

Sexuality and Relationships Education for people with Down syndrome

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All children and young people should be entitled to good quality sex and relationships education that will allow them to develop the qualities, attitudes, skills and knowledge to develop into healthy, happy and fulfilled adults



This article describes why Sexuality and Relationships Education (SRE) as part of the school curriculum is especially important for individuals with Down syndrome and how parents and professionals can work together to ensure that it is delivered effectively.

For decades around the world, and to this day in some countries, people with Down syndrome have lived their lives in institutions, away from their families and communities, their parents told at birth that this was the best option for them. How different the outlook is today, in the light of research that has changed attitudes and deter-

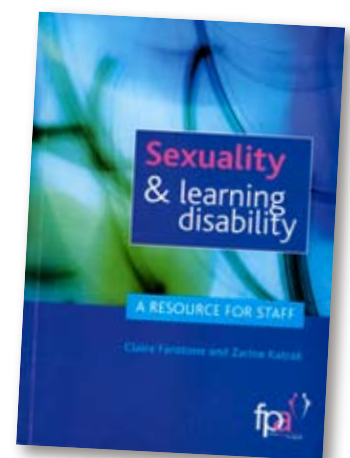
mined legislation, policies and practice ensuring that people with Down syndrome have the right to education, employment, and equal access to health and social care.

However, researching this article has highlighted an injustice that could have the effect of placing people with Down syndrome back in a lonely and isolated world, not necessarily behind closed doors but potentially, in the heart of their communities. In the introduction to her book *Couples with intellectual disabilities talk about living and loving*, Karin Melberg Schwier describes how difficult it can be for some parents and professionals to allow children with Down syndrome to grow into adults, 'whole adults' that is, adults who have adult relationships.^[1]

In some instances, anxieties about abuse, exploitation, pregnancy and sexually transmitted infections have overtaken our appreciation that firstly, personal relationships do not always lead to sexual intercourse and secondly that the positive aspects of sexuality and affection are natural, healthy expressions of our humanity, whether or not we have an intellectual disability. Melburg Schwier describes how our fears may become exaggerated to such an extent that we deny young people with disabilities the right to grow into adults who are able and allowed to have relationships that provide companion-

ship, conversation, trust, love and an appreciation of who they are. Her opening foreword makes poignant reading, as one realises that, in some cases, over-protection and a lack of opportunity to build self-esteem, personal and social skills may deny a person the right to share their life with someone else; a person who is "for themselves, not someone paid to be there, not someone who will disappear in the next wave of staff turnover, someone other than their parents and family".^[1: p.26]

As Fanstone and Katrak state in their handbook for staff "to deny that a person with a learning dis-



ability is a sexual being is to treat them less fully as a person".^[6: p.3] They go on to say that this is an example of discrimination and as

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Box 1: Myths and controversies**A number of myths abound regarding people with Down syndrome and sexuality:**

- *The holy innocent* – Some cultures and religions regard people with Down syndrome as ‘holy innocents’, they are not sexual beings and do not require any education in such matters
- *The eternal child* – Some people believe that children with Down syndrome remain child-like forever and as such are asexual
- *Over-sexed* – Some people believe that people with learning disabilities are over-sexed; that they have increased sexual energy and desire and therefore may be unable to control themselves

X These myths are socially constructed by people without Down syndrome and may serve a number of functions, e.g. the latter is likely to have been constructed at a time when most people with intellectual disabilities lived in single-sex institutions with little or no stimulation of any kind; it could be used to legitimise sexual abuse by staff and/or sterilisation as a means of social control

- *Fertility* – Some people believe that men with Down syndrome are infertile and that women with Down syndrome have an increased risk of conceiving infants with genetic abnormalities

X These beliefs may in part be true, however, there is extremely limited research in these areas; the research that exists is also based on generations from an age when most adults with Down syndrome were living in institutions, under abnormal circumstances. There are documented cases of men with Down syndrome who have fathered children although there are many more documented cases of women with Down syndrome who have given birth. Please see Melberg Schwier and Hingsburger (2000) for a review of current knowledge in this area.^[2]

Reality Check**People with Down syndrome**

- ✓ go through puberty at roughly the same chronological age as their typically developing peers and experience the same body changes
- ✓ experience the full range of human emotions and desires including the desire for intimacy and sexual contact
- ✓ are likely to vary as widely as their typically developing peers with regard to their ‘sex drives’

Sexual abuse and people with intellectual disabilities

- ✓ Relative risk of abuse may be as much as four times higher for people with disabilities compared with the rest of the population, with people with learning disabilities at the highest risk^[3]

Sexually transmitted infections including HIV

- ✓ HIV is a real issue for everyone, including people with intellectual disabilities; it has been suggested that the infection rate in this group is as high as the infection rate in the most rapidly increasing populations in the general population, i.e. perinatally infected infants and heterosexual adults who have contracted the infection through sexual intercourse^[4]

such is “not only an ethical but a professional practice issue.” They too suggest that fear may inhibit some professionals from participating in sexuality and relationships work with their clients. It is important to acknowledge that fears about the vulnerability of people with learning disabilities to sexual abuse are not unjustified (see Box 1: ‘Myths and controversies’). It is, therefore, crucial to find a balance between upholding the basic human right to understand, enjoy and express one’s sexuality but also to be protected from unwanted pregnancy, sexually transmitted infections, including HIV, and sexual abuse.

What do we mean by sexuality and sex and relationships education?

Sexuality relates to our understanding of what it means physically, psychologically and culturally to be male or female. It includes an awareness of our feelings, needs and desires and develops gradually across

the lifespan with our changing life experiences. As we mature physically and developmentally, we will develop a range of strategies to express and fulfil these changing feelings, needs and desires. Sexuality can be said to be an important component of our self-concept and as such, will affect our interactions with others, our behaviour and our life-style choices. As one comes to see how our sexuality develops across time, it is easy to see that we will have differing needs for sex and relationships education at different points across the lifespan, from infancy, through childhood, adolescence and on into adulthood.

In the UK, sex and relationships education is described as a process of “life-long learning about physical, moral and emotional development. It is about the understanding of the importance of marriage for family life, stable and loving relationships, respect, love and care. It is also about the teaching of sex, sexuality, and sexual health.”^[7] Effective sex and relationships education will pay equal attention to the development

of attitudes (e.g. an appreciation of difference; tolerance and respect, openness), skills (e.g. negotiation, problem solving, friendship, communication, assertiveness, personal care) and knowledge (e.g. about puberty, reproduction, sexually transmitted infections).

Box 2 (overleaf) provides an overview of some of the different topics that you might expect a child to learn about over the years. Below, we discuss the significance of these topic areas for children with Down syndrome and how parents and schools can work together to provide appropriate teaching and learning experiences, differentiated to the individual child’s needs and his or her learning style.

These topic areas are likely to be taught both at home and at school. Please see the Department of Education and Skills (DfES) *Sex and Relationships Education Guidance* (2000)^[7] for details of which areas are taught as part of the compulsory

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Box 2: Attitudes, skills and knowledge that may be covered in SRE

- Developing a positive attitude towards self and others including developing self-concept and self-esteem
- Developing effective communication skills including elements of non-verbal communication such as personal space and body language
- Public and private behaviour, modesty and privacy
- Vocabulary to discuss feelings and the body
- Places that are safe and unsafe to play
- Who to talk to and ask for help or support
- Relationship; family, friends, sexual partners, work colleagues
- Bullying; why it can happen and how to get help
- Differences between males and females
- How we change as we grow up; they need to be prepared for puberty
- How to look after their bodies; personal hygiene and health screening
- Appropriate and inappropriate touch of self and others
- The importance of consent to touch another person's body or have someone touch you; how to keep yourself safe and be assertive
- Reproduction and how to prevent pregnancy
- Sexually transmitted infections and how they can be prevented

UK Science National Curriculum and at which key stages and which parts are part of the Personal Social and Health Education (PSHE) and Citizenship Frameworks.

Creating positive messages from the start; how can parents get the ball rolling?

The ability to love and feel loved, to keep safe and know how to protect to oneself physically and emotionally stems from our self-esteem; that is

“we are already giving a positive sexuality message by regarding our children as important people, by having high expectations, by nurturing and caring for them, and teaching them to look after their bodies” [9]

our understanding and knowledge about ourselves and our sense of worth. We build this knowledge from an early age and therefore our early experiences in the home will shape our development and the opportunities that may be open to

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us throughout our lives. This means that the issues relating to personal relationships and sexuality are not constrained only to childhood and the teenage years. In fact, parents are starting to build the foundations for their child's positive transition into adult life right from the start.^[8] Ryan underlines this by saying “we are already giving a positive sexuality message by regarding our children as important people, by having high expectations, by nurturing and caring for them, and teaching them to look after their bodies”.^[9] Melburg Schwier and Hingsburger echo these themes commenting that “to begin an education about sexuality, self-hood, value and worth” a child requires the following underpinning knowledge: “I am loved. I am welcome here. My body is mine”.^[2, p.26] Parents are likely to start to develop this knowledge in their children with and without Down syndrome from a very early age.



As infants with Down syndrome progress into childhood, parents are, in fact, likely to remain the primary source of information about sexuality for their children with Down syndrome, who may have fewer opportunities to observe, develop and practice social skills, and be less able to access information through written materials or through indirect means such as unstructured discussion with peers.^[8] However, it is important to note that formal education also plays an important role and therefore, parents need not feel

alone in tackling these issues. Some parents may fear that discussion of the body, sex and ‘where babies come from’ may encourage sexual experimentation however, research suggests that in typical development, young people who have been raised in families where sex and personal relationships have been discussed as part of everyday life, in an emotionally open and honest household, are more likely to delay the onset of sexual activity and are more likely to use contraception.^[10]

The next section discusses some of the specific topic areas drawn from Box 2 in the context of teaching children with Down syndrome. These areas are likely to make up part of the child's education within school but may also be supported through activities at home. Before looking at these topic areas, however, let us briefly examine the role of formal education in delivering sex and relationships education in the UK and describe some general teaching and learning principles, which are relevant to differentiating the curriculum for pupils with Down syndrome.

The role of schools in the delivery of sex and relationships education (SRE)

In the UK, schools are legally obliged under *The Learning and Skills Act (2000)* to provide sex and relationships education to *all* pupils. They are also obliged to have an SRE policy, which is available to parents and for inspection. This legislation is supported by the *Sex and Relationship Education Guidance (2000)* which explains that SRE should be ‘firmly rooted within the framework for PSHE (Personal Social and Health Education) and the National Curriculum (1999)’. The guidance document aims to clarify what schools are expected to deliver by law, help staff to develop an SRE policy in liaison with parents, pupils, teachers, governors and the wider community, describe good practice in terms of teaching practice and highlight some of the sensitive issues that may be raised through the delivery of SRE.^[7]

The Guidance also outlines *The National Healthy School Standard*, which was introduced in 1999 to

Box 3: Entitlements for all children and young people

Children and young people, regardless of disability, should be entitled to sex and relationships education which:

- Enables them to make responsible and well-informed decisions
- Helps them to develop the necessary skills and understanding to live confident, happy and healthy lives, with as greater degree of independence as possible
- Fosters acceptance of diversity and values marriage and stable, loving relationships as the building blocks of community and society
- Prevents and removes prejudice and fosters respect for self and others

Why is sex and relationships education particularly important for people of all ages with Down syndrome?

- They are less likely to learn effectively from indirect sources
- They may be at greater risk of developing low self esteem and SRE may be helpful in raising this
- Opportunities to learn from social situations may be more limited
- Risk of abuse and exploitation is greater for people with intellectual disabilities than their typically developing peers

support the new PSHE framework. The Standard suggests that the most effective SRE programmes identify “learning outcomes, appropriate to pupils’ age, ability, gender and level of maturity” based on assessment of pupils’ individual needs. The programme should also take account of the views of parents and caregivers and the pupils themselves.

These points are particularly salient to the provision of a differentiated programme of study for pupils with Down syndrome. The DfES guidance clearly states that “main-

stream schools and special schools have a duty to ensure that children with special educational needs and learning difficulties are properly included in sex and relationships education” and that “teachers may find that they have to be more explicit and plan their work in different ways in order to meet individual needs of children with special educational needs or learning difficulties”. Finally, it clearly states that pupils should not be “withdrawn from health education so that they can catch up on National Curriculum subjects”. [7:p.12]

Teachers and other professionals, including for example, youth workers, need to work collaboratively with parents in order to develop programmes of study that suit the individual pupils needs. As noted in the introduction, although most parents want schools to be involved in the provision of SRE, some parents of children with disabilities may be anxious about their child engaging in sex and relationships education for a variety of reasons. Professionals will need to work sensitively to help these parents to appreciate the importance of this area of the curriculum. Staff should use the school’s SRE policy to guide them in their communication with parents about the importance of inclusion in sex and relationships education as part of the wider curriculum.

Having discussed the possible anxieties of parents with regard to tackling sex and relationships issues with their children, we should return to the point made in the introduction, that some professionals may also be anxious or indeed fearful of addressing the issues with their pupils or clients, especially when they have learning disabilities. This implies that staff need adequate training and support in this area. By 2006, secondary schools will be required by the Teenage Pregnancy Strategy to have at least one member of staff who has received accredited training in PSHE. In the meantime, local curriculum development groups made up of representatives from a number of local primary and secondary schools can be helpful sources of good practice and resources for students with learning disabilities. Also, Local Education Authorities (LEAs) will have specialist PSHE advisory services who may

be able to help, whilst The Sex Education Forum which is part of the National Children’s Bureau provide a wealth of detailed fact sheets available to download at from www.ncb.org.uk/sef. They also supply a comprehensive list of resources that are appropriate for teaching SRE to children and young people with learning disabilities.

Effective teaching strategies

Box 4 summarises a number of recommended teaching strategies for delivery of effective sex and relationships education to typically developing pupils. It is interesting to note that many of the techniques listed are comparable with the generally recommended strategies for differentiating any subject for a learner with Down syndrome. This supports the idea that adapting teaching strategies to suit the needs of a pupil with Down syndrome in a mainstream class will in fact be beneficial for many of his or her fellow pupils.

There are several keys to differentiation for children with Down syndrome and these are as important for teaching about sex and relationships as any other topic area. Firstly, it is important to ensure that the child is motivated to learn about the particular topic by carefully choosing teaching strategies that the child enjoys and which have previously been successful. Making the information feel familiar and grounded in the child’s experiences will be important and help the child to use existing knowledge to understand more advanced concepts. Staff could choose characters from the child’s

Box 4: Effective teaching strategies [12]

- Drama and role play
- Discussion of case studies/real-life scenarios: possibly from TV or magazine photo-stories
- Story-telling, poems and songs
- Use of puppets and dolls (www.me-and-us.com supply anatomically correct dolls for SRE teaching)
- Pictures and story-boards
- Videos and photographs: including TV adverts, clips from soap operas
- Art activities including collage and poster making
- Games

favourite books or TV programmes and make up new stories raising various issues. For example, for a child who is using the *Oxford Reading Tree* books, one could cut out pictures of Mum and Biff and make up a story about when Biff starts her periods using language which is suited to the child's level of comprehension but introducing some new vocabulary and ideas. With any new information taught through reading activities, it is important however, to build in activities to ensure that the child understands what he or she has read, i.e. through acting out the information with puppets, dolls or in role-play or through re-ordering sentences or retelling the story.

Children with Down syndrome are typically 'visual learners'; that is they learn and retain more from visual sources of information than from listening. Picture libraries available online or on CD Roms make it possible to download and print all sorts of images, which may be helpful in supporting vocabulary work; see for example *Picture Yourself* at www.me-and-us.com and the *Sexual Awareness Resource Pack* from Signalong (see www.signalong.org.uk/pubs.htm). Please note the author has not seen either of these resources and therefore, this should not be taken as a recommendation of their quality.



specially qualified professional such as a school nurse. It is also likely that themes from the agreed sex and relationships curriculum can be integrated into a variety of different subject areas.

Every child will be different and will start with differing needs and prior knowledge. It is likely that staff will require additional planning time, including some time with the child's parents in order to develop a programme that will meet the child's needs. Effective liaison with parents will also mean that the parents can, if they wish, reinforce new concepts and skills at home through naturally occurring everyday situations. D'aegher et al (1999) use the term 'teachable moments' ^[12:p.16] to describe how helpful it can be to take the opportunity to discuss certain information as situations arise in everyday life, e.g. as children or other family members take a bath, whilst sorting various clothing for the laundry, unpacking items such as toiletries, condoms, sanitary towels or tampons from the shopping or whilst watching various storylines unfold in the family's favourite television soaps and dramas. Therefore it is important that parents are aware of what their child is learning about sex and relationships at school in order to discuss the issues further at home, as appropriate opportunities arise.

Shaping socially-acceptable behaviour

Having said that teaching should follow the same methods, as you would use for teaching any other

information, the general principles of behaviour management can be employed to shape appropriate public and private behaviour and appropriate use of touch for example. Children learn through observing and imitating others and through making associations between behaviours and their consequences. This means that for children to learn socially acceptable behaviour they need to see other people acting in a socially acceptable way and they need to be rewarded for their 'good' behaviour and ignored for their less acceptable behaviour. This implies that it is the other people in the child's social world who need to carefully monitor their own behaviour and responses in order to help the child to behave appropriately.

If, for example, you are teaching your child about appropriate physical contact with other people, it is important that the child is taught how to greet people in a socially acceptable way, e.g. shake their hand or just say 'hello'. They will need to see this modeled to them on a regular basis. Many parents comment on their frustrations as people continue to cuddle their older children and teenagers with Down syndrome, long after it would be socially acceptable to cuddle other people's typically developing children. This type of behaviour does not help the child to learn that it is inappropriate to greet people in this way. With older children, overt teaching about different types of relationships such as family, friendship, school/work, sexual partner (boyfriend/girlfriend and strangers/new people will be helpful for many reasons and part of this work might involve discussion of how you would greet such people and what sort of touch is appropriate. One way of doing this might be to look at body outlines for men and women and select underwear or swimwear from a catalogue to cover up different areas. This will help children to see which parts of the body are always private unless you are in a sexual relationship.

A common behaviour, which can cause distress and anxiety for parents and teachers, is genital touching and masturbation. Firstly, it should be noted that genital touching is a normal phase of development for young children and is not associated with the goal-directed behaviour of



Depending on the individual child, inclusion within the mainstream teaching of the subject, using one-to-one support, group-work, differentiated activities and resources will be enough, however, some children may benefit from extra one-to-one sessions, possibly from a

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masturbation, where a person intentionally seeks sexual gratification. Masturbation should also be viewed as a natural behaviour for both males and females and therefore one should address the context in which masturbation occurs, i.e. in public versus in private. Before discussing methods which might be helpful in preventing or responding to inappropriate genital touching and/or masturbation, it is important to note that most teenagers with Down syndrome learn to carry out this behaviour, only in private.^[13]

In order to stop a child from touching him or herself in public, one should not draw attention to the act by telling the child off, otherwise the behaviour may be repeated as the child has rewarded for his or her actions through attention and verbal interaction. It may be enough to simply make sure that the child has something else to do, e.g. distract them redirect their attention to something else. However, the child or young person may also need some overt training about public and private behaviour. They need to learn that touching themselves is a private behaviour. Family and cultural norms will prevail with regard to where this behaviour is or is not appropriate, i.e. only in the bedroom and/or bathroom with the door shut. Once it is felt that the child understands the words public and private, these words could be used as a prompt to remind the child, should they start to touch themselves in public, e.g. one should calmly and systematically say something along the lines of "hands away please, remember that's private". Social interaction including eye contact should then be withdrawn for a minute or so and then the child should be welcomed back into the interaction without referring to the behaviour, e.g. "where were we, ah, I remember...". Whatever the strategy employed, it is essential that everyone caring for and working with the child or young person uses it with consistency.

Social stories

Teaching methods such as the use of social stories may be helpful for training in many areas. This technique involves regular reading of personal books with illustrations or photographs to teach children about

all sorts of social situations and the associated socially acceptable behaviours. Social stories may provide a useful way of teaching children and young people with Down syndrome about a variety of aspects included in sex and relationships education, e.g. friendship, bullying, acceptable public behaviour and touch, personal hygiene, periods or who to talk to if you are sad or scared. In terms of using the books to change behaviour, the story should introduce the behaviour and then outline the social outcomes for the child if they show socially acceptable behaviour. Please see www.thegray-center.org/Social_Stories.htm for more information about the design and use social stories. It may also be useful to support the bookwork with activities such as encouraging the child to act out the story with dolls or puppets or for older children to make a photo-story using pictures of characters from soap operas cut from magazines. Older children may enjoy role-playing situations that have been introduced in this way.

Social learning

It is important to note that children with Down syndrome are particularly perceptive to non-verbal social cues and emotional tone. Therefore, the way in which certain situations and questions are responded to is very important in shaping the child's attitudes. For example, talking openly about body parts and using accurate language that is suited to the child's level of comprehension will help the child to understand more about their own body and therefore prepare them better to understand body changes at puberty. Parents should aim to foster an atmosphere in the family of openness, acceptance and respect whereby children's questions will be valued and answered. Also, modeling appropriate public and private behaviour will be helpful. Children with Down syndrome are excellent social learners, that is, they learn well from observation and imitation. This means concepts such as privacy can be taught through modeling, e.g. wearing dressing gowns, getting changed with the door closed, pulling the shower curtain across, etc. In some households, mothers and/or older sisters may feel comfortable to model the necessary sequence of



behaviours involved with changing a sanitary towel or tampon.

Learning the language

Children with Down syndrome experience the most significant delays in the area of speech and language, with speech production commonly lagging behind language comprehension. They are likely to need focused teaching work to help them develop a vocabulary for thinking about emotions and their bodies. Just as you would teach the names of other parts of the body, it is important to teach the 'correct' terms for male and female genitals. This is important for several reasons. Openly talking about and naming these body parts will help children develop further awareness and a sense of ownership, pride and respect for their bodies and those of other people. Having a label for each part of the body, including the genitals, shows the child that they are permitted to discuss them when necessary and gives them a language with which to do so and with which they will be understood.^[11] Also, an accurate language for describing the body is important with regard to child protection issues^[14] and personal health and hygiene. The age at which it is appropriate to introduce this vocabulary will depend on the individual's progress in developing his or her receptive vocabulary. For example teaching the words 'vulva' or 'penis' will not be appropriate for example, if the child cannot yet identify his or her shoulder or knee. These new words can be taught

as you would teach any other new vocabulary, i.e. through matching, selecting and naming activities with pictures (outline drawings) and printed words. You could try putting printed word cards with the names of a wide variety of body parts into a bag and asking the child to pick one at a time and stick them onto cut-out pictures of men and women, to show that he or she understands which body parts are the same for men and women and which parts are different.

For children who have made good use of signs to support their vocabulary development, it is possible to acquire PSHE curriculum-specific signs from organisations such as *The Makaton Vocabulary Development Project* (see www.makaton.org) and *Signalong* (www.signalong.org.uk/pubs.htm)

Growing up

Teenage boys and girls with Down syndrome experience the physical and emotional changes of puberty at approximately the same age as their typically developing peers.^[2] Melburg Schwier and Hingsburger describe how these changes may be particularly difficult if the young person has not been prepared for them in

Advance preparation generally helps to take some of the stress out of most things and adolescence is no exception!

advance, if their parents feel awkward discussing various issues with them and if their advances towards others are rejected.^[2] The limited research in this area with teenagers with Down syndrome suggests that most teenagers do not experience significant difficulties at this time and for many the transition from childhood to adulthood will be smooth, with families describing a range of positive and socially-desirable personality traits. However, for some families this can be a difficult time, leading to changes in the individual's behaviour and the possibility of more severe adjustment difficulties, which can be stressful to the family.^[13]

"[She's] a great friend, I've been working with her for a very long time and she is a great friend. She looks lovely and gorgeous tonight in her dress. I am very proud to be her partner as well as her friend" – a man with Down syndrome talking about his partner, as they attended a 'prom' night together.^[5]

Advance preparation generally helps to take some of the stress out of most things and adolescence is no exception! However, the concept of time and, in particular, the future may be particularly difficult for some youngsters with Down syndrome and therefore careful thought and preparation for education in this area may be necessary. It may be helpful to focus on the present and discuss the issues in the context of stories and scenarios involving characters who are experiencing changes 'at the moment' rather than saying this will happen to you 'some time in the future'. The discussion could then move on to look at the similarities between the character and the child or young person with Down syndrome to help him or her to make the connection between the characters and him or herself. Also, photographic timelines showing how the child has changed since they were an infant may be helpful to give an idea of what has past. This timeline could be compared to a timeline for a familiar person of the same sex who is older than the child to show them how their life may continue for them in the future.

Independence

One of the major factors determining our happiness is our ability to feel in control, that we are responsible for things that happen in our lives. This can be difficult for people with disabilities who may be more dependent upon others and be familiar with choices being made for them. Fostering a sense of self-worth and independence is therefore of critical importance to the future quality of life of people with Down syndrome



"When Patsy and I go out on a date, we talk. We walk around the park most often. We ate together. We once were little kids. Little buddies together. Then we grow up and she makes me so proud. Her for me and she is happy. Patsy is a good personality. If someone tell me I can't have her, can't have a girlfriend, would explain most often love I feel for her, comes back to me from her."
- A man with Down syndrome talking about his partner Patsy, who also has Down syndrome.^[1]

and this is particularly important during adolescence when young people may be developing an awareness of their limitations in comparison with their typically developing peers and siblings. Discussion of personal hygiene and appearance, buying clothes, toiletries and cosmetics can be a good starting point for making choices, looking and feeling good. Small decisions such as which deodorant to buy from a choice of two, will pave the way for making more important decisions and may be equally important in enhancing self-esteem.

With regard to independence and self-help skills, most girls with Down syndrome to take care of their personal hygiene needs during their periods,^[13] although some may need more support than others, e.g. reminders about when to change pads or tampons.

Close relationships

Building on the foundation of an understanding of feelings, positive self-esteem, valuing and caring for our bodies, understanding concepts such as privacy and appropriate touch, it is now time to consider that young people with Down syndrome also need direct teaching about sexual relationships including information about how people can give and gain sexual pleasure, the reasons why people might choose to have sex, the possible consequences of unprotected sex including unwanted pregnancy and sexually transmitted infections such as HIV and the options regarding contraception. Parents and teachers may feel that some of these concepts are 'beyond' some young people with Down syndrome, who they may consider to be

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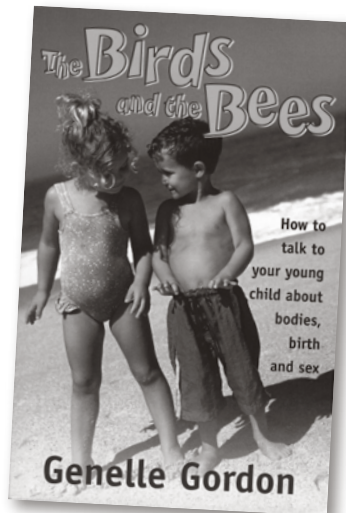
more delayed for example. However, it is crucial to be open-minded and find creative solutions to these concerns for two very important reasons. Firstly, young people with Down syndrome are likely to be more advanced in their social and personal skills than they may be in their speech, language, and cognitive skills. Also, their physical development is likely to be age-appropriate implying that they may have sexual desires and wish to have a physical relationship with their chosen partner. Secondly and sadly, as mentioned previously, the risk of sexual abuse is higher for people with intellectual disabilities and therefore it is crucial that they are able to understand the variety of ways in which people may try to gain sexual arousal and what they may or may not be consenting to.

Useful resources for parents and professionals

Any interested or concerned parent or professional would be hard-pushed to find a more useful starting point than *Sexuality: your sons and daughters with intellectual disabilities*.^[2] The authors employ an excellent, accessible style that blends up-to-date, authoritative information and straight-talking advice with first-person accounts and questions from parents and individuals with disabilities. It confronts the reader and compels them to reflect upon his or her attitudes and values towards sexuality, parenting and disability. Marian Burke, mum of television actor Chris Burke who has Down syndrome, was certainly right when she described this book as "a MUST"^[2:p.ix] as one could easily read it from cover-to-cover.

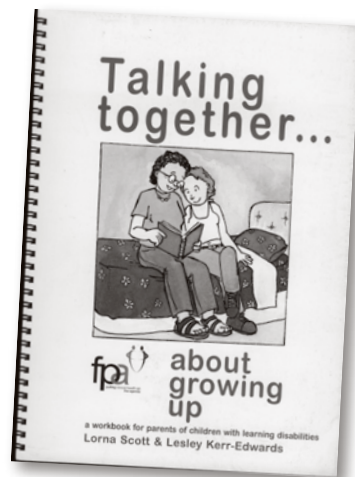
Terri Couwenhoven provides a down-to-earth review of some of the main topic areas that should be addressed in the early years and childhood including teaching about the body, hygiene, public and private behaviour, gender differences, touching (self and others) and socially acceptability in a special issue of *Disability Solutions*.^[8] She writes from the perspective of both a parent and a sexuality educator and as such, her article makes entertaining and informative reading.

Parents may be interested by *The Birds and the Bees* by Genelle



Gordon as this short book provides a very readable guide to how to talk to young children about bodies, birth and sex.^[15] It offers some invaluable guidance for answering children's awkward questions and dissipating anxiety surrounding embarrassing moments in a humorous and down-to-earth manner.

The Family Planning Association have published an excellent workbook for parents of children with learning disabilities called *Talking together...about growing up*.^[16] The book provides a comprehensive set



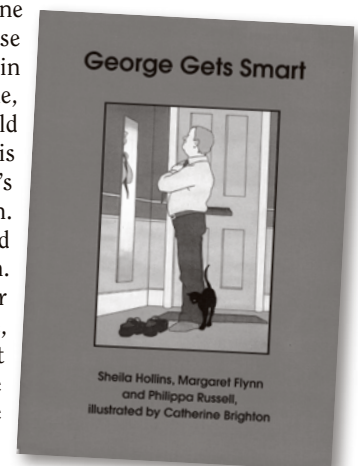
of activities and resources covering topics such as the life cycle, body parts, public and private, keeping safe, feelings and growing up. It also provides guidance for working in partnership with the child's school and creating a flexible curriculum that is appropriate to the child's individual needs. There is also an accompanying book called *Talking together...about sex and relationships*, which provides a resource

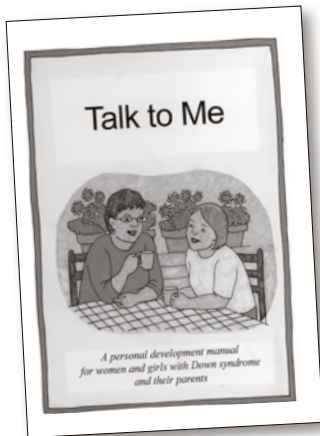
for schools and parents working with teenagers with learning disabilities.^[17] This book covers the topics of preparation for adulthood, keeping safe, relationships, sex, making choices and sexual health. Although these books have been specifically designed for students with learning disabilities, the activities may still require further differentiation for some pupils. However, they would provide an excellent starting point.

Books beyond words published by The Royal College of Psychiatrists provides a comprehensive series of books made up entirely of pictures to teach people with learning disabilities about topics such as periods, hugging and touching, sexual health, personal hygiene and sexual abuse. These books may be useful in providing a storyline, which can then be told using language that is appropriate to the child's level of comprehension. The pictures may be used to inspire discussion. The parent or teacher could then write simple, grammatically correct sentences to support the pictures, based on the individual's naturally occurring language.

The books have been specifically designed for people who find pictures easier to understand than words, however, it should be remembered that many people with Down syndrome learn well from reading and therefore appropriate reading activities may be a useful way to teach new vocabulary and concepts. The books provide ready-made stories at the end, a summary of the issues raised by the story for the parent or professional supporting the work and a list of useful references and resources. It should be noted that these books are about adults and young people and as such, children may not be able to identify as easily with the characters. For further details, please see www.rcpsych.ac.uk/publications/bbw.

Talk to me: A personal development manual for women and girls





with Down syndrome and their parents^[11] is an excellent resource published by the Down Syndrome Association of NSW Inc. Exactly as it says it provides a manual (in the form of a ring bound folder) that will assist parents in talking to their daughters with Down syndrome. It contains a section for parents, that is reassuring without being patronising and a section of

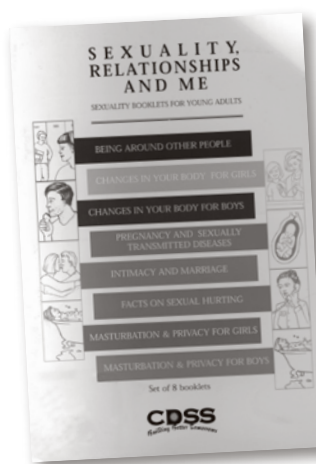
activities and information on feelings, self-esteem, friends and sexuality for parents and daughters to share. Although the manual has been designed for use with girls and women with Down syndrome, the section for parents contains much information that would still be relevant to those with sons and would many of the activities. For details, see <http://www.dsansw.org.au/publications/TalkToMe.html> where, with certain provisos, you can download the resource for free. The site also gives information about other resources.

You, your body and sex: the DVD has been produced by Life Support Productions and uses animated characters, Kylie and Jason and some of their friends, to guide the viewer with a learning disability through topics including personal hygiene, keeping well (e.g. who to tell should you notice anything unusual), growing up and puberty, periods, pre-menstrual tension, masturbation, loneliness, meeting some-one new, appropriate touch, love and sex (mentioning that this can be with some of a different sex or the same sex), consenting to sex and how to say 'no', how to respond to unwanted attention and obtaining and using condoms.

Other forms of contraception are not discussed. Each topic is addressed twice, from a female and male perspective. The language used is simple and repetitive, whilst the graphics are modern and with enough detail to be interesting but not distracting. The DVD is targeted more towards teenagers and young

adults and each topic would probably need to be discussed with a carer or parent. Some of the vocabulary used may be new and would need to additional work to teach and consolidate meaning. This impressive resource has been carefully and considerably produced and may provide a useful tool to facilitate further work or bring together aspects that have been introduced in other ways. For details see www.lifesupportproductions.co.uk.

As mentioned in our last issue of *Down Syndrome News and Update*, delegates at the World Congress in Singapore were introduced to a new resource published by The Down Syndrome Society of South Australia. *Right to know* is a teaching programme consisting of three modules on friendship, sexuality and personal safety. The modules cover all of the topic areas mentioned in this article and more. At present we do not have a copy of the materials in order to provide a comprehensive review; however Dr. Jo Nye and Professor Buckley who attended the Singapore conference agree that these materials may provide an extremely comprehensive addition to the existing materials available to support SRE for children, adolescents and adults with Down syndrome. We hope to review this programme in a future issue of *Down Syndrome News and Update*. For further information, see <http://downssa.asn.au/indexf.html> The Canadian Down Syndrome Society have also published a series of booklets on a variety of aspects of sexuality entitled "Sexuality, Relationships and Me" which can be ordered from www.cdss.ca/SRAcat.html along with a selection of other resources.



It is also possible to purchase differentiated personal, social and health education programmes including sex and relationships education from awarding bodies such as *Equals* and *Asdan*. Again, we have not had the opportunity to review these packages but they may provide a useful starting point for working with children and young people with Down syndrome. Further information on these resources can be found at www.equals.co.uk/home/index.asp and www.asdan.co.uk.

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SRE resources

Picture yourself (www.me-and-us.com)

The Sexual Awareness Resource Pack (www.signalong.org.uk/pubs.htm)

Social Stories (www.thegraycenter.org/Social_Stories.htm)

The Makaton Vocabulary Development Project (www.makaton.org)

Books beyond words (www.rcpsych.ac.uk/publications/bbw)

Talk to me: A personal development manual for women and girls with Down syndrome and their mothers (www.dsansw.org.au/publications/TalkToMe.html)

You, Your Body and Sex: The DVD (www.lifesupportproductions.co.uk)

Right to know (<http://downssa.asn.au/indexf.html>)

Sexuality, Relationships and Me (www.cdss.ca/SRAcat.html)

Equals, a registered charity committed to supporting the work of teachers of pupils with profound, multiple and severe learning difficulties. (www.equals.co.uk/home/index.asp)

Asdan (Award Scheme Development and Accreditation Network) www.asdan.co.uk

First books in DSii Adult Living series now available

We are pleased to announce that the first books in the *DSii Adult Living* series are now available for purchase. These books are:

- *Life for adults with Down syndrome - An overview* [DSii-01-07]
- *Information Communication Technology for adults with Down syndrome* [DSii-16-11]
- *Advocacy for adults with Down syndrome* [DSii-22-10]
- *Spiritual well-being for adults with Down syndrome* [DSii-22-20]

Each of these books costs £5.90 plus postage and packing.

The other books in the series are currently under preparation, and we expect to publish them during the next 12-18 months. They will cover the following topics: transitions to employment • drama and performing arts • reading, writing and numeracy • further and tertiary education • independent living • relationships • family issues • leisure and recreation • women's issues • mental health and emotional well-being • the law in relation to adults with Down syndrome • international and cultural aspects of Down syndrome. Check our Web site at <http://www.downsed.org/dsii-adult/> for updates.

About the DSii Adult Living series

Building on the success of the Education and Development series for children aged 0-16 years, the *DSii Adult Living* series covers the wide range of issues affecting the quality of life for adults with Down syndrome. The *DSii Adult Living* books are designed for families and professionals, specialists and non-specialists. Each book includes reviews of relevant research, backed up by case studies and practical examples. References for original research, supporting materials and further resources are also provided.

The books in the *DSii Adult Living* series are written by expert researchers and practitioners from around the world. Their advice and information is based on the latest knowledge and years of practical experience of supporting adults with Down syndrome and other intellectual disabilities. The series is being edited by Professor Roy Brown – who is a leading expert in this area, and is Emeritus Professor at the University of Calgary, Canada and Flinders University in Australia, and is consultant and Research Director to the Down Syndrome Research Foundation in Canada.

The development of the *DSii Adult Living* series has been supported by the Freemasons' Grand Charity, the Rufford Maurice Laing Foundation, the Marchday Charitable Trust, and Down Syndrome International.

