I'M GROWING UP

Relationship and sexuality education for young people with Autism Spectrum Disorders



Written for Autism South Africa Rebecca Johns



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Rebecca Johns



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Rebecca is the author of Step-by-Step: A sexuality and HIV/AIDS education programme for young adults with intellectual disability (2005). Over the last three years, she has been teaching sexuality education at Vera School in Cape Town and learning how to adapt this work to the needs of learners with Autism Spectrum Disorders (ASD).

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Foreword

Over the past few years Rebecca Johns, a sexuality education consultant, has done enlightening Autism specific work in collaboration with Vera School staff. This experience culminated in the much needed and welcomed resource you are now aware of.

Rebecca employs a direct, sensitive, discreet and Autism-informed approach to the relationship and sexuality curriculum outlined in this booklet. It will be most helpful to clarify issues for both people with Autism and those neuro-typical people who share life with them.

May the information be used to further self-knowledge, demystify relationships and foster fulfilment in many individuals.

Fanie Minnaar Principal, Vera School Psychologist

1. Introduction and aims

Why is there a need for this booklet?

Everyone has rights and needs relating to their sexuality – the right to privacy, the right to dignity, the need to express sexual feelings, and the right to be free from sexual exploitation and harm.¹

Children and young people with Autism Spectrum Disorders (ASD) have the right to achieve their potential in the area of sexual, emotional and social independence.

Sexuality is a complex issue. Many people find it embarrassing and awkward to talk about sexuality, which makes it difficult to offer guidance to young people about their sexuality and sexual behaviour. Sadly most young people learn about sex and sexuality through the media, friends or sexual experimentation, rather than through adult guidance. Yet how can a young person with ASD make sense of information², values and behaviour about sexuality from these sources?

The individual perception of a young person with ASD means that they need even more help to manage the bewildering range of social expectations and conventions related to sexuality. For example, it is fine for a small child to swim naked in the sea, but this behaviour will not be tolerated in an adolescent. Also, young people with ASD may be confused or distressed by the physical changes of puberty, or may long to develop a sexual relationship but have no idea how to achieve this.

As parents, carers and educators, we clearly cannot ignore the issue and simply hope for the best. Lack of guidance may contribute to misunderstandings, socially inappropriate behaviour or even problems with the law. This raises questions such as:

- How do young people with ASD understand their changing identity as they move from being a child to becoming a young adult?
- How can parents, carers and educators engage with sexuality in a way that supports young people with ASD to cope with the changes and challenges they may face in this area?
- How do we teach the socio-sexual skills necessary for a person to be included in society?

What does this booklet aim to do?

This booklet aims to help parents, carers and educators support children and young people with ASD through the social, physical and emotional changes of puberty and adolescence.

The booklet is primarily aimed at children and young people with ASD, rather than adults, and therefore focuses on the foundation work necessary to teach sexuality education from an early age.

The booklet aims to:

- Clarify the term "sexuality" and question how we perceive the sexuality of young people with ASD.
- Encourage parents, carers and educators to see sexuality education as an integral part of the school curriculum and home life.
- Offer ideas for parents, carers or teachers to attempt to facilitate sexuality education to children and young people with ASD.

The author is aware that sexuality education for young people with ASD is a challenging and evolving area of study, and hopes that this booklet will offer ideas and approaches for discussion and development, rather than a definitive guide.

2. What do we mean by sexuality?

When we consider the sexuality of young people or children with ASD, it is important to consider what we understand by the term "sexuality". This is because our understanding will shape what we do and say to young people with ASD in relation to their sexuality.

Sexuality means far more than the sexual act or the biological differences between men and women:

Sexuality ... is the way we see ourselves as men and women. It includes: our bodies, our feelings, our beliefs and values, our fantasies, the way we behave and respond, the way we dress, the decisions we make, our inherited characteristics, and our relationships with others.

(Planned Parenthood Association of South Africa, 1992)³

For young people with ASD, who struggle to understand relationships and social meaning, the social expectations and unspoken rules attached to sexuality are extremely difficult to understand. If we are to help young people with ASD gain an understanding of their sexuality, it is important to be aware of our own beliefs and values first.

We therefore need to take time to think about:

- What messages did you get about sexuality when you were growing up? Messages can be given through spoken and unspoken behaviour. Sometimes refusing to speak about a subject can be the most powerful message of all.⁴
- How have these messages shaped your behaviour as an adult?
- What messages do you want to give your children or learners about sexuality? Are these messages different to the ones that you were given?
- Can you identify issues connected to the sexuality of your child or learners with ASD that make you anxious or worried? It may help to write these issues down and discuss them with someone you trust. You may find a new perspective or approach to the issue.

Remember other parents, carers or educators are likely to share your feelings or fears. Talking together can really help.

3. Approaches to help communicate about sexuality

The individual development and understanding of young people with ASD makes it difficult to give general rules about how sexuality education should be taught. All methods or approaches will need to be adapted to individual perception and needs.

Generally, the approach to sexuality education should follow on from the educational approaches used in all other areas of learning.

It will help you to be aware of the following areas:

- Clear language
- Visual help
- Making time for sexuality education
- Difficult behaviour
- Safety.

We will now discuss each of these issues.

a. Clear language

Spoken language is very confusing for many young people with ASD. It is difficult to understand the meaning of words if you are trying to work out what each individual word means. Imagine the problem if many words are spoken quickly in long sentences. It will help young people with ASD if we talk in short meaningful sentences and allow some time between each sentence for them to process what is being said.⁵

Language connected to sexuality is even more confusing for people with ASD. Think how often sex or sexuality is spoken about indirectly, using slang terms or jokes. This indirect speech most probably reflects the fact that we are unused to talking openly about sex and sexuality. We need to learn to be open and direct in our communication about sexuality if we are to communicate more successfully with young people with ASD.

Language guidelines

Below are some tips for talking about sex and sexuality in plain, understandable language.

- Use the correct names for private body parts from early childhood.
- Make sure that family members and school staff use the same words. For example, if grandma says "spend a penny" for going to the toilet, a child with ASD will be confused.
- Reinforce and repeat key words (or signs) relating to sexuality at the appropriate place and time. For example use the word "private" when using the bathroom or toilet and (if possible) teach your child or learner to shut the door when they are using the toilet. This highlights the need for good communication between school and home so that learning can be reinforced in different contexts.
- Try to teach age-appropriate slang terms to a child moving to secondary school so that they do not stand out from their peers.
- Answer questions related to sexuality. Remember it is okay not to know all the answers and to look something up together. If a question is asked at an inappropriate time, tell the young person, "That is a really good question but let's talk about it once we get home".⁶
- Be aware that some words have different meanings in different contexts, and that each meaning may need to be taught separately. For example, 'private" is used differently in private body parts, private places, private possessions, private conversations, and private thoughts. You may need to select the one or two most important aspects of the word and just teach those meanings.
- Find ways to encourage communication around likes, dislikes and choices as much as possible.
- Give clear messages and communication about appropriate and inappropriate touch. You may need to work on concepts such as 'personal space" and 'asking for a hug or a kiss". Or helping the young person to distinguish between a family kiss and a lover's kiss.
- Give positive feedback whenever possible. This means telling your child or learner about what they are doing well, and reinforcing age-appropriate behaviour and a positive self-image.
- Try not to give negative attention to unwanted or inappropriate sexual behaviour with ambiguous phrases such as "Don't", "Stop that" or "Don't be rude". Be clear about what is inappropriate and try to show an alternative. For example, "Do not touch your penis in the dining room. It is a private touch. Go to your bedroom and shut the door. It's private". Verbal instructions may need to be supported with a sequence of pictures that visually show the young person where the behaviour is appropriate (see *Visual help* on page 6).
- If helpful, discuss difficult sexual behaviour with a professional and decide on an approach together.
- Remember what is cute and acceptable at 3 years, for example, stroking a woman's hair, playing with sister's toes, or sitting on a person's knee, will look very odd at 13 and could lead to police involvement at 23.

b. Visual help

Young people with ASD are often visual thinkers. This makes pictures and signs an important way of making communication easier.⁷

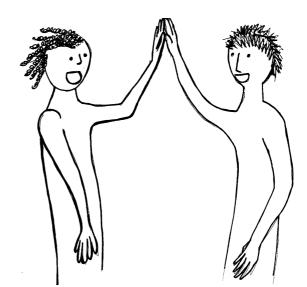
Remember that pictures or signs are not just for children or learners with little or no speech. Pictures and signs will help communication and understanding for all children or young people with ASD. Pictures or signs can be used alongside language or as a means of communication on their own.

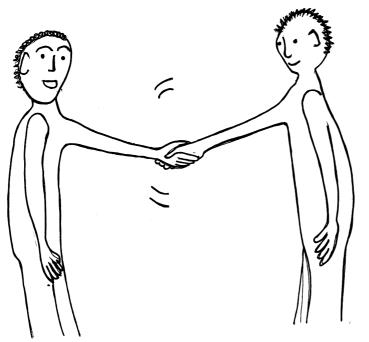
Although it is important to use pictures when teaching about sexuality, it is inappropriate to use photographs of sexually explicit topics such as masturbation or private body parts. This means that we need to develop drawings, symbols and

visual resources that are explicit, yet appropriate, for the age group being taught.

There are some available resources developed for learners with intellectual disability that may be adapted to the needs of learners with ASD, especially learners with additional learning disabilities. Have a look at some of the examples listed in the *Resources* section of this booklet on page 47.

Remember: we need to make and develop pictures and materials suitable for the different learning needs of young people with ASD.



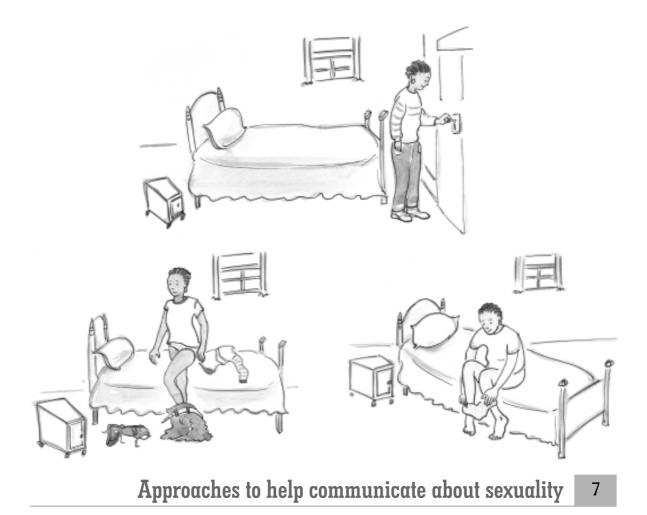




Guidelines on pictures and signs

Use your own drawing skills or find someone who enjoys drawing. Then you can experiment with making these kinds of pictures or signs:

- Signs that show different sorts of touch, for example, shaking hands, a hug, or a kiss.
- Adapted and extended PECS (Picture Exchange Communication System) communication cards, for example, you can make a sequence of small cards that show the different body parts to wash at bath time.
- Large body outlines and cut-out body parts, including private body parts and internal sexual organs.
- Clay for the child to make a male or female body.
- Body outlines like a jigsaw that learners can piece together.
- Pictures of different rooms, for example, bathrooms with doors that close, and beds with blankets that lift up to illustrate the concept of privacy.
- Laminated photos of different rooms in a learner's house if your learner cannot recognise or generalise pictures of another place. The learner could match pictures of different rooms with different activities, for example, bathing, brushing teeth, eating, and watching TV.
- Cut-out characters with painted clothes, dressed, in underwear, and naked.
- Picture sequences of drawings that show private behaviour, such as masturbation, or managing menstruation. These pictures can show the appropriate order of events and can be told as a story in sequence, or placed in sequence to show the behaviour non-verbally. Remember it is not appropriate for these pictures to be photographs, but rather to use clear line drawings (again, see *Resources* page 47).



c. Making time for sexuality education

At school, you can create a specific time slot in the week for giving sexuality education. This means that teachers can be proactive and introduce themes and areas they feel young people need to learn about, rather than responding after the event or to a crisis. Relationship and sexuality education should continue as the child grows older and should not be limited to one age group. It is important not to give more information than the child needs at that time.

For the parent, the timing of sexuality education can be more difficult. For young children, bath time is a time for learning about body parts and personal hygiene. For the older child or learner, bath time or bedtime can be a time where it may be possible to reinforce age-appropriate independence and the concept of privacy.

For the more able adolescent, you may find that TV programmes raise issues that you may want to discuss with your son or daughter. However, it is important to consider which programmes are appropriate. Simple sexuality education books with lots of pictures are another good way to initiate a discussion (see *Resources*, page 47).

Be aware that children or young people with ASD often need a longer period of time to adjust to any changes in their lives, and that preparation for the changes of puberty need to be started well in advance.⁸

d. Difficult behaviour

When we think about sexuality, it is tempting to place sexual behaviour or development into one of two categories: "normal" or "abnormal". This is because we are conditioned to think about sexuality in two ways: "good or bad", "normal or abnormal".⁹

This kind of thinking often means that, if someone has a disability, including autism, their sexuality is more likely to be judged negatively simply because of their disability.¹⁰ Remember that it is non-autistic people who define whether behaviour is inappropriate or difficult. For an individual with ASD, certain behaviour may have "a very significant and specific meaning which isn't 'just being rude' or sexually motivated".¹¹

Most importantly, we need to try to understand the reasons for different behaviour rather than simply interpreting behaviour as sexual, difficult or abnormal. For example:

If an individual with ASD, touches or brushes against a specific woman's breasts every time they meet, they could be trying to determine the woman's mood at each meeting. If they are unable to read a person's facial expressions and body language, they may require a routine action which they can perform each time they see that person in order to determine whether they are "nice lady" or "bad lady" today: that the individual's reaction will convey this information, if they are patient, they are "nice lady" or in a good mood, if they have a more aggressive tone, they are "bad lady" or in a bad mood.

(National Autistic Society)¹²

If we understand why the behaviour takes place, it may be easier to:

- Provide the individual with an alternative means of receiving this sensory input or information, and
- Redirect their behaviour to something more socially acceptable.

e. Safety

Be aware that many people may be hesitant to implement sexuality education to children or young people with ASD because of legal concerns in relation to sexual abuse.

In mainstream education, sexuality education is included as part of the curriculum in the learning area of Life Orientation. It is not necessary to gain parental consent to teach sexuality education, although many schools value the need to inform parents what is being taught and when.

The law gives people with "mental impairment" special consideration in acknowledging their increased vulnerability in relation to sexual abuse.

Mental impairment is defined as "any mental impairment regardless of it's cause".¹³ This means that in special schools, including schools for learners with ASD, extra consideration needs to be given to how sexuality education can be taught in a way that is safe and accountable.



Guidelines for safe and accountable sexuality education

Consider these suggestions in running your own sexuality education sessions:

- Find, and if necessary revise, the sexuality education policy in your school or organisation. The policy needs to clarify why sexuality education is important, and how sexuality education will be approached in the school. Make sure parents and all staff are aware of the policy.
- Do not proceed with any programme without the support and knowledge of your principal and colleagues.
- Make sure that parents are informed about the programme before you begin. Hold a parent information session during and at the end of the programme. Consider whether you need written consent from parents.
- Two members of staff must be present in all sessions. This means there is another witness to what was taught and how. Teaching with another member of staff present also provides important teaching support.
- For introducing sensitive and explicit work, such as masturbation, work in singlesex groups in the same classroom. If possible, plan for a male and female teacher to run the programme together. However, if this is not possible, there is still value in splitting into single-sex learner groups.
- Make a written plan of the content and aims of your programme, and describe how it will be taught.
- Keep written records of your programme, week-by-week, including learner response.
- Make sure that the pictures used in your programme cannot be interpreted as pornographic. It is never appropriate to use photographs depicting sexual body parts or sexual acts. Always use line drawings or pictures that have been developed especially to teach sexuality education to special needs learners. Make sure that the principal and head of department/ governing body are aware of how and when these pictures are used and have given their permission. Put these pictures away when not in use.
- Do not touch the child or young person in teaching him/her about private body parts or masturbation. Physically touching a child or a learner's private body parts is not acceptable as part of any sexuality education programme.
- Keep notes of any emotive language used by children in a session. "I went to bed with my brother" may just mean they share a bed to sleep. Children with autism are usually unaware of some of the terms for sex.

Do not let concerns about the legal aspects of teaching sexuality education prevent you from teaching sexuality education to children or learners with ASD. It would be difficult to interpret a well-planned and documented programme as breaking the law if parents and those who manage the school have been involved and informed, and the above guidelines are followed.

As staff, remember that many parents are concerned about the sexual development of their son or daughter, and may be unsure about how to approach the issue themselves. Most parents welcome and are extremely supportive of sexuality education as part of a school programme. Staff should not assume parents will react in a negative manner.¹⁴

4. Childhood: the foundation work

This section of the booklet looks at the stage of childhood and suggests topics that may need to be taught. The activities in tables suggest approaches to these topics. Remember that these activities will need to be adapted to different ability and perception.

It is important that sexuality education is begun as early as possible in a way:

- That is age-appropriate to the child with ASD, and
- That will establish rules and behaviour appropriate to teenagers and adults.

This is because many young people with ASD will struggle to unlearn the social conventions and language learnt in childhood – in other words, what is learnt then often becomes difficult to change at a later stage.

The themes below provide a basis for a young adult to make more sense of their sexuality and to be more prepared for social expectations around sexuality in the future:

- Growing up
- Physical contact
- Naming body parts
- Modesty
- Personal hygiene
- Sexual abuse.

a. Growing up

Try to encourage children to do more for themselves as they get older, and encourage and praise steps taken towards independence, no matter how small. Always give the child positive messages about changing and growing up.

At this point, it is important to teach gender. They need to know their own gender, to learn to recognise males and females, and, for example, to identify male and female symbols on toilet doors.

In the table over are some suggested activities for the theme of "growing up".

GROWING UP

Photo collage

Make a photo collage of the child at different ages.

Tell the child they are *growing up* and, as they grow, their bodies change. If possible, teach the child to know their age in years.

• Over a period of time, make a height chart on the wall.

Stick photos of the child at different ages next to the appropriate measurement to show the child how he/she is changing.

Tell the child he/ she is becoming a young man or a young woman.

Include pictures of other family members at different stages of growing up.

Sorting pictures

Sort magazine photos of people into different age categories.

Remember that the concept of older and younger is difficult for many children with ASD.

It may be easier to use general categories such as *baby*, *child*, *teenager* and *adult* (or *grown-up*). (*Talking together... about growing up* includes drawings of a young person at different stages from baby to adult. See *Resources*, page 47)

Can the child identify which category they belong to? Can they identify which category their teacher or parents belong to?

Can the child differentiate between males and females? Check what they use to do this.

Make a photo collage of women and men to show different choices (e.g. some men may have long hair, women may wear trousers).

Encouragement

Reinforce a positive and ageappropriate identity whenever possible.

Give the child responsibilities and tasks that emphasise their developing competence.

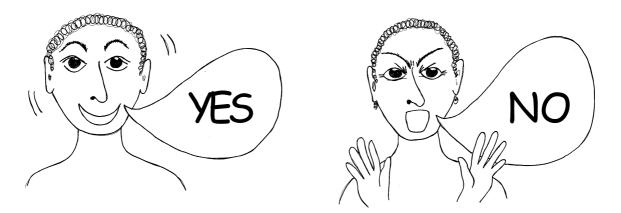
 See ideas for supporting the social and emotional development of young people with ASD on page 25.

b. Physical contact

We need to teach children with ASD that it is possible to refuse and initiate physical contact with others. This means that social interactions need to be made explicit in terms of when, how and with whom they happen.

The child needs to learn that:

- He/She can say "yes" or "no" to touch.
- He/She can request touch from someone else.
- The person asked can say "yes" or "no" to the touch.



These are important and complex communication skills that need to be practised frequently.

Start by encouraging the child to recognise and communicate things they like and dislike. This could start with something as simple as food preferences. This understanding can then later be related to preferences around touch.

Children need to know they have the right to say "no" to touch, and to recognise that it is wrong for an adult to touch or ask them to touch private parts. However, remember that you may also need to teach that a doctor or nurse may need to look at and touch private parts when in a hospital or clinic if a parent or carer is present. It may help to include pictures of people who are allowed to touch you, for example, dentist, hairdresser, teammate to celebrate a goal.

Here, in the table over, are a few activities around "physical contact".



PHYSICAL CONTACT

The greetings game

Make cards that show different sorts of *touch*, such as shaking hands, hugging or giving a high five.

The child needs to learn to ask for physical contact with another person (especially someone outside of his/her immediate family).

A card (showing the touch requested) is offered to the person asked. This person takes the card to accept the touch or says "no" (verbally, signing or with a card) to refuse the touch.

Remember you may need to offer an alternative touch, such as a handshake – e.g. I do not want to hug or kiss, you but I am happy to shake hands.

Yes or no

Try to emphasise that a hug must be asked for. Everyone has the right to say "yes" or "no" to touch. We can choose.

Play games in which the child can choose to accept or refuse different sorts of touch, such as a tickle with a feather duster or a spray of water from a spray bottle. If the child cannot verbalise, help with cards that can be shown for "yes", "no", and "stop".

Encourage the child asked to give a clear "yes" or "no" and to say "stop" when they have had enough.

Make sure that his/her preference is respected.

Emphasise that it is important to listen to people's preferences and stop when asked.

Personal space

Introduce the concept of *personal space*.

Stand in the middle of a small circle drawn on the floor.

Show the child that when we talk to people or shake hands, they do not need to come into our space.

Show the child that if we hug someone, they will come into our space.

Ask the child to practise asking for a handshake, a chat or a hug, and to notice where the person stands.

Remind the child when sitting next to someone or standing in a line that we need space between people, which means we do not touch each other.

• Show pictures of times two people want to be close, e.g. sitting on a couch watching TV with family.

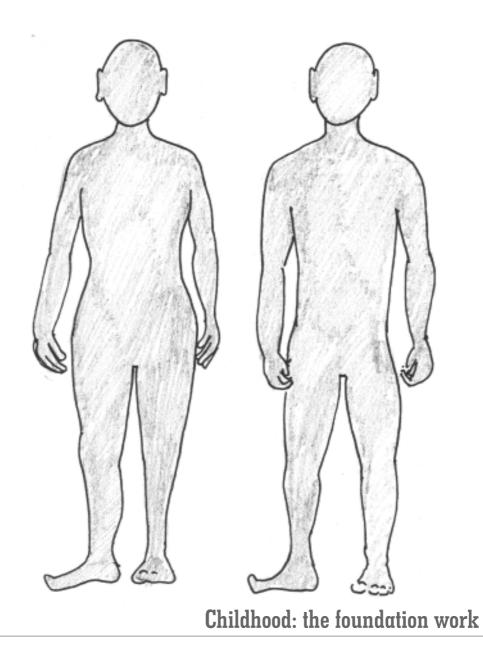
c. Naming body parts

It is important to establish the correct names for private body parts from the beginning of childhood. This ensures the adolescent with ASD will not have to learn a whole new set of words for body parts or become stuck using words that are childish.

Learning the correct names for private body parts will also help the child learn about and manage their personal hygiene.

As parents, carers and educators, we need to become used to using correct private body part words. This may take practice, as most people are unused to talking about private body parts openly. An everyday and confident approach will help us to teach a child how to behave in different social contexts in relation to nudity, and prepare us (and the child) for future discussions about sexual development and masturbation.

We suggest some activities to help you with naming body parts.



15

NAMING BODY PARTS

Body outlines

Clothes games

Make large body outlines. Ask the child to draw on and name the different body parts. Use the correct names for private body parts.

If the child cannot draw, use stick-on body parts or a jigsaw-type body outline that needs to be assembled.

Ask the child to point to different body parts with a small pointing stick. Check their understanding.

Use body outlines appropriate to the age of the child. Older children (aged 10 upwards) may be able to draw child and adult outlines.

Help the child to compare the bodies of child outlines and adult outlines in preparation for work on puberty.

Use cut-out clothes and underwear to show that private body parts need to be covered. Play games with piles of clothes.

The child could role play buying some clothes in a shop, or simply choosing an item, saying what it is, and where it goes on the body.

If you have a group of children, split them into teams. One child from each team must find an item of clothing to cover a particular part of the body, such as the legs, the back, the breasts or the arms. Include terms for private body parts.

Give the child an item of clothing and ask them to think of all of the body parts that it covers. This could be played as a team game for points.

Sort clothing into outerwear and underwear. Layer the clothes on top of the large body outlines.

Hand-to-hand

Play games that encourage body awareness.

Ask the child to choose a partner and stand face-to-face.

Give each pair a kitchen roll tube and ask them to hold the tube using different body parts, such as hand-to-hand, noseto-nose, or back-toback.

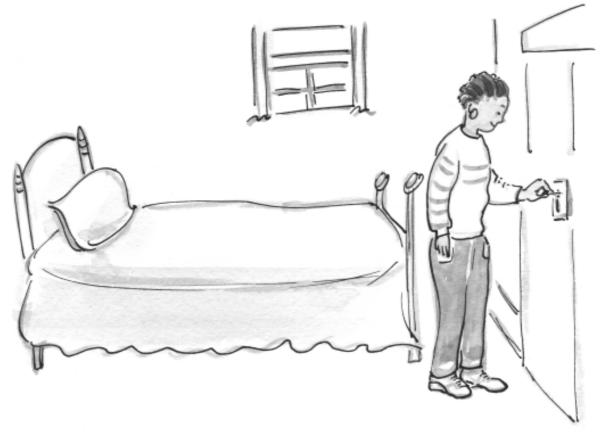
d. Modesty

We need to help the child to build habits around modesty that are socially appropriate. For example, the child needs to learn not to go into or come out of the toilet with their trousers down, not to take off all their clothes in a public place, or touch their private body parts in a public place.

Try to be as consistent and clear as possible in how you manage and teach self-care and independence. This includes awareness of:

- Shutting the toilet door.
- Where to undress.
- The concept of "private body parts".
- When to touch your private body parts.

Try these activities to help develop an understanding of "modesty".



MODESTY			
Touching private body parts	Using puppets	Matching behaviour to places	
If you want to teach more directly about masturbation, use picture sequences (see <i>Resources</i>).	• Use puppets and make them behave appropriately in relation to modesty, and then inappropriately.	Use cut-out characters that show people when clothed and unclothed. Use cut-out pictures of different rooms, such as a bedroom, lounge or dining room.	
Tell the story of what is happening in one picture at a time using clear language and key words. For example, emphasise that the girl or boy is in a private place. Or emphasise the order in which the story happens and the importance of washing hands.		 Private rooms, such as the bathroom or toilet, could be made with a door to open and shut to show privacy. A cut-out bed could have a duvet or blanket that lifts up and down. Ask the child to match the people to the appropriate places. For example, ask where can the girl eat her dinner? Where can the boy wash his penis? The child must place the cut-out character on or inside the appropriate picture. Test their understanding, e.g. ask if the character could eat dinner in the bathroom, or take off all her clothes in the classroom. 	
PRIVATE PLEASE KNOCK		Notice that, at this stage, you do not need to talk about masturbation or ejaculation. The child simply needs to know that touching their private parts should happen in a private place, such as the bathroom or	

place, such as the bathroom the bedroom, with the door closed or under the bedding.

e. Personal hygiene

One of the ways to show development in children is through the change from total parental involvement in personal hygiene (washing and changing nappies) to a gradual and increasing need for independence as the child reaches puberty.

The goal of independence in the area of personal hygiene is extremely important for all children, including those with ASD. Working on this theme gives lots of opportunities to talk about body changes and growing up, for example, the need to use deodorant and wash more carefully, or the need to look good and take care of your personal appearance.

Try these "personal hygiene" activities.

PERSONAL HYGIENE				
Looking in the mirror	Telling a story with characters	Encouragement		
 Encourage the child to look in the mirror and to check each part of their face. For example, is his hair tidy? Is her teeth, nose and eyes clean? Give the child positive feedback about her/his appearance. 	 Use cut-out characters, puppets or dolls. Show the child how the character washes in the bath. Name the body parts. Ask the child to pretend to wash the doll and narrate the body parts being washed, e.g. the girl washes her tummy. Tell the story of the full bedtime routine. 	 Encourage the child to be as independent as possible at bathtime. You may need to support their routine through verbal prompts or a sequence of picture cards that remind them of all the body parts they must wash, rinse and dry. These cards can be placed in sequence next to the bath. 		



f. Sexual abuse

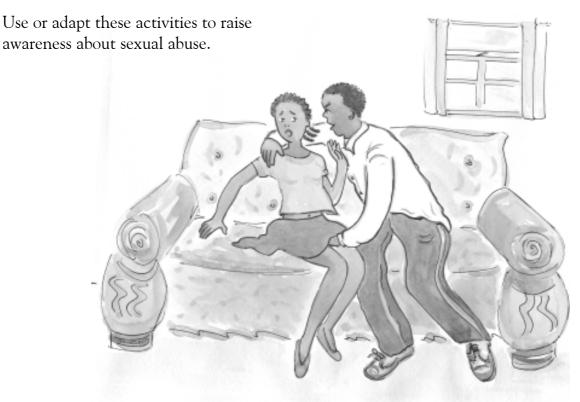
The issue of sexual abuse concerns all parents, carers and educators and it is acknowledged that there is an "increased risk of sexual abuse towards individuals with disabilities of any kind".¹⁵ However, there is a common misperception that strangers mainly perpetrate sexual abuse. This may lead parents to be especially anxious of their son or daughter in public places, particularly toilets where they may need to be left alone.

However, sexual abuse is more likely to occur with someone that the child knows well. The abuser may even spend time building a trusting relationship, where touch becomes gradually more sexual.

It is vital to make every effort to teach a child that they have the right to say "no" to touch (see the activities on *physical contact* on page 14). The child may be able to understand the word "sexual abuse". This can be explained by referring to an adult (or bigger person) touching, or wanting them to touch or look at private body parts.

Explain that sexual abuse is wrong and that it is important to tell a grown-up whom they trust. There are some pictures of "good" and "bad" touch developed for young people with intellectual disability that may help you to reinforce this explanation visually (see *Resources*, page 47).

Try to be aware of any changes in your child or learner's behaviour that may indicate sexual abuse has occurred. Speak to a professional who knows the child. Remember, if you suspect that a child is being sexually abused, you must, by law, report it to the Mental Health Review Board.¹⁶



	SEXUAL ABUSE	
Saying yes or no to touch	Good and bad touch pictures	Talk about getting help
 Reinforce and repeat all the activities on <i>physical contact</i>. Emphasise that it is okay to say "no" to touch. Always respect and listen to your child's preferences and communication 	 Some children may be able to use pictures of "good" and "bad" touch (see <i>Resources</i>). Ask the child to look at the picture and think if both people in the picture are saying "yes" to the touch, or if one person is saying "no". Make cut-out "yes" and "no" faces so that the child can place their answer next to the appropriate face. If possible, draw attention to the facial expression and body language of the people in the pictures. Repeat things such as "the boy doesn't like it" or "she says no, stop". You may be able to explain that it is wrong if an adult touches a child's private parts, or asks the child to touch or look at their private parts. You may need to identify two trusted adults who the young person should tell if this happens. 	 Remind your child that, if they are confused or unhappy about something, they need to ask for help from an adult they trust. Help the child to think of whom they can ask. Talk about the "bad touch" pictures (see Step by Step in Resources, page 47). Ask the child what the victim should do next, especially if the person hurting them is bigger and stronger, and does not stop when asked to. Together with the child, think of and write down ways of saying "no" that can be practised, e.g. "Go away", "I don't like it", "Don't touch me", "Stop it". Remind the child that he/she must get help. They should tell an adult they trust if "bad touch" happens to them. Work with the child to identify two trusted adults to tell if they have a problem.

5. Adolescence: a time of transition

This section looks at the stage of adolescence and suggests topics that may need to be taught. The activities in tables suggest approaches to these topics. As with the childhood section, remember that these activities will need to be adapted to different ability and perception.

Adolescence is the period of transition from childhood to adulthood that begins at the start of puberty.

Young people with ASD also experience this transition, but need more help to cope with these changes. It will be easier to give this help if we understand a little about the different developmental phases of adolescence. When we have an overview of this development, we can relate this understanding to the special needs of young people with ASD.

We will discuss the developmental phases of adolescence under these themes:

- The physical changes of boys and girls at puberty
- Puberty and young people with ASD
- The cognitive development of adolescents
- The cognitive development of young people with ASD
- The social and emotional development of adolescents
- The social and emotional development of young people with ASD
- The sexual development of adolescents
- The sexual development of young people with ASD.

a. The physical changes of boys and girls at puberty

Puberty is a time of rapid growth and development and marks the beginning of adolescence. There is enormous variation in the age in which puberty begins and ends. However, the average age to begin puberty for girls is 12½ and 14 in boys. This growth and development may continue until a girl is 18 and a boy is 20.¹⁷

b. Puberty and young people with ASD

Young people with ASD experience the same body changes at puberty as other young people. They need information to help prepare them for the dramatic changes of puberty:

Common misunderstandings are that periods represent an injury and that "wet dreams" represent a toileting accident leading to a wet bed. Both situations are, of course, likely to cause distress and even fear (especially with the blood and pain that may accompany periods).¹⁸

A young person with ASD may have little natural awareness of the need for privacy and modesty relating to personal hygiene and masturbation. As a result, this may also need to be taught in detail.

Guidelines: the physical changes in boys at puberty

- *Growing:* The head, hands and feet grow to adult size first. The shoulders widen and boys grow taller, often continuing to get taller until their early 20s. The genitals, particularly the scrotum, become enlarged with texture change and a reddening or darkening of the skin.
- *Hair growth:* Pubic hair starts to grow first and then underarm hair appears. Facial hair starts to grow on the upper lip and then the chin.
- *Sweat:* underarms, genitals, hands and feet begin to sweat more, resulting in the need for good personal hygiene.
- *Voice breaking:* The larynx grows larger causing the vocal chords to stretch and the voice to break. The voice may squeak when under stress causing embarrassment.
- The testicles start to produce sperm. The boy may have a wet dream. This is a way for the body to expel excess sperm and cannot be consciously controlled. Wet dreams tend to decrease or even stop once masturbation and other sexual activity occurs.
- With the huge increase in hormones, erections occur frequently, perhaps as a result of thinking of or looking at sexually exciting situations, but may also be because of other physical sensations. They last only a few seconds and control improves as the teenager gets older.
- Masturbation may or may not be experienced at this time. Masturbation is the pleasurable stimulation of the genitals, and may or may not result in orgasm. Remember that masturbation also occurs in children and babies (e.g. when babies masturbate in the womb) and is a natural way that children develop an awareness of their bodies (see page 36 below for more information about masturbation).

(Adapted from Planned Parenthood Association, 1998: 12–14)

Guidelines: the physical changes in girls at puberty

- *Growing:* The growth spurt occurs before the first period and there is only a slight growth after this (although some girls do not experience a growth spurt, but just grow gradually and then stop). The hips broaden and fatty deposits occur on the hips and breasts. The nipples grow first and breast buds appear. As puberty goes on, the breasts mature and enlarge.
- *Hair growth:* Pubic hair starts to grow first and then underarm hair appears.
- *Sweat:* Underarms, genitals, hands and feet begin to sweat more, resulting in the need for good personal hygiene.
- *Vaginal secretions:* The vagina starts to produce a clear, whitish discharge. This discharge usually starts before the first period and is a sign that menstruation will soon occur.
- *Menstruation:* This can start at any age between 8 and 18, usually occurring about a year after the breasts have started developing. It often takes 3 to 4 years to establish a regular cycle. Cycles vary from 20 to 40 days, with an average of 28 days. The menstrual bleed can vary from between 2 to 10 days, but the average is 4 to 5 days.
- Masturbation may or may not be experienced at this time. Masturbation is the
 pleasurable stimulation of the genitals, and may or may not result in orgasm.
 Remember that masturbation also occurs in children and babies (e.g. when babies
 masturbate in the womb) and is a natural way that children develop an awareness
 of their bodies (see page 36 below for more information about masturbation).

(Adapted from Planned Parenthood Association, 1998: 8–11)

Remember, the earlier you begin to establish appropriate routines and behaviour related to modesty and personal hygiene the better (see also sections of *Childhood: the foundation work*, pages 17 and 19).

c. The cognitive development of adolescents

The physical development that occurs at puberty and throughout adolescence happens together with changes in how a young person thinks – this is called *cognitive development*.¹⁹

Children think in *concrete* terms. They struggle with concepts and ideas that they cannot actually see. Adolescents are increasingly able to think in more *abstract* terms. This means that they become able to see issues from another perspective to their own, and may become aware of beliefs and values that are different to what they are used to in their own family:

Cognitively, learners of this age show an increasing interest in more abstract topics, for example, love, fidelity, responsibility and human rights. However, they often still think concretely, especially when under stress and are led by their own experience.²⁰

d. The cognitive development of young people with ASD

Most young people or adults with ASD will continue to think in very concrete and literal terms, and do not easily generalise information or skills to other contexts. People with ASD often adhere to inflexible, rigid patterns of thinking and behaviour.

A young person with ASD will struggle to understand that people have different perspectives or comprehend abstract concepts such as values, love or friendship. Their continuing tendency to think in concrete terms has a profound effect on how we attempt to teach young people with ASD about their sexuality. There is no use talking about "the birds and the bees", or couching the discussion in very technical scientific terms.²¹

Sexuality education for young people with ASD needs to use the same strategies as the rest of their education and learning:

- Sexuality education needs to be as direct and visual as possible.
- Language needs to be simple, and key words and phrases should be used in conjunction with pictures, the written word and the actual learning situation (see *Approaches to help communicate about sexuality*, page 4).

You may need to teach a young person values or social guidelines on friendships and relationships. This could take the form of developing rules for good relationships or friendships.

e. The social and emotional development of adolescents

This is the time when a young person grows towards their adult identity. It is a time when young people discover their values and select role models. At this time, adolescents may test limits and boundaries, and take risks related to drinking, drugs or sexual relationships.

Parents need to be aware and sensitive to the sometimes-contradictory needs of the adolescent:

Adolescents have a need for closeness and intimacy. As they become more independent from their parents, they have an increasing need for intimacy with their peers. They often feel insecure and uncertain, and this is a stage in which they need to gain greater independence, while needing a lot of protection, love and acceptance at the same time.²²

f. The social and emotional development of young people with ASD

Autism is no shield from the seesawing emotions of adolescence. The effects of mood swings may be worse for the young person with ASD because of difficulty in understanding their own emotions and behaviour.²³

A young person with ASD will need to be taught that their identity is shifting from a child to a young adult. As parents, carers and educators, we need to look ahead and give the young person with ASD as many messages and experiences as possible that reinforce an age-appropriate self-identity and a sense of personal competence.

The aim of social and emotional development is the growth towards independence. We need to be aware of how we, as parents, carers and educators, support or impede this growth.

Guidelines to develop social independer	nce
Think how you can encourage your son, daughter or learn social independence as they are capable of. You could en	ner to experience as much
 Participate in social activities with friends. Take pride in their appearance and dress in an age-age Help with chores. Care for a pet. Make their own lunch or drinks. Keep their room tidy. 	opropriate manner.
Be totally independent with personal hygiene.	more over

Adolescence: a time of transition 25

- Experience privacy in their bedroom and bathroom.
- Respect other people's privacy by knocking on bedroom and bathroom doors before entering.
- Sleep in their own bed.
- Earn pocket money.
- Walk independently (not holding hands).
- Shake hands when introduced to someone.
- Take part in vocational activities.

g. The sexual development of adolescents

From the beginning of puberty, the adolescent has to cope with strong sexual feelings. These are caused by the production of hormones in the body.²⁴ Young people start to feel sexually more interested in other people and become much more aware of their self-image and their gender identity.²⁵ For example, they may:

- Spend time imagining what it would be like to experience a sexual relationship.
- Develop sexual fantasies or crushes these are a natural way for the adolescent to begin to understand their sexual feelings.
- Begin to masturbate and experience orgasm for the first time considering the emotional and health risks of sexual intercourse, masturbation needs to be seen as a positive sexual outlet for all adolescents.

Young people may begin to experiment with different levels of sexual experience with others. Although most young people will be heterosexual (meaning they are sexually and emotionally attracted to someone of the opposite sex), at least one in 10 people are either homosexual or bisexual. Research shows that many homosexual or lesbian people know their sexual orientation from a young age and report feeling different from their peers.

However, it is also common for young people to have one or two homosexual experiences that are part of sexual experimentation and growing up. These experiences do not necessarily mean that the young person is homosexual.²⁶

h. The sexual development of young people with ASD

People with ASD have sexual feelings just like anyone else but they understand them less well. $^{\rm 27}$

As sexual development has such a strong social and emotional component, it is hardly surprising that many young people with ASD will struggle to process sexual feelings. People with ASD struggle to understand their own emotions and behaviour, and so will not easily recognise signals of sexual interest in others.²⁸ The nature of autism also means that a young person or adult with ASD is less likely to use fantasy as a tool to understand their sexual feelings.

Generally it seems to be accepted that adolescents with ASD have less interest in developing sexual relationships with other people. However, Tew cautions:

It should be remembered that the lack of understanding of social interaction and communication does not necessarily indicate an absence of feeling or desire for a relationship.²⁹

Whether sexual relationships are unwanted or simply too difficult to manage, it seems that the main sexual outlet for most people with ASD is solo masturbation.³⁰ The way that masturbation occurs depends on the individual:

- Some people with ASD may use objects or particular materials as a stimulus for masturbation rather than the image (either real or in fantasy) of another person.³¹
- Some people with ASD may find it difficult to achieve orgasm as a result of the effects of medication or because they cannot use fantasy to achieve full sexual response. This may lead to frustration and anger, or behaviour problems.³²

Parents, carers and educators need to recognise the importance of masturbation (at the appropriate time and place) in the sexual well being of a young person with ASD, They should give the message that masturbation is a normal and healthy, but private, activity (see more in *Masturbation*, page 36).

Developing your own guidelines

Although it is not possible to give general guidelines about sexual development in relation to a young person with ASD, we can respond in a positive and proactive manner. Think about how you can:

- Get more information and support around sexuality and young people with ASD. Remember that young people with ASD have sexual needs and feelings.
- Talk about it! Form a parent support group. Other parents may be able to offer suggestions and approaches that can help you. You can find someone who is knowledgeable to facilitate an initial discussion or give ongoing support.
- Speak to your school psychologist about your child or learner's sexual development.
- Ask your school if they are delivering sexuality education. If not, set up a working group to get sexuality education started in your school.
- Find and make resources for sexuality education that will help you to communicate about sexuality with your child. As most people with ASD are visual thinkers, books that communicate through picture sequences may be more helpful (see *Resources* at the end of this booklet).

The sexual development of a young person with ASD may have a positive effect:

Puberty sometimes presents as a second opportunity for persons with autism to become attached to others and to develop relationships, even with their parents. It is not that these relationships are themselves sexual, but that the sexual impulse has provided the interest and motivation for them to occur.³³

6. Activities to teach sexuality education to adolescents with ASD

Ideally sexuality education needs to start before a young person reaches puberty and continue throughout adolescence. Think carefully about what content or themes are relevant to your adolescent or learner, and be guided by the needs and abilities of the individual.

Remember:

- Sensitive sexual work should not be attempted until learners have completed and are comfortable with work on privacy, private body parts and body changes.
- Sexuality is not just about physical or sexual development.
- Sexuality cannot be separated from the emotional and social development of the adolescent.

We will suggest more detailed approaches and activities under these sexuality-related themes:

- Privacy
- Private body parts
- Body changes
- Personal hygiene
- Masturbation
- Relationships
- Sexual relationships
- HIV and AIDS.

a. Privacy

Privacy is a complex concept that has different meanings in different contexts. It is important that the young person with ASD can associate different kinds of behaviour with different places, for example, the appropriate place to change their clothes, or touch private body parts. It will help if the young person has experienced consistent messages about privacy from childhood.

Some young people with ASD may be able to extend the meaning of the concept to private conversations. This means they can learn to request a private conversation with someone and understand that other people may want to have private time or conversation alone. It may also be possible to teach the young person with ASD the difference between a private thought (that does not need to be shared) *and* a secret worry (that needs to be told to an adult who can help).

See the activities opposire for some ideas.

PRIVACY

Private places

Show the young person pictures of different rooms. Ask them to match the different rooms with different activities such as eating, washing and watching TV.

Stress that if a young man or woman is washing, taking off their clothes, or touching their private parts, they need to be in a private place or room and shut the door.

You may need to use pictures of people and match the picture to the appropriate place.

Assess the young person's understanding of this concept. You may need to actively and consistently reinforce this concept in response to real behaviour.

Private conversations

Some young people may be able to understand there is private time alone, and there can be private time with another person when we do not want to be interrupted – e.g. a private meeting, or if two people are in a sexual relationship.

Use pictures of people in different situations and ask if they should be in private or in public (see *Resources*).

Role play asking for a private conversation with a teacher or parent, e.g. "Please can I have a private chat, I am worried about...."

The young person may need to learn that an adult may not be available to meet with them immediately, but will make a time when they can talk together.

Role play two people having a private discussion and another person interrupting.

The young person may need to practice waiting to get attention or learning how to interrupt the conversation.

Public or private?

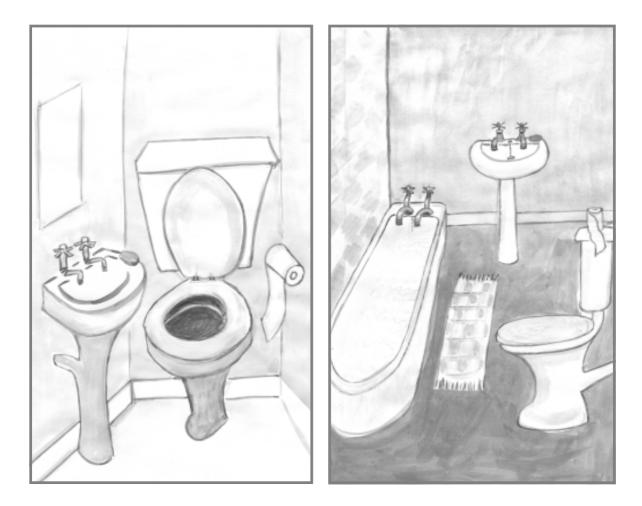
Make a set of cards with public statements written on them that could be told to a group of friends or a class, e.g. "I like going to the Spur and eating burgers".

Make another set of cards with *private thoughts* that do not need to be shared, e.g. "I have just had a huge poo!" or "That woman has big breasts!".

Make the last set with private worries that show a concern that the person needs help with, e.g. "My uncle keeps touching my private parts, I don't like it".

Mix the cards up and then ask the young person to sort the cards in groups of *public statements* (e.g. place next to a picture of a group of friends), *private thoughts* (e.g. place under a cushion to show the thought is private) and *private worries* that need help (e.g. place next to a picture of an adult called "a trusted adult").

• Stress the importance of asking for help when we have worries. Ask the young person to name a person they trust and could go to for help or to talk through a problem. Role play asking for help (see previous activity).



b. Private body parts

The young child needs to know what private body parts look like, what they are called and where they are situated on the body. The older child needs more detailed knowledge of private body parts in preparation for the changes that will happen at puberty.

Most young people, including young people with ASD, will find it embarrassing to look at or name private body parts, but this awkwardness quickly disappears as they become used to seeing and talking about private body parts.

Parents or teachers should make it clear that it is okay to talk and learn about private body parts when we learn about growing up. Clarify when is an appropriate time to discuss private body parts, such as in the sexuality education lesson, or at a quiet time at home. Help the young person to practice asking for a private chat with you if they have questions about private body parts or changes.

Use and adapt these activities to encourage learning about private body parts.

PRIVATE BODY PARTS				
Clothing team game	Body outlines	Learning in more detail about male and female private body parts		
 Play games with clothes to break the ice around saying private body part words. If you are working with a group of young people, split them into small groups. Ask each group to find an item of clothing, e.g. something a woman would wear. Each group must think about all the body parts that the clothing covers. Each group gets a point for each body part named and two points for saying a private body part. 	 Draw the body parts on large body outlines, or use cut- out body parts. Check the young person's understanding and vocabulary for body parts. Use the correct terms for private body parts, but also acknowledge the term that the young person uses. Tell the young person that, now they are becoming a young man or woman, they can use the proper names for private body parts. Use stick on cut-out body parts to practise being used to seeing and hearing private body part words. If you are working as a group, you can play this as a game. Pass one body part around the circle to music. When the music stops, whoever has 	 In a class situation, it may be best to do this work in single-sex groups. (See <i>Guidelines for safe and accountable sexuality education</i>, page 10.) You may feel that, after a few sessions, the young people are mature enough to work in a mixed group. Erections: Include cut-out pictures of a soft penis and a hard penis with your cut-out body parts (see <i>Resources</i>, page 47). Assess and teach the learners the meanings of "hard" and "soft". Ask them which parts of the body are hard and which are soft. Ask if a man's penis is hard or soft? Inform the young person that a man's penis is hard or soft and sometimes hard. When the penis goes hard, it is called "an erection". 		

PRIVATE BODY PARTS

the body part, needs to place it on the outline in the appropriate place.

continued ...

If the young person cannot speak, ask them to point to different parts of the body to check understanding.

Use a small stick so learners are not pointing directly at private body parts with their fingers.

The vagina:

Ask the young women to think about which parts of their own bodies they can see. Ask them if they can see their backs or the top of their head.

Tell the group there are some parts of our body that we cannot see without a mirror.

Tell the group that a woman's private parts (her vagina or vulva) are out of sight between her legs. This means that it is difficult to know what this part of the body looks like.

Use pictures to show what the vulva or vagina looks like (see *Resources,* page 47).

Point out (using a small stick, not a finger) the vaginal opening, the urethra (where urine or wee comes out) and the anus (where faeces or poo comes out).

Use terms that are accessible to your group and stress the private nature of this work.

c. Body changes

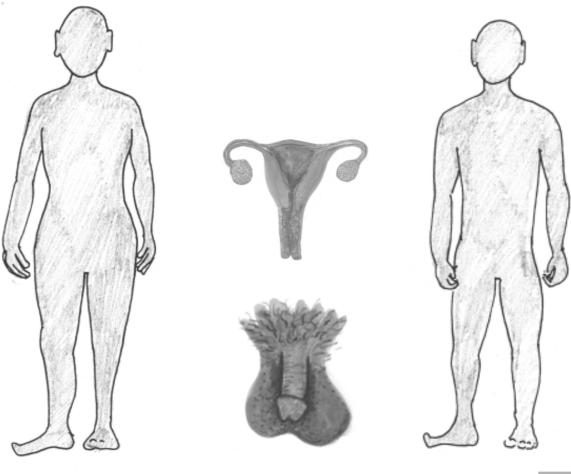
This work will naturally progress from the work on private body parts. If the young person has the vocabulary for private body parts, it is easy to move to the next step and teach about ejaculation and menstruation. Remember you can alter the amount of detail you need to go into depending on the ability of the young person.

Some young people with ASD learn to recognise and name what is happening to them and how to manage the event practically, for example, changing a pad, or asking for clean pyjamas. Other young people with ASD may absorb and ask for more information about why this happens. Be guided by the ability and interest of the young person.

Remember:

- You don't have to know all the answers. It is fine to look something up in a book together, or to find someone who may know the answers to your questions.
- Acknowledge the social and emotional changes that may happen alongside the body changes for example, the young person may be given more responsibilities, or may start to feel moody and short-tempered with their family, carers or educators.
- Look back to the section on social and emotional development for ideas to encourage social and emotional independence.

On the next page are a few activities for working on body changes.



Activities to teach sexuality education 33

BODY CHANGES

Body outlines

Ask the young person to draw on the body parts for a child and the body parts for an adult on separate outlines.

Compare these drawings and ask them to notice the physical differences.

Tell the young person that, when a child reaches puberty, their body changes as they grow into a young man or woman.

For menstruation, it may help to use a cutout picture of the uterus and ovaries that can be placed on the female body outline.

Water-based marker pens can illustrate the passage of the egg and how the menstrual blood breaks down and flows out of the vagina.

A cut-out drawing of male internal sexual body parts may help to explain the how urine or semen leaves the body.

 Be prepared to answer any questions that the young person may have.

Body fluids

Introduce body fluids in preparation for work on wet dreams and menstruation.

Introduce these concepts by talking about wet and dry parts of the body, e.g. the mouth is wet with spit, we sweat when we are hot.

If at school, it may be best to do this work in single-sex groups.

Make fake body fluids in small containers, e.g. diluted rooibos tea for urine, water for sweat and tears, tomato sauce for blood, diluted white conditioner for semen, KY jelly or conditioner for vaginal discharge.

Reassure the young people that these fluids are not real.

Ask the young people to place the fluids on the body outlines to show where they come out of the body.

Assess what they know and find out what terms they use.

Introduce the correct terms along-side the terms they use.

Wet dreams

Use story pictures (see *Resources*, page 47). Show the story of the young man having an erection and a wet dream. Tell the young man that it is normal and means that he is becoming a man.

You may want to provide a towel or tissues for a young man to use at home, or to develop a sign or symbol that he can use to tell you if the sheets need changing.³⁴

Menstruation

Show pictures of a young woman managing her period and changing her pad (see *Resources*, page 47).

Tell the story one picture at a time and emphasise key concepts such as privacy, growing up, and asking for help.

Keep sanitary products in a particular drawer so that a young woman will be reassured that they will be there when she needs them.³⁵

d. Personal hygiene

This work follows on from the previous themes of private body parts and body changes. Think about what support the young person needs to manage their personal hygiene as independently as possible:

- Develop visual support cards to prompt the young person in their personal hygiene routine.
- Encourage the young person to take pride in their appearance.
- Praise them for looking good.

Here are some activities to help you.

PERSONAL HYGIENE					
Chemist products	Story sequences	Encouragement			
 Collect a variety of sanitary products, such as soap, toilet paper, razor and scissors. Ask the young person to place different chemist products on the appropriate body outline in the appropriate place, e.g. a razor next to the man's face. Discuss whether a man, woman or child would use the product, and where it would be used on their body. Discuss differences, such as not all men or women choose to shave. It may be important to relate this discussion to religious or cultural practices. 	 Show the young person a story sequence that reinforces appropriate self-care, e.g. washing, using deodorant, or managing menstruation. Develop visual support cards that help the young person know the steps involved in managing their personal hygiene. Use a tick list to guide the young person through their morning or evening schedule.³⁶ 	 Give positive feedback to a young person who has made an effort with their appearance and encourage an age- appropriate self-image. Try to be aware if the young person is too reliant on a parent or teacher in the area of personal hygiene, and develop strategies to improve independence as much as possible. 			

e. Masturbation

Our attitude towards masturbation will vary depending on our upbringing and values related to sexuality. Many people now recognise that masturbation is a normal and healthy sexual expression (if done at the appropriate time and place). For many young people and adults with ASD, it may be their only sexual outlet.

If we are to help the young adult feel good about their sexual feelings, we need to respond to the issue of masturbation from childhood and throughout adolescence in a way that:

- Is positive, not punitive, and
- Sets clear boundaries and limits around time and place.

Some parents may find it difficult to accept their son or daughter's changing sexual identity and needs, but it is important to be aware that emotional or behavioural difficulties can arise if these needs are denied.³⁷

Although masturbation occurs in childhood, it may increase in adolescence due to the release of sexual hormones and increased sexual feelings during puberty. Young men may also experience ejaculation and need to be prepared for this. Because of the different perception of people with ASD, objects may become the focus of sexual interest rather than fantasy.³⁸

Remember:

- Think carefully how we respond to sexual behaviour that seems different.
- Base your intervention on whether the behaviour harms the individual socially or physically, rather than whether you view the behaviour as "normal" or "abnormal".
- If you find that a young person is having difficulties around masturbation, look for support to help you find the best approach.

With guidance and support, many young people with ASD will manage masturbation in a way that is pleasurable and socially appropriate.

It may be possible to create a picture or symbol for masturbation that can be part of the young person's schedule: "No, not now. Yes, later. Look at your timetable".³⁹ This gives the young person clear rules about where and when masturbation is allowed.

To work on the theme of masturbation, you need to have completed work in the areas of privacy, private body parts, body changes and personal hygiene. The work on masturbation reinforces and combines these concepts.

The next set of activities helps you to build on previous work.

MASTURBATION

Story sequencing

Show the young person or group pictures of the young man or woman masturbating.

Show the pictures one at a time and emphasise that the young person is in a private place, that they are touching their private parts, and that they feel good.

At this point, you may want to introduce the fact that the young man or woman feels sexy and wants to touch and rub their private parts.

If working with young men, ask them to notice the sperm/ semen coming out of the boy's penis and how this feels good.

You may or may not want to introduce the words "ejaculation" and "orgasm".

Body fluids

Repeat the work on body fluids. Tell the young men that semen may come out of the boy's penis when he masturbates and that this feels good.

You may need to go into more detail about where sperm is made and what it is for.

Young men may need reassurance that they are not wetting themselves when they ejaculate.

You may find it helpful to make a clay penis over a small syringe. The fake semen can then be squirted out of the syringe to show ejaculation.

Tell the young women that it is normal for a woman to produce vaginal fluid or wetness, and that a woman's vagina will produce more fluid or wetness when she feels sexually aroused.

Public or private?

Repeat the activity *Public or Private?*, page 29.

Then add statements that refer to masturbation, such as "I want to rub my penis" or "I have just finished masturbating".

Assess if the learners understand that this is a private thought that does not need to be shared socially.



f. Relationships

For children and young people with ASD, intuitive knowledge about relationships and behaviour is not present. They will not make sense of facial expressions or body language, and they will not understand when it is appropriate to be formal or when they can be more relaxed and familiar. This lack of understanding about communication means that the area of relationships is likely to be confusing and stressful for young people with ASD.

Parents, carers and educators of children and young people with ASD need to help them in responding to others and behaving in different situations. This means that the area of relationships can broadly be looked at as developing and encouraging personal and social skills.

Remember:

- Be sensitive to the needs and abilities of the child or young person, and work slowly on skills that can be achieved and then built upon further.
- Develop a few simple rules around relationships, such as knowing whom you can approach for a hug or a kiss, and knowing to ask the person first.
- See if it is possible to establish rules for a friendship, for example, the person needs to be a similar age, and both people need to listen to each other and enjoy being together.

Here are some activities for exploring relationships.



RELATIONSHIPS		
D	Friendship rules	

Relationship sorting

Find pictures in magazines and pictures of "good" and "bad" touch (see *Resources*, page 47).

Make signs that show the categories of friends, family, lovers (or couples) and strangers.

Give the young person different pictures and ask them to place it in a category that shows the relationship.

Use this activity to assess whether the young person can interpret pictures, but also be aware that there may be more than one interpretation of the picture.

Draw attention to the body language and facial expressions of the people in the pictures. For example, do they both say "yes" to the touch? Do they look relaxed together? Can the young person name the relationship?

• Can they think of a relationship in their own life that is like the one in the picture? Use this relationship to discuss roles and behaviour in a relationship.

• Draw attention to the fact that some relationships in the pictures are not happy and that sometimes we have to be able to say "no" to people we know (see *Sexual Abuse*, page 20). Together with the young person (or group), think of rules relating to friendship and behaviour.

Write up these rules in word and picture form.

These rules can be used to affirm a relationship or to guide behaviour.

You can separate rules into "yes" rules and "no" rules. For example:

- I can listen.
- I can say "yes" or "no" to my friends.
- I can share.
- I can talk with my friends.
- I must not shout at my friends.
- I must not touch my friends' ears unless I ask and they say yes!

My special circle

Ask the young person to make a large circle on a sheet of paper.

Ask her to think about people in her life who are important. These are people who she loves and trusts.

The name, photo or drawing of each person can be written or stuck inside the circle.

Tell the young person that these are people they can ask for a hug with or have a private chat with.

Building relationships

Stories

If possible, use puppets or cut-out characters to explore different behaviour and scenarios relating to relationships.

For instance, you could look at the issue of *bullying* in a story.

See if the young person can recognise the situation.

Try and get their suggestions about what the victim could do.

Try and establish the rule that, if we are unhappy or confused about something, we must ask for help from a trusted adult.

g. Sexual relationships

We may question whether it is possible for people with ASD to truly understand or reciprocate in a sexual relationship. People with ASD may misunderstand and misinterpret social signals, and may have a literal and superficial understanding of their sexual education (for example, you ask someone for sex and go somewhere private). This can leave them vulnerable to being sexually abused, but also perhaps able to sexually abuse others.⁴⁰

Yet if an adult with ASD wants a sexual relationship and there is the possibility of a reciprocal relationship, is it right to prevent this relationship developing simply because of their disability? Is it possible to apply strict moral codes to people with ASD that certainly are not followed within the general population? There are no easy answers.

Sexual relationships are all around us. Young people with ASD have brothers and sisters who get married and have children. They see TV programmes with characters in sexual relationships, and they hear about HIV and AIDS. How are young people with ASD going to interpret the different messages they encounter about sexual relationships?

This booklet argues that sexuality education aims not to encourage sexual relationships, but to help young people to make sense of the world around them. A young person with ASD who is interested and able to learn about sexual relationships has the right to this information even if they do not necessarily experience a sexual relationship.

Yet, the most difficult aspect of sexual relationships to teach a young person with ASD will be to connect sexual behaviour with values and social roles. The goal of sexuality education should be to frame teaching sexual relationships within a value context that encourages safe, healthy and happy sexual relationships.

This may mean you need to give the young person with ASD very clear guidelines about what a positive sexual relationship looks like. This could be expressed by teaching about issues such as:

- An appropriate time scale and age in relation to sexual relationships.
- The concept of *consent* and *permission* in relation to all sexual touch.
- The need to recognise feeling relaxed or tense with a partner.
- How relationships may shift and change.

If possible, relate these discussions to relationships and roles that the young person experiences in his/her family.



Guidelines for building on previous work:

- If you have worked on the themes of privacy, private body parts, body changes and masturbation, it may be that you have already touched on the theme of sexual relationships. You may have already explained why a man produces semen, or why a woman has a period once a month. You may have talked about masturbation, sexual feelings, sexual responses and privacy.
- If you have done some previous work, you will already have many tools and words to teach about sexual relationships.
- Consider what value system or moral framework you are going use to teach sexual relationships. For example, you may want to stress that sexual relationships should happen between consenting adults, or you may only be comfortable teaching about sexual relationships within the context of marriage.
- Whatever your decision, be aware of the possible implications or contradictions in these messages, for example, some young people with ASD may never get married, or they may know of people in sexual relationships who are not married.

The activities below are a general introduction to sexual relationships. The response and learning of the young person in all the other areas of this work will guide whether it is possible or appropriate to teach about sexual relationships. Be guided by the interest and needs of the individual.

SEXUAL RELATIONSHIPS			
Themes for sexual relationships	Rules for relationships	Story sequencing	
 Try to work on these themes related to sexual relationships: 1. The concept of <i>friendship</i> and <i>reciprocating friendship</i>. You may need to work on rules for friendships and then extend these into relationship rules. 2. The concept of <i>permission</i>, especially in relation to touch. Repeat the activities on initiating and refusing physical contact, page 14. 3. The concepts of <i>rough touch</i> and <i>gentle touch</i>. Make this concrete by hitting a balloon or cushion roughly or gently. 	 If the young person can recognise sexual relationships in pictures from the relationship sorting activity (page 39), then they may begin to work on the idea of rules for sexual relationships. For example: 1. We can have a relationship with someone of a <i>similar age</i> as us. For some young people with ASD, you may need to specify how much 	Over time, build a relationship between two fictional people. You could use two cut-out characters. Try and show the stages that are important in building a positive sexual relationship, e.g. permission, respect and trust. You could show how relationships continued over	

SEXUAL RELATIONSHIPS

Say that we can also touch people roughly or gently.

Sort the "good" and "bad" touch pictures into "rough" or "gentle" touch.

In pairs, do a "trust lead" with one person blindfolded. Emphasise how the person blindfolded needs to be touched gently.

4. The concept of *attraction* between two people. Repeat the relationship sorting activity, page 39.

Use magnets to show the force of attraction between things. Ask the young person to match photos of people who may feel attracted to each other.

If necessary, use examples of people in the young person's life who are attracted to each other and who are in a relationship.

5. The concept of *sexual feelings*. Repeat your work on body parts and body fluids using cut-out body parts and body outlines.

Repeat the work on masturbation. Tell the young person that a person may feel sexy on their own and may choose to masturbate (at the right time and in a private place).

If two people are in a sexual relationship, they may feel sexy together. This means that they may choose to be sexy together and touch each other's bodies. Link this to the *story sequencing* activity in this table. older or younger the person could be. This is to guard against the young person with ASD entertaining inappropriate ideas about who may be available to them.

2. *Respect:* we must always ask the person if we want to stand and talk to them, or touch them. And we must listen to the answer.

All sexual touch must be requested and consented to.

3. We must *get to know someone well* before we start a sexual relationship with them.

4. We must *be gentle* in a sexual relationship.

5. We must *ask for help and information* when we need it.

Decide together whom the young person can go to for help on relationship issues.

continued ...

may change, such as a break-up.

• When

appropriate, show the young person the story sequence of a couple in a sexual relationship having sexual intercourse using a condom.

Tell the young person that the couple must use a condom every time they have sex. This is to prevent the spread of sexually transmitted infections, including HIV, and to prevent the couple making a baby.

Use your cut-out body parts on the body outlines to talk about what happens physically in sexual intercourse and sexual touching.

You may need to make a diagram of the uterus and ovaries to show how a baby is made.

Open up for questions at different stages of the activity.

h. HIV and AIDS

In South Africa, the high rate of HIV infection means that HIV/AIDS is an issue that affects us all. It is important we all understand as much as possible about HIV/AIDS to protect ourselves, to stay healthy, and to be caring and supportive to people living with HIV.⁴¹

Yet for a young person with ASD these concepts are difficult to grasp because they are so abstract. This means we need to consider what (or whether) to teach an individual with ASD about HIV and AIDS. This decision will depend on:

- The interest and ability of the young person.
- Whether the young person has been exposed to HIV/AIDS information.
- Whether he/she asks questions related to HIV/AIDS.

Any decision not to teach about HIV and AIDS will need to be revisited periodically as the young person develops.

HIV is spread mainly through sexual relationships. If a young person with ASD is unlikely to experience a sexual relationship, their risk is considerably reduced. However, this young person is still likely to be affected by HIV/AIDS through the media, through hearing discussions concerning HIV/AIDS or by knowing someone who is affected. This means they need information and guidance to help process what they hear.

Remember:

- It will help a young person with ASD to understand HIV and AIDS if they have worked on topics outlined in this booklet around private body parts, body fluids and sexual relationships.
- Choose carefully the amount of scientific or medical detail that will be relevant or helpful to the individual. For example, HIV is *a virus* that is scientifically different from germs. However, the concept of *a germ* may be easier for some people with ASD to understand. Thus scientific accuracy may need to be sacrificed for greater accessibility.⁴²

Try to use and adapt these activities in passing on information and advice on HIV and AIDS.

HIV and AIDS

Assess what they know

Discuss what they know about HIV and AIDS, e.g. do they know the difference between HIV and AIDS? Try and get a sense of their understanding and the gaps in their knowledge.

- Assess if the young person has fears or anxieties around HIV/AIDS that will need to be addressed.
- Work on the concepts of *health* and *illness*. They need to understand that germs and viruses are so small we cannot see them.

Relate this to the need to wash hands before handling food or going to the toilet.

Ask the young person to think how their body feels when they have a cold or the flu. Then explain that white blood

Give information about how HIV is transmitted

Explain that the HIV virus (or germ if a simpler explanation is needed) is found in body fluids. It is not an air-borne virus and cannot be spread by handto-hand contact.

It is not possible to tell if someone has HIV by looking at them. It may take many years before the HIV virus makes someone living with HIV become sick.

The only way to know if someone has HIV is through a blood test.

Go over the work you have done on body outlines and body fluids (page 34).

Explain that HIV needs to be warm and wet, and can only survive in semen, blood and vaginal discharge. For your own knowledge, remember HIV is present in all body fluids, but has high concentrations in blood, semen and vaginal discharge.

• Talk about the decision to begin sexual relationships and that HIV is an important factor to consider.

Testing and confidentiality

Explain that the only way that someone can know if he/she is living with HIV is from a blood test.

You may want to talk about the decision to have a test and the reasons to know your HIV status.

It may be important to help the young person understand that information about HIV is confidential. Look back to the activity *Public or private*, page 29, and include statements related to HIV.

You may need to teach that it is not appropriate to ask someone about their HIV status, and that people may not want others to know this information.

It is also important to understand that if cells in the blood fight infection so that we become well again.

You may want to show pictures of how the blood looks under a microscope and explain that red blood cells carry food and oxygen, while white blood cells fight infection and germs.

Healthy living

Explain the importance of healthy eating and lifestyle.

Ask the young person to sort different foods (pictures of foods or eating habits) into "healthy" or "unhealthy" categories.

Stress it is important to look after our bodies and get enough exercise, rest and healthy food. Explain that the main way that HIV is passed from one person to another is through sexual intercourse.

Decide on the detail needed for the individual. It may be necessary to discuss vaginal, anal and oral sex, and the need to use condoms.

Use the cut-out body parts and fake body fluids to show the young person how body fluids are exchanged and how condoms prevent the body fluids being exchanged.

Discuss ways in which blood may be exchanged, e.g. accidents, and the need for universal precautions.

Sort cards that show different sorts of behaviour into "safe" or "unsafe" in relation to HIV (see *Resources*).

Give the young person one card at a time and ask them to place the card to show whether the activity is "safe" or "unsafe".

If possible, ask the young person to share their reasoning.

You may want to include pictures of masturbation and stress that masturbation is completely safe. someone tests HIV positive, this information is confidential.

If relevant, work with the young person to decide who they would tell if they tested HIV positive, and perhaps more importantly who they would not tell.

It may be appropriate to invite someone who is living with HIV to come and speak to a young person or group about living healthily and positively with HIV.

If possible, ask a younger person to speak, who the person or group could more easily relate to.

7. A final word

The most important aspect of this work is to recognise that it is ongoing. Sexuality education needs to be reinforced and repeated with varying detail as the child or young person develops.

Always be guided by the ability and interest of the child or young person, as well as keeping in mind their age in relation to sexual development.

One of the most difficult skills for a child or young person with ASD is being able to generalise information to other contexts. This means that it is best if school and home can work in partnership, informing and supporting each other to reinforce concepts consistently. Homework books can share what is being taught in sexuality education and, where appropriate, include some of the pictures or symbols so that they can also be used at home. It is important to recognise that it is not possible to have all the answers, and that some methods or resources will not communicate successfully with all children or teenagers with ASD.

However, we need to see sexuality education as an integral part of the child's or teenager's development and education. For example, this means that:

- We need to create environments where sexuality can be raised and discussed.
- We can include the issue of sexuality at parent meetings.
- We can set up parent and teacher support or discussion groups.
- We should invite speakers and share reading material.

The author hopes that this resource book will help parents, carers and educators to be more confident in conducting sexuality education for children and teenagers with ASD, and that this book is a contribution towards the development and sharing of skills, experience and resources.

8. Resources

1. Step-by-Step: A sexuality and HIV/AIDS education programme for young adults with intellectual disability.

This facilitator's manual and DVD is aimed at carers and educators wanting to deliver sexuality and HIV/AIDS education to young people with intellectual disability, and offers a planned programme described over 16 sessions. Although the manual is geared towards learners with intellectual disability, some of the activities or resources may be successfully adapted to the needs of young people with ASD, and many are included in this booklet.

The manual includes the picture resources below, they can be ordered as a 33-page laminated set.

- 10 colour pictures of consenting and non-consenting touch
- Male and female masturbation sequence
- Male and female genitals
- A sexual relationship picture sequence
- Putting on a condom
- Examples of cut-out body parts and cut-out characters.
- HIV transmission work cards

Step-by-Step is written by Rebecca Johns (2005) and published by the Western Cape Forum for Intellectual Disability (WCFID), a support network for service providers in the field of intellectual disability. Order from WCFID, PO Box 142, Maitland 7404. Tel: 021 510 4686. Email: wcfid@kingsley.co.za. ISBN: 0-620-35371-6.

2. A new edition of the *Step-by Step* manual, aimed at children and teenagers with intellectual disability, will be published in 2007

It will include the picture resources below.

- 10 colour pictures of consenting and non-consenting touch focusing on children rather than young adults
- Growing up pictures from child to adult (baby girl to woman and baby boy to man)
- Learning about wet dreams picture sequence
- Learning about menstruation picture sequence
- Cut out characters for story telling: boy and girl (dressed and undressed), teenage boy and girl (dressed and undressed), a man and woman (dressed)
- Pictures of places (that the characters can be matched to) bathroom, toilet, lounge, bedroom, kitchen, classroom, bus stop, public park

3. Training Workshops Unlimited has developed a sexuality HIV/AIDS education programme for learners and adults with intellectual disabilities that may be adapted.

This programme has 6 sessions and includes education materials, such as posters, a sexuality education board game, leaflets, and anatomically correct dolls (male and female).

The sexuality education board game and anatomically correct dolls can be ordered separately. This training programme can be ordered from Training Workshops Unlimited: Tel: 021 638 3143/Fax: 021 637 9642. Email: santie@trainingworkshops.co.za.

4. Asperger Syndrome publications

- Aston M, (2003) Aspergers In Love, Jessica Kingsley.
- Henault I, (2006) Asperger's Syndrome and Sexuality, Jessica Kingsley.
- Newport J and Newport M, (2002) Autism-Asperger's and Sexuality: Puberty and Beyond, Future Horizons: USA.

5. Taking care of myself: a hygiene, puberty and personal curriculum for young people with autism

Can be ordered over the internet from Amazon.com. By Mary Wrobel, (2003) Future Horizons: USA.

6. Toilet training for individuals with autism and related disorders: a comprehensive guide for parents and teachers

By Maria Wheeler, (no date) Jessica Kingsley Publishers (code NAS 398). ISBN 1-885-47745-7.

7. Talking together ... about growing up: A workbook for parents of children with learning disabilities

This book is aimed at young adults with intellectual disabilities, and their educators and carers. It is available from the UK and recommended by the National Autistic Society (UK).

It includes cartoon-like pictures and stories that can be used for discussion and learning relating to these themes: growing up, body shapes, private places, keeping safe, menstruation and masturbation. This book is available through the FPA website (see below for details).

By Lorna Scott and Lesley Kerr-Edwards, (1999) Family Planning Association, 2–12 Pentonville Rd, London N1 9FP. ISBN: 1-899-19496-7.

8. Talking together ... about sex and relationships: A practical resource for schools and parents working with young people with learning disabilities.

This book is aimed at young adults with intellectual disabilities, and their educators and carers. It is available from the UK and recommended by the National Autistic Society (UK).

It includes contains cartoon-like pictures and stories that can be used for discussion and learning relating to these themes: changing roles from child to teenager, keeping safe, being assertive, family relationships, peer pressure, different relationships, a relationship story, sexual relationships and responsible sexual choices. This book is available through the FPA website (see below for details).

By Lesley Kerr-Edwards and Lorna Scott, (2003) Family Planning Association, 2–12 Pentonville Rd, London N1 9FP. ISBN: 1-899-19457-6.

9. Talking together ... about contraception

This two book pack support young people with intellectual disability who wish to access contraception. Book 1 contains a guide on methods of contraception and book 2 is written for young people with intellectual disability and has clear pictures, easy to read stories and picture posters. This book is available through the FPA website (see below for details).

By Lesley Kerr-Edwards and Lorna Scott, (2005) Family Planning Association: London.

10. Further Family Planning Association publications

The FPA is a UK registered charity working in the area of sexual health. They produce a wide range of publications and resources, many of which include resources for people with intellectual disabilities, such as *Learning Disabilities: Sex and the Law* (2005). Visit their website: www.fpa.org.uk.

11. National Autistic Society (UK)

National Autistic Society (UK) recommend this interactive science and nature website for learning about puberty from a biological or clinical point of view: www.bbc.co.uk/science/humanbody/body/index.shtml?lifecycle or www.bbc.co.uk / science/humanbody/body/index.shtml?lifecycle.

12. Making choices: Sexuality Education for Senior Phase (Grades 7–9) Teachers

This resource is aimed at mainstream senior phase teachers, but has a chapter on including learners with mild intellectual disabilities, as well as detailed information on HIV/AIDS, gender power and sexuality.

By Tania Vergnani, Elzan Frank and Rebecca Johns, (2006) Heinemann: Sandton, South Africa. ISBN: 0-796-2156-6.

13. Picture Exchange Communication Systems: PECS

A training manual and extensive resource of picture communication cards available on disc. By Lori Frost and Andy Bondy, (2007)Pyramid Educational Products, London.

14. National Children's Bureau: Sex Education Forum

This is a UK organisation with over 48 members committed to quality sex and relationships education for all children. Their website has fact sheets and resources to download, as well as links to other relevant websites, such as:

http://www.ncb.org.uk/sef/ and www.lifesupportproductions.co.uk.

They also have these videos:

- Jason's Private World
- Kylie's Private World
- Jason and Kylie's Private World.

15. Usborne Facts of Life Growing Up: All about adolescence, body changes and sex.

This publication is aimed at adolescents generally, but contains some pictures and is written in an accessible style.

By Susan Meredith, Usborne: London (2004). ISBN: 0-746-03142-4.

16. Responsible Teenage Sexuality

This is a manual for mainstream educators, youth leaders and health professionals, providing a lot of in-depth information about sexuality education, as well as ideas for facilitation.

Published by the Planned Parenthood Association of South Africa, Van Schaik: Pretoria (Second edition, PPASA, 1998). ISBN: 0-627-02332-0.

9. Useful organisations

Autism South Africa (ASA)

Autism South Africa hold a comprehensive list of books and resources available. Contact them at: P.O. Box 84209. Greenside 2034.

P.O. Box 84209, Greenside 2034, Tel: 011 484 9909/9923 Fax: 011 484 3171 email: info@autismsouthafrica.org website: www.autismsouthafrica.org

AIDS Law Project

For information on HIV/AIDS, human rights and different legal issues. Postal Address: P.O. Box 32361, Braamfontein 2017 Tel: 011 356 4100 Fax: 011 339 4311 email: fichardtv@alp.org.za website: www.alp.org.za

AIDS Training, Information and Counselling Centres (ATICC)

Training, teaching aids and resources. Johannesburg ATICC: Tel: 011 725 6711, Fax: 011 725 2579 Cape Town ATICC: Tel: 021 763 5320, Fax: 021 797 3356 Durban ATICC: Tel: 031 300 3104 Port Elizabeth ATICC: Tel: 041 506 1415

Department of Health

including HIV, AIDS and TB Directorate) website: www.health.gov.za

Lifeline

Manages the AIDS Helpline for the Department of Health – contact your nearest provincial Lifeline office to find out the number of the Lifeline centre nearest you. AIDS Helpline: toll free 0800 012 322 Lifeline regional offices: Cape Town: Tel: 021 461 1111 Durban: Tel: 031 312 2323 Johannesburg: Tel: 011 728 1331 Pretoria: Tel: 012 342 2222

Mental Health Review Board (MHRB)

Any person witnessing any form of abuse against a mental healthcare user must report it to the Mental Health Review Board on the form MHCA 01, available in Regulations No R1467. The form can be faxed to the complainant on request. MHRB Western Cape: Tel: 021 370 1221 Fax: 021 371 2877 MHRB Northern Cape: Tel: 053 861 5096 Fax: 053 830 0542 MHRB Gauteng: Tel: 011 555 3375 Fax: 011 355 3401

Planned Parenthood Association of South Africa

Provides material and speakers suitable for adolescents – at present, they do not have materials specifically aimed at people with ASD, but it may be possible to adapt some materials or show selected videos that may be borrowed.

National Office: Tel: 011 634 1500

Cape Town Office: Tel: 021 448 7312

Rape Crisis Cape Town Trust

Information, advice and support around rape and sexual abuse.

Cape Town:	Tel: 021 447 1467	24-hour counselling: Tel: 021 447 9762
Khayelitsha:	Tel: 021 361 9228	24-hour counselling: Tel: 021 361 9085
Heideveld:	Tel: 021 633 5287	24-hour counselling: Tel: 021 633 9229

Treatment Action Campaign (TAC)

HIV treatment access, treatment literacy, and access to health care and support. National Office: Tel: 021 788 3507

email: info@tac.org.za website: www.tac.org.za

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- Campbell J (2006) Sex Education, the key to your child's well-being, (4th edition) Self-published.
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- National Autistic Society (UK) Sex education and children and young people with an ASD, retrieved from http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=296&a=6001 on 23 February 2005.

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