A Training Manual for Parents and/or Caregivers Addressing Sexual Behaviours in Adolescents with Autism Spectrum Disorder (ASD)

by

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The procedures in this staff training manual are meant to be used by agency staff, as part of the broader services they provide, or under supervision of agency staff
Abstract

Sexual education adapted for individuals with ASD is uncommon. A program under current development by the Canadian Mental Health Association – Kingston Branch aims to provide sexual education tailored toward adolescents with ASD. The goal of the present thesis project was to create an accompanying educational manual for parents and/or caregivers of adolescents with ASD. As an understudied topic, there is limited research available. The most relevant and recent information was collected and presented in a user-friendly manual. The chapters included in the manual were as follows: Myths about adolescents with ASD and sexuality; sexual education and the need for it; adolescents with ASD vs. typically developing peers; an explanation of why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD; and common parental concerns. A feedback form was created for future reference. Recommendations for future research included the collection of user feedback as well as the incorporation of personal experiences and suggestions provided by parents and/or caregivers of individuals with ASD.
I would like to express my utmost gratitude to my college supervisor, Christian Keresztes. Your guidance and support have been absolutely invaluable to me, and I honestly believe your influence has helped shape this thesis into something I can be truly proud of. I would also like to thank my second reader, Pamela Shea. Your thoughtful feedback and recommendations were priceless to me, and I cannot express to you how grateful I am for your words of encouragement. I would also like to acknowledge Alexis Brough, my close friend and fellow BPSYC student whose unwavering encouragement and reassurance made me believe that I could do this. You were an irreplaceable support for me during placement, and our weekly study “parties” saw me through the completion of my thesis. Finally, I would like to thank all of my friends and family who encouraged and supported me throughout this entire process.
A TRAINING MANUAL FOR PARENTS

Table of Contents

Abstract .............................................................................................................................................. ii
Acknowledgements .......................................................................................................................... iii
Table of Contents ............................................................................................................................ iv
Chapter I: Introduction .................................................................................................................... 1
Chapter II: Literature Review ......................................................................................................... 2
  Myths About Adolescents With ASD and Sexuality ................................................................. 2
  The Need for Sexual Education .................................................................................................. 2
  Sexual Education ......................................................................................................................... 3
  Adolescents With ASD vs. Typically Developing Peers .............................................................. 4
  Reasons Why Adolescents With ASD can be Sexually Inappropriate ..................................... 4
  Sexual Orientation ..................................................................................................................... 5
  Girls With ASD ........................................................................................................................... 5
  Common Parental Concerns ...................................................................................................... 6
  Summary ...................................................................................................................................... 6
Chapter III: Method ......................................................................................................................... 9
Chapter IV: Results ......................................................................................................................... 10
Chapter V: Discussion ..................................................................................................................... 11
References ....................................................................................................................................... 13
Appendices ......................................................................................................................................
  A. Feedback Form ....................................................................................................................... 15
  B. Autism & Sexuality Manual ................................................................................................. 16
Chapter I: Introduction

The diagnosis of autism spectrum disorder (ASD) involves impairment in social skills, communication, and/or behaviour (American Psychiatric Association, 2000). For children diagnosed with ASD, adolescence is a profoundly different experience from that of their typically developing peers. One of the most notable differences involves the development of appropriate sexual behaviours. While most adolescents acquire knowledge of sexuality informally amongst themselves, adolescents with ASD are generally not privy to such social situations. As an understudied topic, most parents and caregivers are unprepared for providing sexual education to adolescents with ASD. The creation of a manual which outlines the various aspects of sexuality will lead to insight and understanding of inappropriate sexual behaviours and how to address them as a parent or caregiver.

Sexual education adapted for adolescents with ASD is rare. It is a severely understudied topic, and there are many myths surrounding it. It is a common belief that people with ASD have no interest in sexuality or that they are sexually immature. However, according to the literature to be reviewed in the present thesis, this is completely false. Adolescents with ASD do have sexual impulses and desires, but many lack the knowledge that comes from any form of sexual education as traditional education does not address their specific needs. That lack of education can lead to serious consequences (e.g. incarceration for behaviour misperceived as sexual deviance, injury as a result of hypermasturbation, increased risk of sexual abuse, etc.).

The creation of a sexual education manual for the parents of adolescents with ASD is justified for several reasons. Many parents and/or caregivers either do not know how to approach sexual education, or they do not see the value in it. There are minimal resources available, and literature is sparse. The manual will complement a program currently under development by the Canadian Mental Health Association – Kingston Branch that will directly provide sexual education to adolescents with ASD. The manual will serve as supplementary reading material for parents, caregivers, siblings, friends, and anyone who wishes to learn more about teaching appropriate sexual behaviour to adolescents with ASD. The purpose of the manual is to increase understanding of sexual behaviours and needs, and how parents and/or caregivers can help adolescents with ASD transition through puberty.

The present paper will provide an overview of the manual and its contents. The topics covered are as follows: Myths about adolescents with ASD and sexuality; sexual education and the need for it; adolescents with ASD vs. typically developing peers; an explanation of why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD; and common parental concerns.
Chapter II: Literature Review

Based on the literature reviewed, it can be concluded that there is no universal approach to sexual education for adolescents with ASD. There are recurring themes throughout the literature in terms of topics to cover and suggested teaching methods, but it is clear from the literature that education tactics must be personalized for each individual learner. Although the studies reviewed demonstrated a variety of limitations, there were a large number of recurring strengths as well. To provide parents and/or caregivers with insight and understanding regarding the sexual behaviour of adolescents with ASD, the following sections include: Myths about adolescents with ASD and sexuality; the need for sexual education; sexual education; adolescents with ASD vs. typically developing peers; reasons why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD, and common parental concerns. These sections present a summary of common themes established across the studies.

Myths about Adolescents with ASD and Sexuality

There are many popular misconceptions regarding the sexuality of adolescents diagnosed with ASD. Possibly the most common is the idea that people with ASD are asexual or are uninterested in sexuality (Konstantareas & Lunsky, 1997; Tissot, 2009). It has also been suggested that people with ASD are entirely self-centred and use relationships with others simply as a means of satisfying personal needs (Sullivan & Caterino, 2008).

Another common belief is that the social deficits involved with ASD result in a disinterest in the pursuit of social or intimate relationships (Koller, 2000; Stokes & Kaur, 2005). There are also those who hold the belief that adolescents with ASD would be better off never going through puberty as it would be too confusing a transition (Ballan, 2012). Because of the lack of sexual education available, there is a common concern that sexual expression could pose a threat to typically developing peers and it could be mistaken as deviant (Realmuto & Ruble, 1999; Tissot, 2009).

Research indicates that people with ASD do in fact engage in sexual behaviours, and many express desire for romantic relationships (Sullivan & Caterino, 2008). There is also evidence that many people with ASD express a desire for getting married and having children of their own (Konstantareas & Lunsky, 1997). Furthermore, there is no evidence in the literature that supports the belief that individuals with ASD pose a threat to their typically developing peers. While it is true that the transition through puberty can be confusing for individuals with ASD, research indicates that effective and properly timed sexual education can make the transition no less manageable than that of typically developing peers (Ballan, 2012).

The Need for Sexual Education

Another commonality in the literature is high demand for sexual education for adolescents with ASD. There are many risks when sexual education is either delivered too late or not at all. According to Stokes and Kaur (2005), a lack of sexual education for adolescents with ASD can result in inappropriate sexual behaviours such as removal of clothing or masturbation in public, unwanted touching of strangers, and/or kidnap of a sexual nature. It has
APPLIED THESIS

also been suggested that individuals with ASD often fixate on others to the point of harassment (Stokes & Kaur, 2005). Stokes, Newton, and Kaur (2007) suggest that the social deficits involved with autism can result in inappropriate dating behaviours, such as stalking. Furthermore, research indicates that a lack of sexual knowledge can result in sexual behaviours toward individuals who do not wish to reciprocate, such as parents, strangers, and/or children (Stokes & Kaur, 2005).

Without individualized sexual education, adolescents with ASD may suffer personal injury or contract sexually transmitted infections. Research indicates that sexual ignorance can result in masturbation with foreign objects or repeated, unsuccessful attempts to masturbate to the point of injury (Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010). Furthermore, a lack of sexual knowledge can leave the adolescent more vulnerable to sexual abuse (Mansell, Sobsey, & Moskal, 1998; Wolfe, Condo, & Hardaway, 2009). According to Ballan (2012), individuals with ASD are more vulnerable to sexual abuse than their typically developing peers as they struggle to judge the intentions of others. Research indicates that individuals with ASD have difficulty reporting sexual abuse (Backeljauw, Rose, & Lawson, 2004; Ballan, 2012). A suggested explanation for this occurrence is that the lack of sexual education results in a weak vocabulary regarding body parts and a limited understanding of personal boundaries (Backeljauw et al., 2004; Ballan, 2012). According to Koller (2000), it is important to incorporate personal rights, the ability to deny unwanted sexual advances, and privacy awareness into sexual education.

According to Tarnai and Wolfe (2008), it is possible for adolescents with ASD to acquire a healthy understanding of sexuality, but it can be difficult without early intervention. They suggest that proper sexual education can aid in the prevention of sexual abuse, sexually transmitted infections, and unplanned pregnancy.

Sexual Education

Due to the nature of ASD, it is critical that sexual education be personalized and adapted for each specific learner (Hatton & Tector, 2010; Koller, 2000). It is also suggested that the subject be taught by a parent, caregiver, or someone else who is familiar to the adolescent as sexuality can be an uncomfortable topic for teachers (Hatton & Tector, 2010; Koller, 2000). Suggested topics to cover in sexual education include “body parts and function, social/sexual behaviour, sexual life-cycle, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, assertiveness, and self-esteem” (Sullivan & Caterino, 2008, p. 387). The selection of topics should be based on need and level of understanding (Koller, 2000).

According to a study by Wolfe et al. (2009), there is a variety of applied behaviour analysis (ABA)-based strategies that can be effective in teaching sexual education to adolescents with ASD. The empirically-based nature of ABA has been suggested to be particularly appropriate teaching strategies for individuals with ASD. They suggest five ABA-based strategies to specifically address sexual education: Video modeling, visual strategies, social script fading, task analysis, and social stories. Video modeling is a strategy that includes the preparation of a video to target a specific skill or behaviour, and allowing time for the video to be viewed and practiced (Wolfe et al., 2009). Visual strategies can be similar to video modeling.
except that the representation of steps is photographic and act as a series of prompts (Wolfe et al., 2009). Social script fading is a strategy that involves the preparation of a script which can be practiced and faded out as the skill or behaviour is mastered (Wolfe et al., 2009). The fourth strategy mentioned is task analysis which involves a step-by-step break down of a skill or behaviour into smaller, more manageable tasks (Wolfe et al., 2009). The behaviour is then taught with the use of forward, backward, or total task chaining (Wolfe et al., 2009).

The final and most frequently recommended ABA-based strategy is the use of social stories (Wolfe et al., 2009). According to Tarnai and Wolfe (2008), social stories are short stories that describe specific situations in a way that is significant for individuals with ASD. They are written in the first person singular and use active voice (Tarnai & Wolfe, 2008). Social stories must be adapted for each individual in an effort to optimize learning.

**Adolescents with ASD vs. Typically Developing Peers**

There are a variety of differences between adolescents with ASD and their typically developing peers in terms of sexuality. Adolescents with ASD tend to experience more difficulties with the physical changes of the body that occur throughout puberty (Hellemans et al., 2010). According to Realmuto and Ruble (1999), typically developing adolescents learn at a young age to be discrete when it comes to the display of sexual behaviours. Sexual impulses develop, but the informal learning that occurs through socialization prevents typically developing adolescents from acting on those impulses in an inappropriate manner (Sullivan & Caterino, 2008). Adolescents with ASD however are typically uninvolved in socialization with peers. Ray, et al. (2004) suggest that adolescents with ASD often behave sexually inappropriately as a means of securing social approval. In other words, the adolescent with ASD who hears his peers laughing at a sexual joke during recess misinterprets the laughter as social acceptance. The adolescent becomes more likely to repeat the joke at inappropriate times. As suggested by Konstantareas and Lunsy (1997), a further explanation for this phenomenon is that individuals do not perceive sexuality as a taboo topic.

According to the available literature, there are similarities between adolescents with ASD and their typically developing peers as well. When it comes to desires and aspirations for the future in terms of sexual development, both groups share similar goals. Both typically developing adolescents and those with ASD generally have the desire to get married and have children of their own (Stokes et al., 2007). It has also been suggested that both groups follow similar developmental patterns; however the social differences create an estimated delay of five years (Stokes et al., 2007).

**Reasons why Adolescents with ASD can be Sexually Inappropriate**

The social deficits that are typical of ASD are a key factor in the sexually inappropriate behaviour. As suggested by Ray, Marks, and Bray-Garretson (2004), most adolescents cannot differentiate simple kindness from attraction. Such misunderstandings can lead to inappropriate behaviours such as stalking or sexual harassment. For typically developing individuals, it is not uncommon to call, send love letters to, or go out with the object of one’s affections. For individuals with ASD, the inability to recognize whether these advances are wanted can cross the
line from appropriate courtship to sexual harassment (Stokes et al., 2007). Furthermore, it is not uncommon for individuals with ASD to be excluded from socialization with typically developing peers (Realmuto & Ruble, 1999). Adolescents with ASD often learn through experience that socialization with others is only achieved with persistence (Stokes et al., 2007).

According to Ray et al. (2004), the biological changes that occur throughout puberty can also be the cause of the numerous challenges that adolescents with ASD must face. During puberty, adolescents with ASD may experience the “desire for greater social isolation, episodes of oppositional behaviour, anger and depression, increased rigidity and inflexibility, poor organization and school performance, and increased preoccupations with special interests and isolating hobbies” (Ray et al., 2004, p. 267). A possible motivation for the increase in aggressive episodes is that adolescents with ASD struggle to understand the changing social expectations which accompany puberty (Koller, 2000).

Adolescents with ASD are also discovering sexuality. Stokes and Kaur (2005) note that adolescents with ASD often do not seek privacy for sexual activities such as masturbating and/or changing clothes. The lack of social awareness and the tendency toward self-stimulatory behaviour pose a challenge in terms of sexual inappropriateness if sexual education is not handled effectively (Sullivan & Caterino, 2008).

**Sexual Orientation**

In regard to sexual orientation, there is a great deal of variance across the literature. According to a study by Hellemans, Colson, Verbraeken, Vermeiren, and Deboutte (2010), the prevalence of homosexuality and bisexuality among individuals with ASD falls within the typical range. However, an earlier study by Hellemans et al. (2006) indicated that individuals with ASD displayed a higher instance of bisexuality than that of typically developing peers. It has been suggested that the higher level of bisexuality could be the result of the lack of social awareness that accompanies ASD (Hellemans et al., 2006). Because individuals with ASD are not concerned with what others think about them, it is suggested that they would not be governed by any societal expectations in terms of sexual orientation.

**Girls with ASD**

In addition to the introduction of sexual behaviours, girls with ASD must deal with the inevitable onset of menstruation. According to Cridland, Jones, Caputi, and Magee (2013), parents of girls with ASD reported the beginning of menstruation as their most concerning puberty-related anxiety. According to Backeljauw et al. (2004), there are a number of behavioural challenges that can accompany puberty as a result of menstrual cramps and overall discomfort. They suggest that girls with ASD can express their discomfort by means of increased aggression or agitation, and in some instances self-mutilation. In some cases, contraception has been implemented in an effort to minimize the effects of menstruation (Backeljauw et al., 2004). It is proposed that birth control can promote feminine hygiene and suppress the hormonal changes associated with menstruation. According to Koller (2000) however, most girls with ASD accept the arrival of menstruation in an unemotional and practical manner, and typically do not require the use of contraception to control it. Furthermore, Hatton
and Tector (2010) suggest that with advanced preparation and the implementation of some sort of visual calendar, menstruation can become even more manageable.

For girls with ASD, there is also the concern of sexuality in regards to popularity. Girls with ASD are not only different from their typically developing peers, but because the majority of individuals with ASD are male, they are also different from their peers who share their diagnosis (Cridland et al., 2013). As a result, many girls with ASD have difficulty integrating at school. There is a common misconception among girls with ASD that participating in sexual behaviours will lead to an increase in popularity (Hatton & Tector, 2010). In a study conducted by Hatton and Tector (2012), a woman with ASD explains “I thought to get a boyfriend you had to agree to have sex with them and so I told the first boyfriend I had that I knew about this and would have sex,” (Hatton & Tector, 2013, p. 71). Such misconceptions should be addressed in sexual education.

Common Parental Concerns

It is not uncommon for parents and/or caregivers to have fears and concerns regarding their children’s wellbeing. When the children are diagnosed with ASD, a plethora of additional fears and concerns may arise. In regards to sexual education, the most common concern is that parents and/or caregivers do not want to influence their children toward any inappropriate behaviours (Konstantareas & Lunsky, 1997; Tissot, 2009). According to Ballan (2012), many parents and/or caregivers fear that the introduction of sexual behaviours such as masturbation will replace any current self-stimulatory behaviours in which they may already engage. For example, an adolescent who currently exhibits rocking behaviour will replace it with masturbation once sexual education begins. According to the literature, there is no evidence to support this conclusion (Konstantareas & Lunsky, 1997; Tissot, 2009). Furthermore, it has been suggested that any sexual behaviours such as masturbation can easily be modified to be more socially acceptable (Ray et al., 2004).

According to a survey by Sullivan and Caterino (2005), 75% of parents worried that their child’s autistic behaviour would be misconstrued as sexually deviant. Beyond perceived deviance, another concern arises in terms of their children’s lack of social understanding. Due to the increase in sexual behaviours and the social deficits, many parents fear that their children’s behaviour will result in public embarrassment (Koller, 2000). Fortunately, these concerns can all be addressed and prevented with proper sexual education according to the research.

Summary

There are many and varied aspects to understanding the sexuality and sexual behaviour of adolescents with ASD. To provide parents and/or caregivers with insight and understanding regarding the sexual behaviour of adolescents with ASD, the manual covers a broad range of topics, including: Myths about adolescents with ASD and sexuality; the need for sexual education; sexual education; adolescents with ASD vs. typically developing peers; reasons why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD; and common parental concerns.
As an understudied topic, there is very limited research available. Only sixteen relevant sources were referenced in the research for the manual. Of those sources, there were 11 empirical studies and 5 general articles. Each article defined the diagnostic criteria for ASD in a consistently similar manner, but there were numerous recurring limitations noted across the literature. Several of the empirical studies identified small sample size as a limitation, and there was one report of a lack of control group. Case studies conducted by Ray et al. (2004) and by Tissot (2009) both indicated a lack of random selection.

There were five empirical studies that reported on data based on participant self-report. The studies conducted by Hellemans et al. (2006), Hellemans et al. (2010), and Stokes and Kaur (2005) all collected data based on questionnaires and rating scales which resulted in more measurable responses. The studies conducted by Ballan (2012) and Cridland et al. (2013) both asked participants open ended interview style questions. While open ended questions typically elicit more thoughtful, personal responses, the data collected by such questions is considered to be less measurable than questionnaires with a specified rating scale.

Due to the limited research available on sexuality and adolescents with ASD, some of the studies included in the research for the manual were not specific to individuals with ASD. Backeljauw et al. (2004) and Konstantareas and Lunsky (1997) included individuals with developmental delay (DD) as well as individuals diagnosed with ASD. Furthermore, the population included in the study conducted by Hellemans et al., (2010) was comprised of individuals with ASD and borderline/mild mental retardation. There was also a fair amount of variation across the literature in terms of the age range of selected participants. The study by Ballan (2012) represented the youngest participants with ages ranging between 6 and 13 years old. The studies by Hellemans et al. (2010) and Stokes et al. (2007) represented the mid-range of selected participants with the inclusion of individuals aged 15 to 21 years old and 13 to 30 years old, respectively. The Konstantareas and Lunsky (1997) study included the oldest participants, with ages ranging between 16 and 46 years old.

The study conducted by Hellemans et al. (2006), as well as the study conducted by Hellemans et al. (2010), reported on interviews with residential caregivers rather than the participants’ parents. Furthermore, the studies that included interviews with parents of participants did not indicate any exclusion criteria or data on parental characteristics. This creates a limitation as different parents have different levels of education, and therefore the reports may not be truly representative.

Finally, there was a common limitation across the literature in terms of the gender of participants. The studies conducted by Hellemans et al. (2006) and Konstantareas and Lunsky (1997) reported mostly male participants while the study conducted by Hellemans et al. (2010) reported exclusively male participants. However, according to Cridland et al. (2013), the most universally accepted ratio in terms of the gender breakdown of individuals with ASD is four males for every one female. As a result of there being significantly more males with ASD, the likelihood of male-dominated studies is high. Despite this probability, females with ASD have gender-specific concerns that arise during puberty which should also be incorporated into any specialized sexual education program.
The use of parental reports is a common feature throughout the literature reviewed. Such reports are considered to be an asset in terms of the understanding of adolescents with ASD. However, none of the reviewed studies reported any data collected about the parents themselves. For future research, it is suggested that parents of selected participants be screened with some exclusion criteria to ensure validity and reliability of results.

In summary, the limitations of the studies included in the current literature review include: Small sample sizes, lack of random selection, lack of control group, lack of consistency regarding self-report data, inclusion of other diagnoses besides ASD, lack of data regarding parental characteristics, and lack of diverse participants specifically in regards to gender. In terms of future research, it has been suggested in the literature that larger sample sizes be implemented in an effort to gain a better understanding of adolescents with ASD as a whole. It is also recommended that future studies select participants randomly and attempt to demonstrate more diversity across selected participants. Such recommendations would increase the generalizability of research findings as larger, more diverse samples would better represent the population as a whole.
Chapter III: Method

The format of the current thesis project is an education-based training manual to provide insight about the various aspects of sexual education for adolescents with ASD. The manual will complement the aforementioned sexual education program under current development by the Canadian Mental Health Association (CMHA) - Kingston branch and will require an estimated Grade 8 reading level for comprehension. The manual is primarily intended for the parents and/or caregivers of adolescents involved in the sexual education program who wish to learn about the topics covered in the program while it is being run. It will also be available as supplementary reading material for anyone who wishes to gain an understanding of sexual education for adolescents with ASD. Following the program, the manual will be made available as part of the existing library of training manuals and resources in the CMHA - Kingston branch.

The manual addresses several aspects of sexuality for adolescents with ASD organized around the themes identified in the literature review. The sections of the manual include: myths about adolescents with ASD and sexuality; the need for sexual education; sexual education; adolescents with ASD vs. typically developing peers; reasons why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD; and common parental concerns.

The optimal method for evaluating the impact of the training in the manual is a pre-test, post-test and follow-up design. Unfortunately, it was not possible to complete any evaluation as there was insufficient time. However, a user feedback form (Appendix A) is available for use in evaluation when the education program for adolescents with ASD will be offered.
Chapter IV: Results

The manual that accompanies this current thesis project is presented in Appendix B. It features original artwork as well as a user-friendly version of the information presented in the literature review. The manual also includes examples of the ABA-based teaching strategies outlined in the literature review in an effort to provide further guidance for parents and/or caregivers. As stated previously, there was no data collection involved in the current thesis project.
Chapter V: Discussion

Summary

Adolescence can be a difficult transition for anyone. For individuals diagnosed with ASD, it can be even more of a struggle. Sexual education adapted for adolescents with ASD is extremely rare, yet highly important. The goal of the current thesis project was to create an educational manual that would highlight various aspects of sexuality and sexual education specifically for individuals with ASD. The chapters included in the manual covered the following topics: Myths about adolescents with ASD and sexuality; the need for sexual education; sexual education; adolescents with ASD vs. typically developing peers; reasons why adolescents with ASD can be sexually inappropriate; sexual orientation; girls with ASD; and common parental concerns.

Due to the limited time available, it was not possible to collect user feedback based on the quality of the manual. However, a hypothetical feedback form was created for future use. The manual has been made available for distribution at the Canadian Mental Health Association – Kingston Branch.

Strengths and Limitations

The manual created for the current thesis project provides a well-rounded overview of the current information available in the literature. It is visually appealing and easy to read. The manual clearly describes various aspects of sexuality adapted for individuals with ASD, and provides simple instructions in regards to teaching strategies for parents and/or caregivers to implement. The content presented in each chapter of the manual is a summary of the available literature and therefore provides an unbiased synopsis of current information.

The manual also demonstrates a number of limitations. There are different levels of severity of ASD, and many individuals with ASD have comorbid diagnoses. The manual created for the current thesis project does not address these concerns, and therefore it may not apply to all adolescents with ASD. Furthermore, the available literature on the subject of sexuality and ASD is sparse. While the research conducted was thorough, there is still much to learn on the subject. In regards to the manual itself, a limitation exists as there was insufficient time to collect user feedback.

Impact and Contribution

In respect to the Canadian Mental Health Association – Kingston Branch, the manual created for the current thesis project serves as an additional resource for individuals involved with the sexual education program for adolescents with ASD that is under current development. As stated previously, sexual education that is specifically adapted for individuals with ASD is rare. The most relevant and recent literature was collected and presented in a clear, user-friendly manner. The manual will continue to be available for use at the Canadian Mental Health Association – Kingston Branch following the program that is under current development, and
offer insight and understanding in regards to the unique challenges faced by individuals with ASD as they transition into young adulthood.

**Recommendations for Future Research**

There are a number of recommendations should any similar research be conducted in the future. In terms of a manual, it is recommended that researchers allow sufficient time to collect user feedback and incorporate any suggestions that may result. It would also be beneficial to incorporate data from empirical studies with larger sample sizes. However, this recommendation is only possible if the available literature allows.

Another recommendation comes from the current available research. According to Ballan (2012) and Stokes and Kaur (2005) who both reported on parental perspectives, the experiences of other parents and/or caregivers of adolescents with ASD can provide invaluable information. While the manual created for the current thesis project offers some material in this capacity, future researchers may find it beneficial to interview parents and/or caregivers and use any resulting information.
References


1. On a scale of 1-5, what is your overall impression of this training manual?

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2. On a scale of 1-5, how much would you say your understanding of your child’s sexuality has increased after reading this manual?

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<td>Not at all</td>
<td>Somewhat</td>
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3. What did you gain from reading this manual? (Check all that apply.)

- [ ] Answers to my questions
- [ ] Resources that I can use
- [ ] Ideas that I can try
- [ ] Nothing new
- [ ] Other: __________________________________________

4. Name 3 things you liked about this manual.

- ______________________________________________________
- ______________________________________________________
- ______________________________________________________

5. Name 3 things you would add/remove/change in this manual.

- ______________________________________________________
- ______________________________________________________
- ______________________________________________________

Additional comments:

__________________________________________________________________________
__________________________________________________________________________
Autism & Sexuality

An Educational Manual for Parents of Adolescents with Autism Spectrum Disorder (ASD)
Autism & Sexuality
An educational manual for parents of adolescents with autism spectrum disorder (ASD)

Available from:
Canadian Mental Health Association – Kingston Branch
400 Elliott Ave. Unit #3
Kingston, ON
K7K 6M9
Welcome to Autism & Sexuality

Adolescence is a difficult transitional phase in everyone’s life. There are tools and resources available to help children on the verge of puberty to navigate through this transition with ease. However, there are very few resources specifically geared toward adolescents with ASD. The purpose of this educational manual is to provide insight into your child’s specific needs as he or she proceeds through adolescence.

There is no “right way” to teach your child.

The information presented in this manual was gathered from a variety of relevant articles and studies, the full references for which can be located at the end of this manual.

The most important thing to remember is that everyone is different. There is no “right way” to teach your child, and this manual is not meant to be used as a “how-to” guide. The purpose of this manual is to help you to understand your child’s needs and learn how to tailor teaching to his or her specific requirements.
Chapter 1: Myths
There are many myths surrounding adolescents with ASD and sexuality. As a parent to a child with ASD, you are likely aware of the most common misconceptions. The following is a collection of the most common myths according to the literature reviewed.

**Popular Misconceptions**

People with ASD are:

- **Asexual**, uninterested in sexuality, or sexually immature
- **Self-centred** and use relationships with others to satisfy personal needs
- **Not interested in or able** to pursue social or intimate relationships because of social deficits
- Better off never going through puberty because it would be **too confusing**
- **A threat** to typically developing peers as their sexual expression could be mistaken as **deviant**

“The teacher was very concerned about my son because he wants to approach children but is not sure how to, girls in particular. He’ll go over and touch their hair and want to hug them. It seemed like this teacher thought he was a sexual offender instead of a kid struggling with autism.”

-Mother of a mainstreamed first grader

According to research, there is absolutely no evidence to support these misconceptions. Research actually indicates that people with ASD do in fact engage in sexual behaviours and many express desire for romantic relationships. There is also evidence that many people with ASD express a desire for getting married and having children of their own.
Chapter II: The Need for Sexual Education
There is high demand for sexual education designed specifically for adolescents with ASD, and there are a number of risks involved when it is delivered too late or not at all. Without individualized sexual education, adolescents with ASD may suffer personal injury or contract sexually transmitted infections. Research indicates that sexual ignorance or misunderstanding can result in masturbation with foreign objects, or repeated, unsuccessful attempts to masturbate to the point of injury.

It has also been suggested that a lack of sexual knowledge and understanding can leave the adolescent with ASD more vulnerable to sexual abuse. Many parents worry that they have accidentally delivered opposing messages to their children in regards to privacy. As young children, we are taught that it is okay to receive assistance in the bathroom and to have help getting dressed. As children with ASD who still require assistance as they get older, it can be difficult to understand boundaries. It is important to teach your child the difference between “okay” and “not okay” when it comes to their private parts.

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<tbody>
<tr>
<td>- Removal of clothing in public</td>
</tr>
<tr>
<td>- Public masturbation, hypermasturbation</td>
</tr>
<tr>
<td>- Unwanted touching of strangers</td>
</tr>
<tr>
<td>- Kidnap of a sexual nature</td>
</tr>
<tr>
<td>- Fixation on others to the point of harassment</td>
</tr>
<tr>
<td>- Intrusive dating behaviours</td>
</tr>
<tr>
<td>- Stalking</td>
</tr>
<tr>
<td>- Sexual abuse</td>
</tr>
<tr>
<td>- Unplanned pregnancy</td>
</tr>
</tbody>
</table>
Chapter III: How to Teach Your Child
Sexual education for adolescents with ASD must be personalized and adapted for each specific learner. You know your child better than anyone else, which means you know how to make things understandable to him or her.

It is suggested that parents are the most suitable teachers of sexual education, but it is not uncommon for other caregivers or adults who are familiar to the adolescent to provide the education.

**Suggested Topics to Cover**
- Body Parts & Function
- Social/Sexual Behaviour
- Sexual Life-Cycle
- Dating
- Marriage
- Parenting
- Establishing Relationships
- Abuse Awareness
- Boundary Issues
- Assertiveness
- Self-Esteem

**Who Makes the Best Teacher?**
- Parents
- Other caregivers
- Anyone who is familiar with the learner
- Regular teachers may be uncomfortable with the subject matter

While a list of suggested topics to cover has been included, topics can be added or omitted based on need and level of understanding.

According to the research, there is a variety of applied behaviour analysis (ABA)-based strategies that are particularly effective in teaching adolescents with ASD. There is a detailed description of each strategy located on the next pages.

**ABA-Based Teaching Strategies**
- Video Modeling
- Visual Strategies
- Social Script Fading
- Task Analysis
- Social Stories
### Video Modeling

<table>
<thead>
<tr>
<th>Description</th>
<th>Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing a video to target a specific skill or behaviour</td>
<td>Taking birth control pills</td>
</tr>
<tr>
<td>Allowing time for the video to be viewed and practiced</td>
<td>Using condoms</td>
</tr>
<tr>
<td></td>
<td>Using menstrual pads</td>
</tr>
<tr>
<td></td>
<td>Expressing sexual feelings</td>
</tr>
</tbody>
</table>

#### Implementation Procedure

1. Select the skill or behaviour to target
2. Write the script
   - Should be personalized to the specific learner in terms of length and reading level
3. Prepare the video
   - Models in the video could include adults, peers, siblings, or the learner him/herself
4. Play the video for the learner
   - Play the video several times in a row before attempting to imitate the skill or behaviour
5. Allow to learner to imitate and practice the behaviour

### Visual Strategies

<table>
<thead>
<tr>
<th>Description</th>
<th>Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steps are photographic and act as a series of prompts</td>
<td>Photos of appropriate places to undress</td>
</tr>
<tr>
<td>Photos/Drawings/Words</td>
<td>Photos of human anatomy</td>
</tr>
<tr>
<td>Used to organize the environment</td>
<td>Photos of contraceptives</td>
</tr>
</tbody>
</table>

#### Implementation Procedure

- Create visual cues and place them where they will be used (e.g. A schedule reminder on the bathroom mirror as a reminder to take birth control pills)
- Draw attention to the visual cues and provide verbal prompts to ensure adherence to the learning technique
<table>
<thead>
<tr>
<th>Description</th>
<th>Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing a script to target a specific skill or behaviour</td>
<td>Asking someone out on a date</td>
</tr>
<tr>
<td>Allowing time for the script to be practiced and faded out as the skill or</td>
<td>Saying “no” to unwanted touching</td>
</tr>
<tr>
<td>behaviour is mastered</td>
<td></td>
</tr>
</tbody>
</table>

**Social Script Fading**

**Implementation Procedure**

1. Select the social or communication skill to target
2. Write the script
3. Teach the script
   - Ask the learner to read and practice each line in the script
   - If it is too difficult, modify the script accordingly
4. Implement the script during a chosen situation
   - Place a checklist of each line so that the learner can mark off as they recite each one
5. Fade the script
   - Once the skill is mastered, use of the script must be faded so that the learner no longer relies on it

**Example**

**Asking someone out on a date:**
1. Hello [name].
2. You look nice today!
3. Do you have plans for [day & time]?  
4. Would you like to [activity] with me?
5. I understand, maybe another time OR Great, I’ll see you then!
6. I’ll talk to you later.

**Fading Procedure:**
I’ll talk to you later. → I’ll talk to you → I’ll talk → I’ll → I → No Prompt
### Task Analysis

<table>
<thead>
<tr>
<th>Description</th>
<th>Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>A step-by-step break down of a skill or behaviour into smaller, more manageable tasks</td>
<td>Changing a menstrual pad</td>
</tr>
<tr>
<td>The skill or behaviour is taught one step at a time, and a new step is not taught until the previous ones are mastered</td>
<td>Changing bed sheets after a nocturnal emission</td>
</tr>
</tbody>
</table>

### Implementation Procedure

1. Select a target behaviour
2. Break the behaviour into manageable tasks
3. Create a list of steps in the order in which they must be performed
4. Teach the learner to perform the steps using a chaining procedure
   - Forward Chaining: Steps are taught in order. Reinforce successful behaviour as each step is mastered
   - Backward Chaining: Steps are taught in reverse order
   - Total Task Presentation: Each step is taught all at once every time

### Example

**Changing a menstrual pad:**
1. Bring new pad to the bathroom.
2. Pull down underwear.
3. Sit on toilet.
4. Remove soiled pad.
5. Fold and place in paper bag.
6. Throw paper bag with soiled pad in garbage.
7. Apply new pad to underwear.
8. Pull underwear up.
   - Steps can be added or removed based on individual need
<table>
<thead>
<tr>
<th><strong>Social Stories</strong></th>
<th><strong>Description</strong></th>
<th><strong>Applications</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>Most commonly recommended strategy</em></td>
<td><em>Sexual awareness</em></td>
</tr>
<tr>
<td></td>
<td><em>Short stories describing a situation in a way that is significant for adolescents with ASD</em></td>
<td><em>Puberty</em></td>
</tr>
<tr>
<td></td>
<td><em>First person singular, active voice</em></td>
<td></td>
</tr>
</tbody>
</table>

**Implementation Procedure**

1. Select a situation or social skill that is difficult for the learner
2. Write a story using age appropriate text
3. Sentences should be literal and allow for potential schedule changes (e.g. “usually” instead of “always”)
4. Incorporate photographs/drawings if desired
5. Select a title that indicates the overall goal of the story (e.g. “Where Can I Take My Clothes Off?”)
6. Read the story to the learner

**Example**

**Sexual Awareness (Boy)**
My name is Dawson. Sometimes I think about sex and private areas. It’s okay to think about sex and private areas. I will try to keep my thoughts to myself. This is very important. I may ask my mom or dad a question if I’m confused.

**Puberty (Girl)**
My name is Jen. I am 13. My body is growing and changing. My mom knows about growing up. Sometimes, girls get breasts when they are 13. Soon, I will have breasts too. Most women wear bras to hold and cover their breasts. This is a good thing to do. I will wear a bra. If I forget to wear a bra, my mom may remind me before I go to school. Wearing a bra is part of growing up.
Chapter IV: Adolescents with ASD vs. Typically Developing Peers
There are many differences between adolescents with ASD and their typically developing peers when it comes to sexuality. For example, adolescents with ASD tend to experience more difficulties with the physical changes of the body that occur throughout puberty.

Typically developing adolescents learn at a young age to be discrete when it comes to the display of sexual behaviours. Sexual impulses develop, but the informal learning that occurs through socialization prevents typically developing adolescents from acting inappropriately.

However, adolescents with ASD are usually left out of social situations and therefore never pick up on those social cues.

**Case Study**

A female student began self-injurious behaviours (SIB) following the onset of menstruation. She had never behaved in such a way before, and was causing herself a great deal of harm. Upon investigation, a therapy team suggested that she might have been experiencing premenstrual cramping. The implementation of pain medication before her expected period resulted in a significant reduction in her SIB.

**Similarities**

- Goal of marriage & kids
- Similar developmental pattern (Social differences create a delay of ~5 years)

Some theorized explanations include the association of sexually inappropriate behaviour with acceptance as well as the perception that sexuality is not a taboo topic. For example, a child with ASD who overhears his peers laughing at a sexual joke at recess mistakes the laughter as social acceptance. The child then becomes more likely to repeat the joke at inappropriate times, such as in front of the teacher.
Chapter V: Why Mistakes Happen
The lack of social understanding that comes with ASD is a key factor in the sexually inappropriate behaviour that develops during puberty. Most adolescents with ASD cannot tell the difference between kindness and attraction. That misunderstanding can lead to inappropriate behaviours like stalking or sexual harassment.

For typically developing individuals, it is normal to call, send love letters to, or go out with the object of one’s affections. For individuals with ASD, the inability to recognize whether such behaviours are wanted can cross the line from regular courtship to sexual harassment. Furthermore, adolescents with ASD often learn through experience that socialization with others is only possible with persistence.

Adolescents with ASD are also discovering sexuality. Their lack of social awareness plus the tendency toward self-stimulatory behaviour create a challenge when it comes to sexual inappropriateness.

Adolescents with ASD often do not seek privacy for sexual activities such as masturbating or changing clothes. They struggle to understand the changing social expectations which accompany puberty, and simply do not care how they are perceived by others.

**Common Behaviour Changes Throughout Adolescence**
- Increased desire for social isolation
- Episodes of oppositional behaviour, anger, & depression
- Increased preoccupations with special interests
- Increased rigidity and inflexibility
- Poor organization and school performance
Chapter VI: Sexual Orientation
There is no conclusive information regarding patterns of homosexuality among people with ASD. One study determined that the prevalence of homosexuality and bisexuality among individuals with ASD falls within the typical range. A previous study indicated that individuals with ASD displayed a higher instance of bisexuality than that of typically developing peers. Whether or not the prevalence is higher among individuals with ASD, there is one common explanation that appears across the literature: Because individuals with ASD are not concerned with what others think about them, it is suggested that they would not be governed by any societal expectations in terms of sexual orientation. In other words, there is nothing keeping individuals with ASD “in the closet”.

**Case Study**

Two 19-year-old male students at a residential school in England were noticed spending time together, and staff often watched them trying to go into each other’s bedrooms. The relationship was described as “mutually consensual”, but sexual behaviour between students was not allowed at the school. The staff did their best to accommodate the relationship with an emphasis on friendship as they coordinated outings and other supervised joint activities. Upon leaving the school to pursue adult placements, the parents of one of the students made sure to keep the boys apart as they did not approve of the homosexual nature of the relationship. Both students reportedly struggled with the separation. How would you have handled the situation?
Chapter VII: Girls with ASD
In addition to the introduction of sexual behaviours, girls with ASD must deal with the inevitable onset of menstruation. According to the available literature, there are a number of behavioural challenges that can accompany puberty as a result of menstrual cramps and overall discomfort. It has been suggested that girls with ASD can express their discomfort by means of increased aggression or agitation, and in some instances self-mutilation. In some cases, contraception has been implemented in an effort to minimize the effects of menstruation. It is propose that birth control can promote feminine hygiene and suppress hormonal changes associated with menstruation. However, most girls with ASD accept the arrival of menstruation in an unemotional and practical way, and usually do not require the use of contraception to control it. Another study suggests that with advanced preparation and the use of some sort of visual calendar, menstruation can become even more manageable.

Why do Girls with ASD Tend to Spend More Time with Boys?

It has been suggested by a recent study that typically developing girls use more complex and subtle social cues than boys, which can be confusing for girls with ASD. Boys tend to express aggression physically which is easier for an individual with ASD to understand. Girls are more likely to ignore others, eye-roll, giggle, etc. This difference leads to a preference toward friendships with boys.

Feminine Hygiene: How to Prepare Your Daughter

- Practice with panty liners in advance
- Create a visual calendar to prepare for menstruation (When to wear/change napkins, carrying extra underwear, etc.)
- Use a social story to explain the process, including PMS symptoms
- Teach her how to properly dispose of soiled napkins
Chapter VIII: Common Parental Concerns
It is not uncommon for parents to have fears and concerns about their children’s wellbeing. When the diagnosis of ASD is added, the number of additional fears and concerns greatly increases. Specifically talking about sexual education, the most common concern is that parents don’t want to influence their children toward any inappropriate behaviours.

““If you have a pattern on your shirt and my son likes it, he is going to touch it, not because he wants to touch your breasts but because he wants to feel the shirt.”
-Mother of an adolescent with ASD

Most parents also worry that their child’s autistic behaviour would be mistaken as sexually deviant. Furthermore, most parents express concern that their child’s social ineptitude and the increase in sexual behaviours will result in public embarrassment for their child. According to the literature, all of these concerns can be addressed and prevented with properly timed sexual education.

“What if I tell my son it is a penis and for the next 10 months, his fascination is with his penis instead of a computer game or train?”
-Mother of an adolescent with ASD

Many parents fear that the introduction of sexual behaviours such as masturbation will replace any current self-stimulatory behaviours like rocking or hand-flapping. However, there is no evidence in the research supporting any such conclusions.

There is no evidence to support any of these concerns in the research

**Most Common Parental Concerns**
- Masturbation will become a substitute for current self-stimulatory behaviours
- Normal autistic behaviour might be mistaken as sexually deviant
- Child may be publicly embarrassed
- Child may overgeneralize (information has to be carefully worded or child may misunderstand)
Additional Resources

For more information about autism and sexuality, check out the following websites:

**Autism Speaks**
http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/health

**Sexuality & Autism: Sexual Education for Children and Teens**

**Autism Sex Education**
http://www.autismsexeducation.com/#!information-resources/c23qn

**Pathfinders for Autism**
http://www.pathfindersforautism.org/ages/13-17/social-and-relationships/sexuality