaching concept

What You Will Find in This Curriculum

Several authors have outlined essential topics to include in a sex education curriculum for individuals with ASD. Topics include the following: body parts and function, reproduction, birth control, sexual health, appropriate behaviors, privacy issues, establishing relationships, dating, marriage, parenting, abuse awareness, boundary issues, self-esteem, assertiveness, gender identity, sexual orientation, values and sexual decision making, intercourse, masturbation, contraception and sexually transmitted infection protection (Koller, 2000; Ray et al., 2004; Sullivan & Caterino, 2008).

We have designed this curriculum to include lessons on both sex education and relationship education. It begins by assessing students' knowledge and learning priorities as a guide for individualizing your emphasis when teaching the curriculum. It then introduces students to the concepts they will be studying and raises their awareness of some of the issues related to portrayal of sexuality in the media. The earlier lessons focus more on the "technical" aspects of sex education (anatomy, reproductive health, sexual responses, partnered sex, contraception, and sexually transmitted infections), followed by lessons that explore in more detail the social aspects of romantic relationships (preparing for dating, regular dating, stages of relationships, moving into longer term relationships). While the curriculum begins to teach students about long-term relationships issues such as maintaining a relationship over many years, these and other related issues (such as parenting) are not the focus here, since we are targeting individuals with ASD who are at earlier stages of relationships than this. The curriculum then tackles the more complicated socio-sexual topics of attitudes, values, differences (e.g., sexual orientation), and sexual coercion. The final lesson provides an evaluation and feedback format.

Part of this curriculum includes explicit anatomical sexual information. It is recommended that you read the entire curriculum before you begin teaching, in order to ascertain whether there are specific materials that you might want to modify or skip due to constraints of your organization or if you are using the materials with a much younger age group. Sexuality Information and Education Council of the United States (2004) has developed guidelines to assist you in determining what is developmentally appropriate for individuals in grades kindergarten through 12 to learn.

We have attempted to make the curriculum applicable to a wide variety of age groups and situations. However, we encourage instructors to make adaptations should this become necessary. For example, if you find your students struggling with the lesson on dating, you may decide to spend a couple of lessons on exploring basic social interaction skills.

We understand that with time and resources often being at a premium to educators, it can be tempting to skip sections or not use supplementary materials such as video clips. Our experience is that students with ASD require a lot of detailed teaching (and repetition), particularly of topics with a social element, in order to begin to acquire and utilize these skills and knowledge. Therefore, we urge you not to shorten or reduce any of the lessons, as this is likely to risk presenting a curriculum that your students are unable to access sufficiently to achieve the desired outcomes.

Who Can Teach the Lessons?

The most effective instructor for this curriculum is someone who is familiar with strategies that maximize the learning of students with ASD. In addition, completion of some form of professional development involving sexual health topics is recommended. Several educational backgrounds could form the foundation of the expertise needed to teach this curriculum. For example, instructors could be special or general education teachers, occupational therapists, speech-language therapists, health teachers, nurses, social workers, private therapists, parents, psychologists, or consultants.

The curriculum may be taught by one person. Indeed, it is written from this point of view, since we recognize that, in many circumstances, only one person will be available. However, given the complexity of the topics and the difficulties that some students with ASD have working in groups, a co-leader or assistant is desirable.

Further, although we provide all the content needed for each lesson, for some topics (most notably those with a heavy medical bias), the instructor may decide to invite an outside speaker to present part of the lesson or to answer questions (e.g., nurse or public health/sexual health educator). In such cases, we have learned from experience that it is critical to provide guest speakers with sufficient information prior to their visit to make the activity successful. For example, it is essential that the guest speaker understand students' ability levels and the teaching modalities that are most effective for them. Giving the guest speaker some examples of the kinds of questions posed by students ahead of time can aid this process.

Throughout this book the person teaching the curriculum is referred to as "the instructor," and the individuals with ASD that you are teaching are referred to as "students" (whether they are adolescents or adults or seen in a school, clinic, or institutional setting).

Participants and Class Size

The most appropriate students for this curriculum usually have IQ scores around the average or above-average range, are able to talk, and understand complex spoken sentences (e.g., be able to have a 5-minute back-and-forth conversation about a TV show they just watched). They should also be able to read sufficiently in order to comprehend the written materials in the student handouts that accompany each lesson and comprehend visual-verbal media such as video clips and websites. If you are looking for information for learners who have more significant intellectual disabilities, Gabriels and Van Bourgondien (2007) provide many helpful strategies and resources as do McLaughlin, Tooper, and Lindert (2009).

Our curriculum is designed to be taught to a group consisting of both male and female students to allow for discussion and exchange of ideas. However, as the instructor, you know your students best and may choose to divide up the students in smaller groups for some of the lessons. In addition, it is possible to use the curriculum to teach one individual; for such instances, we have provided suggestions at the end of each lesson on ways to adapt the teaching concepts.

Keep in mind that much of the material you will be teaching is complex and difficult for students to learn since it involves social relationships. There are no hard and fast rules about class size, since it largely depends on the strengths and challenges of individual students. However, we recommend a class size of no more than 15 students (ideally fewer) with opportunities for students to work in smaller groups of 2 or 3 for some of the group activities.

Utilizing Evidence-Based Best Practices and Central Strategies

As noted above, knowledge of strategies that maximize the learning of students with ASD is desirable to ensure effective delivery of this curriculum. Throughout the lessons, we describe approaches and techniques that have been shown to be effective (both from a research perspective and our own experiences) for learners with ASD.

The idea behind developing this curriculum arose from necessity, since we were asked to teach human sexuality to a group of young adults with diagnoses of ASD. At the time, we were unable to locate a suitable curriculum that met the precise needs of our students and that covered sex education and relationship building with strategies appropriate for the learning styles of individuals with ASD. Therefore, we started creating our own.

The curriculum presented here has been revised and adjusted based on both our own direct experiences with our student group and the students' recommendations of what they found most helpful. In directly obtaining our students' views, we were able to gain more insight into the priorities for our curriculum. A summary of these views is shown in Table 1.1 (*Summary of Student Comments About the Curriculum*) at the end of this chapter.

While each lesson describes specific techniques, keep in mind the following central strategies:

- **Know your students.** Since your students' social communication is impaired as part of their ASD, they may communicate and interact in ways that can be misinterpreted. Therefore, it is beneficial to spend some time getting to know how each individual best expresses and absorbs information. The key to effective structuring for students with ASD is individualization (TEACCH staff, n.d.). We provide some general strategies but urge you to assess the needs of each student in order to make them as effective as possible (see *Lesson I, Introductory Class, Teaching Concept 4: Initial Assessment*, for more information about ways to do this).

  Be aware of any accommodations (e.g., scribe, computer to type rather than write, extra time, taking test in another room, non-fluorescent light source) each student may need during the lesson or for tests. Plan how you are going to incorporate these needs into your lesson.

- **Be honest.** Be aware of what you know and what you don't know. Adolescents are exposed to quite a bit of misinformation; they need reliable educators. If you are unsure of an answer, say so and then do some research to find the correct information.

- **Include breaks.** Since you are requiring your students to interact and communicate, they will likely encounter some stress. Avoid actively engaging students for longer time periods than they are able to comfortably tolerate. We have planned a break during each lesson, but the timing of the break is left to your judgment, according to the needs of your students. You may also decide to have more than one short break if this will better meet your students' needs.

- **Make the information concrete.** Your students are likely to find abstract information difficult to understand (Koller, 2000). Given that many aspects of relationships are abstract, we have attempted to make concepts as factual and concrete as possible in order to maximize understanding. If your students struggle with the lessons as presented, you may need to break tasks into smaller steps, provide a model, give increased practice opportunities, and reinforce students for their efforts and success (Nichols, Moravcik, & Tetenbaum, 2009).

- **Keep an open mind.** Human beings are sexual and have the right to become aware of their choices with regard to their own bodies (Hingsberger, 1990). While this may not always be easy or even comfortable to discuss, it is important that the instructor remain neutral without expressing personal opinion on students' decisions while being able to share a wide range of choices. Be especially aware of your nonverbal communication, including your facial expressions, to avoid communicating a personal opinion (either positive or negative) when discussing a student's preference and/or a controversial issue (Wilson, 2009).

- **Add a visual element.** Material presented visually is likely to be easier for your students to understand and learn and provides a support for their organizational deficits (Hodgdon, 1999; Hogan, 2006). Throughout the lessons, we provide or suggest the instructor add as much visual material for students as possible in the form of written handouts, illustrations, photographs, icons, and video suggestions. Students are then supported in putting together this material in an individual resource binder. We also note other ways that you can supplement these visual supports, such as making the handout material into a PowerPoint presentation or writing it on a flipchart.

- **Allow time for role-play and practice.** Support your students in understanding and expressing emotions (which will help them in their relationships) using role-play and practice that incorporate perspective taking and non-verbal communication (Attwood, 2007; Winner, 2002).

- **Don't skip the videos.** In order to illustrate key social concepts (e.g., asking a girl on a date, body language), in many lessons we have suggested using video clips from the students' favorite movies and television shows to use as a medium they can relate to. This has

been demonstrated to be an effective way to teach social skills to individuals with ASD (Koller, 2000).

- **Use your own experiences to illustrate points.** We are not suggesting that you reveal intimate details about your own relationships to your students. Rather, we are suggesting that you draw on your life experiences (in a neutral way without students being able to identify the people you are referring to) to enable you to give some perspective to their learning. For example, sharing an anecdote about someone you know who picked a bad place for a first date.

- **Have a sense of humor.** Some of the topics discussed in this curriculum can be embarrassing for you as well as your students. Acknowledging this can help to break the tension. It can also sometimes help to use humor. However, we caution against using forms of humor that cannot be understood literally, such as sarcasm, as these are likely to be misunderstood by your students. If you do find yourself using abstract humor, be sure to provide some explanation (e.g., by acknowledging that what you just said was a joke because you were using a word in a different way than the way it is often used) of the concept in order to ensure understanding and prevent your students attempting to use the same humor in an inappropriate situation.

- **Maintain appropriate boundaries between you and your students.** Maintaining social boundaries is a subtle social skill that your students may find particularly difficult. When you teach sensitive sexual-social topics, students may assume a level of familiarity that could be inappropriate. Make boundaries very clear by specifically addressing issues as they arise. For example, if a student asks you a question that crosses a boundary, such as "When was the first time you had sexual intercourse?," address the boundary issue directly by explaining that it is not appropriate for instructors to talk about their own personal histories with students but that you can give them statistics about the population in general. Where possible, add some general rules that students will be able to utilize in the future, such as who they can talk to about personal history. See Wilson (2009) for more information on ways for sex educators to answer student questions.

Room Arrangement

The ideal room arrangement includes access to multiple rooms or one large room with furniture situated in different areas. The arrangement of the classroom can help or hinder the independent functioning of the student with ASD and his or her compliance with rules (TEACCH staff, n.d.).

Factors to consider include setting up furniture in such a way that it sets clear expectations and minimizes potential distractions (TEACCH staff, n.d.). For example, tables or desks that can be arranged in a circle or semi-circle for group activities to show students that they are expected to be a part of a discussion or to watch a media image is desirable. Avoid situating students so that they are facing obvious distractions (e.g., a large window). Have available either multiple dry-erase boards or chart paper to hang on the wall for visuals to be shown. The adjoining rooms (or areas within the large room) may be used when the students are divided into smaller groups. If the same rooms are used for each class, this may minimize organizational confusion.

It may be helpful to have a bookshelf or filing cabinet where students can keep their binders. If you are using a bookshelf, it is important (because of the explicit nature of some of the materials) that it be private and off limits to others (e.g., it could be in a lockable office). Be sure to check your organization's confidentiality guidelines (or those of the organization that is hosting your class) and include those strategies as you organize your lessons.

Having specific areas for specific tasks, marking clear boundaries, and making materials easily accessible helps students with ASD to know where they are supposed to be and where to get their own materials (TEACCH staff, n.d.).

Session Length, Frequency, and Duration

Each lesson is based on a two-hour segment of time. It is possible to teach the lesson in parts, if less time is available or your students' needs so dictate. Further, the curriculum may easily be adapted to a semester in high school or college, a set amount of times with a private therapist, or for a school year with a parent. The students could repeat aspects of the lessons on some target skills if more practice was required while continuing to develop new skills.

Organization of Lessons

Each lesson plan follows a similar format to provide participants with a sense of consistency and predictability, as this can alleviate anxiety for individuals with ASD (Attwood, 2007). The lesson plans begin with ...

- List of materials for each lesson
- An estimate of instructor preparation time
- An estimate of actual lesson time
- Student objectives to keep in mind as outcomes

Each lesson starts with the distribution of a list of objectives and an agenda to each student – having a written agenda is reassuring for many students as it makes your expectations clear and helps them to anticipate activities while they become more organized (Faherty, 2000).

We recommend that you ask your students to write in break activities ahead of time, so that the expectations are clear and you have the flexibility to provide activities that will be most relaxing to your students.

Each lesson plan includes teaching concepts that outline the main information to be targeted. At the end of each lesson is an assignment (you could call this "homework" for younger students) that students are to complete before the next lesson. Assignments are a combination of priming (Wilde, Koegel, & Koegel, 1992) for the upcoming lesson and consolidation of concepts from the current lesson. You will assist your students with some basic organizational tasks (e.g., filing handouts, noting assignment in their schedules) before leaving each session. Finally, each lesson concludes with guidelines for delivering the lesson to an individual student and a checklist of follow-up items for the instructor.

For your convenience, all handouts are available at the end of each chapter as well as on the CD that accompanies this book. This will enable instructors to print handouts directly from the CD as well as copy key diagrams (these can then be displayed in class, for example, by using Powerpoint and a projector).

Tips for Instructors New to Teaching a Sexual Health Curriculum

If you are uncomfortable talking about sex topics, here are some tips to make it easier for you:

- Try thinking of body part labels or sexual acts as medical terminology. Practice talking about the topic you are about to teach with a colleague or spouse to become more accustomed to the language.
- Consult with someone about your discomfort (e.g., a work colleague or supervisor or if you are a parent, your partner or another parent) to receive guidance and support.
- Ask a professional (e.g., a counselor who already knows your student/s) to deliver the parts of the curriculum that are most difficult for you.
- Stay calm and don't overreact if your students tell you or ask you information that makes you uncomfortable. If necessary, buy yourself time to think about an answer by saying you will come back to it later. Then give students factual information or refer them to readings (make sure you check that they have understood what they read) or a person who can provide the information.

Table 1.1
Summary of Student Comments About the Curriculum

Aspect of the Class That the Comment Referred To:	Summary of Student Comments
Instructor Displaying the Materials in a Projected PowerPoint Format	• Helpful to have visual information to look at. • Less helpful if the slide had a lot of text.
Visiting Guest Speakers Who Were Experts on a Topic (For example, a nurse from a student health center)	• One speaker was very helpful – she clearly had a lot of expertise, and she showed video and diagrams that were clear. • One speaker was unhelpful – her material was too simple, and she was condescending. • Speakers who just talk are not helpful – I cannot follow a purely verbal lecture.
Watching Videos and Videotaping Ourselves	• Short clips were informative and had helpful information. • Helpful to show positive things or what to do as well as what not to do.
Factual Lessons on Anatomy, Reproduction, Partnered Sex, Contraception and Sexually Transmitted Infections	• A lot of stuff I had heard before, but good to have a refresher. • A lot of the information was new to me. • Good to have the opportunity to ask questions. • Thanks for making us laugh in class. The material is uncomfortable at times to talk about but alright in this class.
Lessons on Dating and Stages of Relationships	• Sensory – more information about coping strategies would have been helpful. • Difficult to teach topics like these that are open to interpretation, but these are the areas I feel I need to work on the most. • These lessons were helpful, and I will need to continue to work on this stuff probably the rest of my life
Lesson on Attitudes, Values, and Differences	• The individuals on the gay, lesbian, and bi-sexual panel were interesting, but it would have been helpful if there had been more questions (I didn't know what to ask). • The attitudes and values reading material was not new to me, but it was helpful to think about other people having different perspectives. • It was good to hear from people who are going through the same things as me.
Lesson on Sexual Intimidation	• A lot of the factual information was stuff I already knew, but it was useful to think about the social blunders aspect.
Personal Feedback	• It was helpful to be able to talk over some specific details with instructors after class. This is when I was able to figure out a solution to understand what someone in my class was trying to communicate and how best to respond. • I liked being able to take the handouts to share with my therapist and do some more work on the ideas given.

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