

Growing up, sex and relationships:
a booklet to support parents of
young disabled people



contact a family
for families with disabled children

The PROUD Consortium

PROUD is the name of a group of individuals and organisations brought together by Sharon Baker of The Arthrogyposis Group. Sharon Baker developed the initial idea for the resource and is the lead author. Working with Contact a Family, the consortium came together to raise awareness of the many issues of growing up with a disability. Members of PROUD include disabled adults, parents of disabled children and young people, professionals from Worcestershire's Health and Education Authorities working with young people with disabilities and representatives from the Association for Spina Bifida and Hydrocephalus and Disability Awareness In Schools. PROUD has consulted widely with disabled adults and parents and carers of young disabled people and children and thanks them for their help in developing this pack. The quotes in this booklet are taken from a survey conducted by The Arthrogyposis Group on growing up with a disability and caring for a disabled child.

The Arthrogyposis Group

The Arthrogyposis Group (TAG) is a national organisation that supports people who are affected by the physical disability Arthrogyposis Multiplex Congenita. This is a term used to describe stiff and fixed joints and covers a wide range of conditions.

Contact a Family

Contact a Family provides support, advice and information to families with a disabled child across the UK. It is the only UK charity providing support to parents whatever the medical condition of their child.

Council for Disabled Children

The Council for Disabled Children provides a national forum for the discussion, development and dissemination of a wide range of policy and practice issues relating to service provision and support for children and young people with disabilities and special educational needs.

Also contributing to this booklet are:

National Children's Bureau

The National Children's Bureau (NCB) promotes the interests and wellbeing of all children and young people across every aspect of their lives. NCB advocates the participation of children and young people in all matters affecting their lives. NCB challenges disadvantage in childhood.

Sex Education Forum

The Sex Education Forum is the national authority on sex and relationships. It is an umbrella body of 48 national organisations that work together to share good practice and to articulate a common voice in support of all children and young people.



introduction

Parents are key people in teaching their children about sex and relationships, helping them cope with the emotional and physical aspects of growing up and preparing them for the challenges and responsibilities that sexual maturity brings. Parents of *all* young people face a range of issues around sex and relationships. Disabled young people are sexual beings like everyone else and have the same rights and needs for good sex education and sexual health care, and the same opportunities for socialising and sexual expression as their non-disabled peers. Parents of disabled children and young people have a special role in providing support and guidance to enable their children to embrace the challenges of adolescence and grow into informed and confident adults.

About this booklet?

This booklet has been written for parents and families whose children have physical disabilities, including those who may also have mild to moderate learning disabilities. There are thousands of different causes of disability and the range of difficulties a child may have will depend very much on the diagnosis, how their condition is managed and what support and help is available. The booklet looks at how *being disabled* might impact on issues around sex and relationships and offers guidance on what parents can do to support their child as they grow into young adults and start to form intimate relationships.

The booklet is divided into five main sections:

Section 1 looks at how disability may affect different aspects of sexual development, identifies what factors may prevent disabled young people from achieving sexual and emotional fulfilment and gives pointers on what parents can do to help

Section 2 focuses on the importance of self-esteem and personal relationships and gives suggestions about what parents can do to help their child develop confidence and close friendships

Section 3 gives information on why it is important to talk to children and

young people about sex and relationships and covers specific issues such as puberty, contraception and sexually transmitted infections.

Section 4 describes how sex and relationship education is organised at school and looks at how parents and schools can work together to support disabled children and young people.

Section 5 lists useful organisations and resources available for parents, young people and professional workers.

Part of a series

This booklet is part of a series of publications on sex and relationship education for children and young people with physical disabilities and mild to moderate learning disabilities. The series has been produced by a group of organisations with expertise and experience in the field of disability and Sex and Relationship Education (listed at front).

In addition to this booklet for parents, the series also includes:

- A leaflet for young people which answers some of the questions they may have about growing up, sex and relationships
- A booklet for schools to help teachers, carers and other

professionals to provide quality Sex and Relationship Education (SRE) working in partnership with children, young people and their parents

Each booklet can be used independently, or in conjunction with the others in the series. Further copies can be ordered from Contact a Family.

Notes

Throughout this booklet we use terms such as 'talk to' and 'discuss'. We recognise that not all children are able to communicate verbally, and you will know best how to explain some of these ideas to your child. This might mean using pictures rather than words and there are some useful resources in the Directory section of this pack, which can help you. This series includes an information leaflet for young people which is written for a physically disabled young person in or approaching their teenage years. Parents may wish to read some of the information with a younger child or a child with learning disabilities. Alternatively, you may want to obtain some of the resources listed in the Directory which explain the process of puberty and growing up in simple words and pictures.

Attitudes to issues such as contraception, masturbation, homosexuality and sex outside of

marriage vary widely. The needs of the young person will be different for many reasons including culture and values, religious beliefs, age, and the nature of their disability.

Further help

The Directory Section lists useful organisations and publications if you would like to find out more about specific topics. Support groups for particular conditions may have information about growing up with a particular disability. Contact a Family can tell you if there is a support group for your child's disability and has access to telephone interpreters if you would prefer to discuss your situation in a language other than English.



section one: sexual awareness and development

Sexual awareness is the result of all the physical, emotional, intellectual and social factors that have influenced our development throughout our lives. The use of the word *sexuality* in this booklet refers to awareness as a sexual being, and not just to sexual orientation. Defining sexuality as wider than just physical function is particularly important for the young disabled person. A person who is not able to use part of his or her body still has an equal right to full sexual expression. Similarly, the disabled young person should have the same access to sex education, sexual health care, and opportunities for socialising and sexual expression as other young people.

Disability often affects many different aspects of sexual development. For example, a lack of privacy and independence in daily living can mean a young disabled person often misses out on early sexual experiences such as kissing and flirting. Many other things stop disabled people achieving sexual and emotional fulfilment, including cultural prejudices, professional and parental attitudes, lack of social opportunities and a lack of appropriate services.

Some families and professionals working with young people may avoid discussing issues of sexuality. Fear of exploitation and pregnancy or the reluctance to see their child as a sexual being makes some parents unwilling or unable to tackle the many issues surrounding sex and relationships. Others may want

'At special school it was terrible. The assumption was that we wouldn't have and didn't deserve sexual relationships'

their child to have sex education, but are unsure how to go about it. Parents who are not disabled themselves may not have personal experience on which to base their advice to a disabled child and may not know the answers to their questions.

All parents –including those with non-disabled children- find talking about sex and relationships difficult, often worrying they may not know enough or have the confidence to talk and listen without embarrassment.

Gender identity

Stereotypes of disability are often asexual. Children may be described only in terms of their disability, rather than as a young man or woman.

'I think that those of us with a visible impairment are seen as sexless and without gender, unless we work to contradict this..'

Young women

Young girls are increasingly encouraged to dress and behave like adults at an early age. This can be a way of exploring sexual attractiveness.

However, some disabled young women may be encouraged to continue dressing and acting like children, with little say over their lives and choices.

Young men

There tends to be an assumption in



society that disability and masculinity are conflicting identities, because of the contradiction of the two stereotypes:

- Masculinity = power, physical strength
- Disability = vulnerability, frailty

The popular media often reinforces such an attitude and the theme of many films, television programmes and books is one of 'coming to terms with' a loss of masculinity through impairment or injury. Also, most workers in special education and other services for disabled children are women. It's not surprising that for many children, there may be a lack of male role models for boys to emulate.

Feelings of isolation

'At sixteen all my friends had boyfriends and I hadn't and I wondered then if my disability was the reason. I didn't know anyone else with a disability so I couldn't swap notes and whilst my friends listened they didn't know how I felt..'

Whilst most people can expect to find role models and support from within their community or within the family, a disabled child is more likely to experience isolation when he/she is the only member with a disability.

In some cases parents may actively encourage disabled children not to identify with other disabled children. Yet it can be helpful for disabled children to be able to discuss experiences and share difficulties with others who understand because they have been through similar experiences.

Coming to terms with being disabled

'I definitely went through this stage, perhaps in my teens. I never saw myself as being disabled, I would find it hard to look at photos of myself or see my reflection walking, for example in a shop window. I still find it hard sometimes...'

For some disabled people accepting their disability can be a difficult journey. Getting support from other disabled teenagers can be vital. It is important that teenagers get support from others who understand the issues through social activities e.g. through penfriends, safe internet chat rooms with other young people and so on. Parents may also have a difficult journey to make, towards accepting their son or daughter as a young adult who may have developed

'Being an identical twin it was hard for me to understand I was not the same as my sister...'

their own, and different, values and opinions.

Body image

Images and attitudes around disability are among the main problems faced by disabled people attempting to assert themselves as independent adults and positive sexual beings. There are many negative images which focus on dependence, guilt, pity and fear. These images can impact upon the self-esteem of the disabled child and young adult.

In the age of "the body perfect" the media, fashion industry and popular culture generally reinforce stereotypes and promote superficial and skin deep ideas about what is attractive. This in turn can reinforce the view that disabled people are inadequate and unlovable. Expressions such as "survival of the fittest" and "body beautiful" are in everyday use. The concept of "physical correctness" is introduced at a very young age, as most toys do not represent an image of anything other than physical perfection demonstrated in quite fantastical proportions on Action Man or Barbie Doll.

'Top school was harder because we had to go swimming. I would get myself as close to the pool as possible, a towel would be covering my skinny legs, and then I'd jump in...'

Rather than feel their body to be an object of sensuality, some disabled people see their body as an obstacle that impacts negatively on their quality of life, or some even as a source of pain.

Privacy

For disabled children who have been taught to be "good for the doctor" and to comply during medical appointments whilst a stranger examines his or her body, the notion of private areas of the body may be a concept difficult to understand.

'When you're disabled you don't have privacy...'

Equally, for any child or young adult who relies upon someone else for intimate care, the concept of private and public areas of the body can be unclear. Not only does this leave them vulnerable to abuse but also to "socially inappropriate" behaviour or language.

'As a child my body was 'owned' by doctors. I was treated without respect. My body was treated as a problem...'

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'My daughter went from being very independent to being cared for very closely by us, as the result of a brain injury. It was very hard as she retained a memory that she was too old for her parents to be helping her bathe and dress. As she recovered we had to relearn to let her go and it was even harder the second time around '

For a disabled child or young adult, a lack of privacy can also mean a lack of opportunity to explore his or her own body.

Issues around privacy may also come up if your child is born without a disability but becomes disabled whilst growing up – for example if they are injured in a road accident.

Making friends at school

'School was very hard...not being accepted in groups because I was different...'

Schooling can sometimes create additional obstacles to forming friendships

- Attending a school some distance from home can make it difficult to forge friendships within the local neighbourhood
- Making the transition from Primary to Secondary often means severing friendships

- Where friendships do develop they are sometimes dominated by the assumption that the disabled child needs helping and may not be based upon mutual respect
- A child with a full-time learning assistant may enjoy little opportunity to mix with peers
- Facilities and venues for leisure activities and parties may not be accessible to some disabled children and this can make friendships difficult to maintain

Throughout this booklet we look in more detail at many of these issues and how as a parent or carer, you can help your child to move positively towards adulthood and the ability to form loving relationships. There is much good practice and experience and in the next section some of the young people we talked to express appreciation and reflect well on the support offered by families and schools.

'The Teacher's aides at school caused me a lot of problems as they would choose who they wanted me to be around and if I had friends they did not approve of they would send them away. Also I had a lack of privacy with girls to form relationships...'



Body image

'I have never been teased or bullied because of my disability. I have always had a positive attitude towards my body image. I have had to choose clothes to suit my body shape and that are easy to put on/take off but I think that applies to everyone to some extent'.

'I class myself as a physically abled person with limitations, not disabled'.

Role models

'My parents as they were both helpful and positive'.

'My role models are the late Christopher Reeves and Stephen Hawkins. Both refused to lay back and pack in, and have shown the world that disabled people can be just as good if not better than the mainstream world'.

'I think one person who sticks in my mind a lot is Tanni Grey-Thompson. The reason for this is because she has done so well for herself. Winning marathons, Olympics and really shows us disabled people it can be done. You have a disability but it should not stop you from at least trying to do things on your own'.

Coming to accept being disabled
'I didn't know anyone else

with a disability so I couldn't swap notes and whilst my friends listened they didn't know how I felt. However, at 17/18 this was no longer an issue'.

'I was quite happy to accept me for disabilities and myself. It was others who had problems'.

'I don't think this applies to me. I have always been comfortable with my body image'.

'I am me and I am what I am, if people don't accept that is their hard luck'.

'I believe that being honest and open about my disability is the best way, because it removes shyness and allows, in my case, ladies to see me as I am. I am not afraid or nervous about being disabled, but if the other gender is, then it is their loss not mine'.

Friendships

'I had a strong group of friends and I'm mobile enough to get about most places. My friends always made an effort to keep up and are well practiced at helping me dress/taking me to the loo!'

'I was lucky to have good friends at school who didn't treat me any differently but as my social life increased and I learnt to drive, I soon found access to some venues a

problem, but had lots of mates who wanted lifts'.

'Because I am a tutor and also nearly always an electric wheelchair user now, I have a lot of friends who assist me when I am away from class, but accept and respect me when I am teaching'.

Private/public areas of the body

'Needing help with the loo, undressing, fastening buttons is part of my life and I don't need help with more personal care so I can just get on with it'.

'I have not been treated any differently by doctors/nurses than any 'normal' person would have been. Privacy kept where appropriate'.

Do you feel that certain ages were more difficult than others?

'The older I get the better it gets'.

These more positive comments, although inspirational, also emphasise the importance of parents and carers taking responsibility in ensuring disabled young people's entitlement to good support and quality SRE.

section two: self esteem and personal relationships

Growing up is not just about having sexual partners, but is also about growing into a confident adult with a range of close friendships. It is about developing self-esteem, a good body image and the confidence to be happy with who you are. It is also about developing a sense of responsibility for your own actions. These are important issues for all teenagers.

How can I help my child develop self-esteem and good relationships?

All children and families are different and what works for some may not work for others. What feels right for you and your child is very important. The following suggestions from parents and disabled young people may help.

Self-esteem

- Reinforce with your child the fact that everyone is different
- Encourage your child to take interest in their appearance, eg wear fashionable clothes, use make up etc if they want to. Make up can be used to camouflage scars and fashionable clothes can be adapted to suit a disabled person's needs.
- Encourage your child to keep clean, use deodorant, wash their hair regularly and so on.
- Be generous with compliments
- Remind them of the things they are good at
- There are more and more positive role models in the media – point them out to your child without making too much of an issue
- Encourage them to be assertive
- If your child is self conscious about certain aspects of their appearance, don't dismiss it, support them by helping them to dress in a way that will divert attention

'I used to wear skirts and shorts to school and around town. I supposed what changed that was the constant bullying from school kids...'

- If your child is happy with an aspect of their appearance directly affected by their disability, be proud of their confidence. For example if they wear a wig, but do not feel the need to wear it all the time be proud of that. If they wear callipers do not assume they want them covered up with trousers or long skirts. That might give them the message that the way they look is not acceptable.

'Before the age of about 10 years old my mother used to dress me in long dresses because she thought it best to cover up my callipers. Only as I got older and expressed myself did I manage to try and dress a bit more trendy.'



- Be aware that disabled people often feel that they are seen as disabled first and as a male or female afterwards.
- Help your child to develop diversion tactics for any questions about their disability that they do not choose to answer e.g. by changing the subject
- Respect their opinions.
- Encourage them to learn about and manage their condition, as they get older.
- Encourage them to make their own decisions about all aspects of their life as far as possible. This will help them to become more assertive, independent and to feel that they have some control over the way they look and their life in general.
- Try not to talk about your child and/or their disability as if they were not present. This often happens in medical appointments.

Friendships

'My friends don't see I have limitations which is good but causes problems when I can't do certain activities like ice skating, 18 – 30 holidays, catching an underground with a wheelchair etc.'

- If your child goes to a mainstream school where there are few or no other disabled children, find opportunities where he/she will have the chance of having contact with other disabled children. This

might be directly through clubs or through having penfriends or via email

- If your child goes to a special school find opportunities for mixing with non-disabled peers
- Try not to be over protective
- Encourage your child to invite their friends home
- If it is not possible for your child to go out much, encourage them to keep in telephone or email contact with friends
- Enquire about local clubs that your child could go to, whether specifically for disabled people or inclusive

Bullying

Bullying takes many forms that may include verbal abuse, physical attacks, and racial and homophobic harassment. All bullying is unacceptable.

Bullying can be teasing or name calling as well as physical assault. It is not always obvious when a child is being teased as he or she might not tell parents or teachers but there may be a change in their behaviour. Teasing and name-calling can have

a serious impact on a child's self-esteem and self worth and action needs to be taken to deal with and to prevent it.

- Talk about name calling and teasing with your child by creating opportunities e.g. regularly ask how things are going at school, who they like playing with or who they try to avoid.
- Give them lots of praise for coping if they deal with a difficult situation.
- Teach your child some simple sentences about their disability. Encourage them to practice until they can explain about their disability confidently.
- Check that they are happy with the explanation that you give to other people about their disability.
- Some families find role-play useful. Work with your child through difficult situations they have encountered or they fear happening. Decide upon appropriate comments and reactions. The more the child is involved in deciding on the best responses the more likely they are to use them.
- Remember that as your child gets older the explanations and



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responses will need to change.

If your child is being bullied at school

- Speak with the school and explain just what effect bullying has on your child. They may not be aware that it is happening or they may not understand just what an impact it has on your child's self-esteem.
- Try to arrange to have an appointment rather than a quick word in the playground.
- Be specific about what is being said and the effect it is having on your child.
- A teacher might see persistent questioning of your child about their disability as innocent. If it upsets your child it is not acceptable and it needs to be stopped.

All schools should have a policy on bullying to which you should have access as a parent. Schools should look at four key points

- They should not ignore suspected bullying
- They should listen carefully to all accounts
- They should adopt a problem solving approach

- They should follow up to make sure that bullying has not resumed.

There are a range of effective approaches for dealing with bullying. One example is an anti-bullying policy that refers specifically to the needs of disabled children and young people. For further information see the Directory and resources section.

Unfortunately bullying is common, with many children experiencing it. Children who are passive and lacking in self-confidence are more likely to be bullied. Disabled children or those who simply look 'different' may be more likely to be bullied.

It is thought that fifty per cent of children who are bullied do not tell their teacher or parent. It is important to ask your child whether he or she is being bullied especially if your child starts to:

- show reluctance to go to school
- seem anxious or depressed
- have a variety of unexplained illnesses which require time off school which may seem to clear up once it is decided they are not going in
- regularly lose money, items of clothing or books at school
- have unexplained bruising

If you think or know your child is being bullied what should you do?

- Think if there is a simple way to avoid it – e.g. suggest they walk home a different route, go home with a friend and you will pick your child up later
- Find out what happens, where, by whom, when and why the child thinks it is happening

- Encourage the child to report it rather than fight back or put up with it
- See the teacher or head teacher to ask for action to stop it
- If you don't get anywhere, ask the school governors to consider the matter and adopt one of the programmes for combating it
- If this does not resolve the situation, speak to the Local Education Authority
- Talk to a charity like Kidscape who have lots of useful advice for parents and children, anti bullying programmes that schools can adopt and lots of information that you can read. (see directory)

The very last resort should be to change schools or to take your child out of school altogether and educate him or her at home. In most cases this is not necessary, although for a few parents, this is the preferred solution. Home education can further isolate your child from other young people.

section three: talking to your child about sex and relationships

Why does my child need to know about sex and relationships?

Sex and Relationship Education (SRE) informs children and young people about relationships, emotions, sex, sexuality and sexual health. It also enables them to develop life skills and a positive attitude to sexual health and well being.

SRE starts at home and is received from friends, television, media as well as school. Learning about sex and relationships is a lifelong process, beginning in early childhood and continuing through adult life.

Why is SRE important for all children and young people?

- research tells us that young people and their parents want better SRE
- research tells us it improves sexual health and well being and reduces teenage pregnancies and sexually transmitted infections

Young people have said for many years that their sex education is 'too little, too late and too biological' and that it avoids the broader issues of relationships, emotions, sexuality, contraception, sexually transmitted



infections and abortion. (Sex and Relationship Education Framework 2003)

A recent survey from British Market Research Bureau (BMRB, 2003) reports that young people say that their main information about sex and relationships is school (77%), friends (53%), mother (52%), magazines, books, posters and newspapers (45%) and TV and video (45%).

The later National Attitudes and Sexual Lifestyles Survey (Natsal 2003) found that the average age for first sex for both boys and girls is now 16. Earlier first sex is most common with those who are more vulnerable. More vulnerable individuals are more likely not to use contraception or practice safer sex when they first become sexually active.

A number of reviews have shown that high quality SRE, when linked to confidential sexual health advice services, can delay the start of sexual activity and can promote an open and accepting attitude towards sex and sexuality (SEM, Factsheet 23).

Teenage pregnancy in the UK has been decreasing for sometime now, but it is still five times higher than in the Netherlands, three times higher than in France and two times higher than in Germany. Sexually transmitted infections (STIs) continue to rise.

The sexual health of young people as well as adults in the country is poor and much is being done through the Teenage Pregnancy Strategy and Sexual Health Strategy

to improve sexual health and SRE in school, in the wider community and at home and to improve sexual health services.

SRE and my disabled child

There is a tendency to think that disabled people, including those with severe disabilities, do not have sexual feelings, sexual needs and sexual capabilities. But they do. Parents sometimes feel uncomfortable about this. They may feel concerned about this for a number of reasons. They may fear that their child will be vulnerable to exploitation, abuse or may become pregnant. They may feel a conflict with their own religious or cultural beliefs about sexual relationships outside marriage, or homosexuality for example. To love, care for and want to protect your child is a natural instinct.

Many parents worry that teaching children about sex will encourage them to become sexually active at a younger age. However, those children who have received sound sex education are likely to become sexually active later than their peers.

Accepting that your child has these sexual feelings and talking about sex will help them to understand the difference between a loving relationship and abuse. It may also make it easier for your child to discuss difficult and painful feelings with you.

Not knowing and understanding the changes and developments of your body can be frightening and bewildering. Especially as, without 'formal' sex education, learning still takes place in the playground and



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from the television etc. There are many 'myths' and consequently a real risk of misunderstandings and misconceptions. Avoiding the issue of sex and sex education will not make your child's sexual development, feelings and desires go away but may cause your child confusion and fear.

You have a right to uphold your own beliefs and to bring your children up with knowledge of where you and your community and your religion stand on moral and religious questions. But children may grow up to believe quite different things and regard as acceptable, relationships and activities that you may not feel comfortable about. Open communication based on respect for your son/daughters own attitudes and beliefs, which may be very different from your own, is key.

What does my child need to know?

Disabled children, like every other child, need to learn about:

- How their body works and grows
- What changes to expect at puberty
- The name and function of the sex organs
- Relationships and responsibility
- How society expects them to behave in public
- Keeping safe from exploitation and abuse
- How to prevent unplanned pregnancy and sexually transmitted infections

Disabled young people, like everyone else, have a need of:

- A social life with children or young people of a similar age
- Friendship
- Romance

- Exploration of their sexuality
- Access to sex education
- Privacy for private activity
- Understanding of private and public areas of the body

You should assume that your child will go on to have as independent an adult life as possible and that this will include experiencing sexual desires and taking responsibility for their sexual behaviour.

As puberty approaches you need to prepare yourselves and your son or daughter for a more adult status by allowing them to be as independent as possible. Even if they are very dependent upon the care of others they should increasingly take responsibility for their own decision-making with support from parents and teachers. This will help to have a feeling of control over their life. Giving your child responsibilities will directly affect their confidence, self-esteem and self-worth.

Talking about sex and relationships

'For me sex education at home was unheard of, but I was no different to my brother or sister...'

Despite a willingness to talk about sex and relationships, many parents are unsure how to go about it. They worry and think they may not know enough and lack the confidence to talk and listen confidently without embarrassment. For some parents of disabled children reluctance to



see their children as sexual beings may complicate matters further. These anxieties may peak when a child reaches puberty.

'I received sex education at home and my disability was not really discussed as an issue. My mum once said to me that she thought it might take me longer than most to get a boyfriend but she was sure I would eventually and she was right!'

Children are more likely to want to talk to you about sex if they are used to talking openly to you, not just about their disability in general, but other things like money, school work, friends etc. Showing an interest in what your child does and says will boost their self-esteem. Encourage your children to talk to you about anything that worries them. Even children with severe communication difficulties may be able to indicate to a family member who knows them well that there are things they are worried about or which make them unhappy.

When and how to talk about sex and relationships

- Start talking to your child early so that problems are less likely to arise – certainly before puberty
- Talk openly and casually – while you're doing something else, like washing up or driving the car- as this gives the message that it is not something secretive or to be afraid of
- Be open about your own beliefs and attitudes, but be prepared to discuss them and listen to your child's point of view
- Read books, leaflets and watch videos or take advantage for example of a situation that might arise on the television and which might help trigger a conversation
- When talking about sex, take into account your child's disability and be realistic. E.g. it might take longer; it might mean experimenting a little.

'The first time I...saw other people with arthrogryposis with wives, husbands and children, who were driving/work-ing/living independently I never worried about my future.'

- Reinforce the fact that the most important aspects of a relationship are love, friendship and mutual respect
- Listen rather than judge. Try asking them what they think
- Answer questions and don't be afraid to say: *'I really don't know – let's look it up together'*
- Don't bombard your child with questions or talk too much. Many children say it is awful to get a formal lecture on sex or have questions fired at them: *'I asked a question and she immediately came back with are you having sex then?'* Try and hold on to your anxieties, answer the question and respect privacy
- Remember that disabled people have relationships with other disabled people and with non-disabled people
- Remember that same sex relationships are as common for disabled people as for non-disabled people

What words or language should you use?

To begin with use the words that your child is familiar with and gradually introduce the correct medical names for the genitals and other body parts. These are going to be more consistently used by others. Even if your child chooses to use the original words he/she needs to understand, and be able to use the correct medical terms in certain situations. This is especially important if your child will have to be in hospital on their own when you may not always be there. Your child may be embarrassed if they cannot explain a problem to a doctor or nurse because they do not know the correct words.

For everyone involved in the personal or intimate care of the child

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or young person, consistency in the language used to describe the genitals and other areas of the body is also very important.

For the child with a physical impairment who relies on the help of care workers when going to the toilet, or who is used to undressing regularly for doctors or therapists, the concept of private parts of the body may need reinforcing.

There are many useful publications and helpful organisations listed in the *Directory* section.

Puberty

Disabled children grow up too and they go through the same process as any other child. Although puberty may be early for some and delayed for others it is a biological and emotional process that cannot be stopped even if some parents would like it to. There are some very rare medical conditions which mean that medication might be needed to bring on puberty and its associated changes.

As much as possible all children and young people need to be prepared for the changes to their body before they take place:

Girls

- Body hair starts to grow
- Breasts begin to grow
- Periods begin
- Mood swings can be more noticeable

Boys

- Body hair starts to grow
- Voice starts to break
- Wet dreams begin
- Mood swings can be more noticeable

You may wish to talk to a teacher at school about their sex education programme. Especially if you feel that it might bring up some worries or concerns for your child or you feel that your child might benefit from being prepared for the lessons beforehand at home. Also, it may be that your child would benefit from having certain points reinforced at home afterwards. They may come home with some worries relating to their medical condition or disability for example:

- Will my body go through the changes at puberty?
- Will I be able to have sexual relationships?
- Will I be able to have children?

As much as possible, as their parent or carer, you need to be able to allay any fears they may have. If you do not have the answers it might be useful to contact the support group for your child's condition. As your child becomes a teenager, it might be helpful for him or her to see a genetic counsellor. Also, you may find it helpful to contact the fpa (Family Planning Association). They produce a range of leaflets and a video to help parents overcome difficulties talking about puberty and sexuality issues with their children (see the section 'Directory and Resources' for more information).

As much as possible you need to pre-empt any worries or issues that might arise from lessons.

Changes for girls

Having periods is part of the visual process of growing up. It is a new phase in the development of emotional and physical maturity. Ideally information should be given well before the first period so that the young person can be reassured

that this is a normal process. She needs to know that she is menstruating and that it will stop in a few days. She may have little or no sensation in the vaginal area, and therefore may not be aware when her period has started. It is important to watch out for the start of any bleeding. This will be simpler once a regular cycle is established, and it may be useful to keep a diary of the menstrual cycle, or encourage her to do so.

The age at which menstruation may begin can vary – as young as nine years old is not uncommon. There is nothing 'wrong' if menstruation begins early, or if it starts much later than the average.

Make sure that your daughter has information about pads and tampons, what they are for and how they are used. Buy some products, take them out of the wrappings to show her, and perhaps demonstrate on a doll. Usually these are quite easy for a girl to put in place herself, but sometimes she will need help because of the nature of the disability. There needs to be an emphasis at this time on personal hygiene and cleanliness.

It is important to emphasise that it is a private thing, and she should not talk to everybody about it. Let her know that she can talk to her carer, her teacher, the school nurse or a girl friend.

Changes for boys

Most young disabled men are likely to go through adolescence and puberty at about the same time as anyone else. The voice will change; facial hair, pubic and body hair will start to grow. Tell your son about wet dreams and that they are perfectly normal and may sometimes happen when they are

asleep. Your son needs to understand that ejaculation can also occur during masturbation.

Boys may be embarrassed or worried and need reassurance that this is a normal part of growing up. They also need to know that this is a private thing, and that the semen should be wiped up with a tissue, and thrown away. This also is a responsibility, which, along with personal hygiene, is a part of personal care and growing up

There are a number of very good resources to help you explain to a child with learning disabilities the changes that a boy and girl go through at puberty. See Directory section for more information.

Personal care

Intimate personal care is a necessary part of some disabled people's lives. As a child grows up and goes through puberty they may find personal care to be more embarrassing and feel more awkward having intimate or private parts of their body touched. They may also feel shy of others seeing their body.

It is very important that parents are respectful and sensitive when delivering intimate personal care to their son or daughter and that they encourage similar behaviour in all care workers. This means

- Knocking before entering a bedroom or bathroom
- Asking permission on each occasion before providing intimate care – e.g. Is it OK if I help you take off your pyjamas now?
- Discussing personal care plans and any changes to these with the child or young person as far as possible
- Reassessing whether intimate

personal care is still necessary and whether it could or should be provided in a different way. Are there aids and equipment which could enable the young person to manage alone?

- Reassessing how many different people need to be involved in a young person's personal care and keeping this to a minimum
- Clear communication and explanation of why a procedure is necessary.
- Use consistent language for genitals and for bodily functions. Ensure any new care workers are informed of the appropriate language to use.

Masturbation

Discovering one's body is a natural part of growing up and, as much as possible, every child should be given the opportunity and privacy to explore the parts of their body that feel good to touch. Masturbation – when a boy strokes his penis or a girl strokes her clitoris because it is pleasurable - is a natural expression of sexuality. For a disabled young person there can be issues over both opportunities and privacy.

As your child grows up, you should try to knock and wait a moment before coming into a bedroom or bathroom. Encourage others, such as care workers, to be equally respectful.

Parents often assume that their child's physical impairment means that they are unable to explore their body or to masturbate. However, quite often they do find a way.

Night splints can be a barrier to exploration of the body. While it is very important that these be worn, you may like to ask your child's doctor whether it would do any

'Splints stopped me from playing with myself, when younger when you want to explore but now splints are no longer needed. Great! I found an adaptation of a normal way due to hand problems but you just get on with it...'

harm if occasionally you "forget" to put them on.

Continence wear can be another barrier. If this must be worn at all times, perhaps you could allow your child some "private time" in the bath – providing that you know your child is safe. Even if your child is unable to explore their own body with their hands they may be able to look at themselves and notice any bodily changes as they mature. This may lead naturally to questions on body changes and the opportunity to discuss the wider issues.

'I was quite nervous on my first sexual experience and what my partner would think of my body'

It is important for all of us that we are comfortable with our body and for this to happen we need to know our body.

Some children and young people masturbate because it helps them to feel warm, relaxed and loved. Young people with learning difficulties sometimes do not understand the difference between private and public. It is important to



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try and support children to know that what they are doing is natural and not wrong, but that it is only right on their own in a private place, such as their bedroom.

Contraception

There are many different contraceptive methods available, including the contraceptive pill, male and female condoms, the Intrauterine Device and the diaphragm or cap.

There are also other methods such as contraceptive injections, which contain a slow-release supply of a hormone. These work by stopping the ovaries releasing eggs and by thickening the mucus in the cervix, creating a barrier to sperm. It will give 99% protection against pregnancy for 12 weeks. Prescribed medicines such as those for epilepsy and tuberculosis make it less effective. It is also possible to have a contraceptive implant where a small flexible tube is placed under the skin of the inner upper arm. It releases the hormone progesterone and this stops the ovaries from releasing an egg.

A GP or fpa (formerly the Family Planning Association) will give advice as to which method might be most suitable. Your daughter/son should explain any medication that your she/he is already on (because some drugs e.g. antiepileptic drugs may reduce the effectiveness of the pill) and any allergies (e.g. to latex) which may affect the method chosen. They should also let the clinic staff know about their disability and its features. For example, the insertion of an IUD in a young woman with epilepsy may trigger a reflex seizure.

How effective any contraceptive is depends on how old the young

person is, how often they have sex and whether the instructions are followed.

Can a young person obtain contraception without parental consent?

Research findings tell us that many young people fail to get help because they fear that they will not receive a confidential service from health professionals. This is a difficult issue because parents naturally want to know what is happening. Health professionals will always encourage young people to talk with their parents.

Young people have the right to a confidential service and doctors can prescribe contraception and advise them on sexual health matters without their parents' knowledge. But doctors use their professional judgement to decide whether the young person is mature enough to understand the treatment and advice given and they will break confidence in circumstances where they believe that there is limited understanding or where the young person is being abused.

It is also known that most young people who seek advice will involve their parents either before the first appointment or very soon afterwards. Parents report disappointment when their son or daughter has not involved them initially but also express relief that the young person has been sensible and responsible in getting advice.

Emergency contraception

If your daughter forgets to use contraception or has had an accident, she may be at risk of an unplanned pregnancy. Advise her to contact her doctor or Family Planning Clinic as soon as possible. There are two methods of

emergency contraception:

- Fitting a coil (IUD)
- Two doses of a special pill

Sterilisation and abortion

Some parents are so worried about pregnancy that they consider whether their son or daughter should be sterilised in order to prevent any chance of an unplanned pregnancy. There are substantial ethical, psychological and legal concerns about this and organisations of disabled adults generally regard sterilisation without the informed consent of the disabled person as an act of abuse.

With newer, more reliable forms of contraception, such as contraceptive injections, it is likely that sterilisation will continue to decline. At present, a handful of parents of young people with learning disabilities do go to court each year to argue that their son or daughter should be sterilised.

If you are considering this as an option, you need to be aware that it is a major operation (especially for women), it is often irreversible, doctors will be most reluctant to agree to this drastic step and you may have to go to court. It may be better to have a discussion with a family planning specialist about the different methods of contraception available and see if you can find an option which is reliable, but not permanent.

Similarly some parents, on finding that their daughter is pregnant, will try to persuade her that terminating the pregnancy is in her best interests. Some parents may find the prospect of an abortion unacceptable, due to their own religious and cultural beliefs. It is possible that either option may be in your daughter's best interests, but

she needs time and your support to help her make her decision. As her parent you may also need support as her parent at this difficult time.

Many disabled people will form lasting and loving relationships and the mutual desire for a child may be part of this. Disabled people can and do become able and effective parents. The Disabled Parents Network (see Directory) can advise.

Sexually Transmitted Infections (STIs)

Anyone can get a sexually transmitted infection, including HIV, the virus which causes AIDS, if they do not have safer sex. There are at least 25 different Sexually Transmitted Infections (STIs). The most common are:

- Chlamydia
- Gonorrhoea
- Genital Warts
- Genital Herpes
- Syphilis
- Trichomonas Vaginalis
- HIV and AIDS

HIV stands for the Human Immunodeficiency Virus and affects men and women. The virus damages the body's immune system so that over time it becomes vulnerable to illness and infections.

AIDS is caused by HIV. When a person has AIDS it means their immune system is very weak and they have developed certain infections or cancers. These can be fatal.

STIs are most commonly passed on through vaginal, oral and anal sex. You don't need to have a lot of sexual partners to get an STI although the more partners that a person has, the greater the chance is that one of

them may pass on an infection.

Common symptoms of an STI are:

- unusual discharge or liquid from vagina or penis
- pain or burning when passing urine
- itches, rashes, lumps or blisters around the genitals or anus
- pain and/or bleeding during sex
- bleeding after sex and/or between periods.

Symptoms can vary from infection to infection and many STIs show no symptoms at all. It is not uncommon to have more than one infection at the same time. Most STIs can be completely cured if found early enough and may only require a course of antibiotics. However, if left untreated these infections can be painful and uncomfortable or at worst cause permanent damage to health and fertility.

If your son or daughter is, or may be, sexually active and appears to have any of these symptoms, you should advise them to see a doctor. It is important not to become angry or show your disapproval, otherwise they may find it harder to confide in you and you may also lose the



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opportunity to talk openly about safer sex and avoiding these infections in future. Reassurance that you will help them to get treatment and explain how to avoid re-infection is likely to keep better lines of communication open in the long term.

Safer sex – how to avoid sexually transmitted infections

You should advise your son or daughter to

- Use a condom (male or female) correctly and consistently when they have sex to prevent the transmission of most STIs including HIV
- Discuss with their partner before they have sex how they will both protect themselves
- Have a routine check up at a sexual health clinic

If your son or daughter or their partner has symptoms or think they might have an infection tell them to seek advice before they have any more sex. If they have an infection ask them to tell their partner so they can be treated too.

Where to go for help and advice Sexual health clinics specialise in diagnosing and treating all STIs

Most large hospitals have a sexual health clinic. You can find details of your nearest clinic by:

- calling the fpa's helpline on 0845 310 1334
- looking in the phone book under genitourinary medicine, STD or VD
- calling the National AIDS helpline on 0800 567 123 (24hrs)
- calling NHS Direct on 0845 46 47 (24hrs)
- check www.ruthinking.co.uk

Protecting your child from abuse

Disabled children and young adults may be more vulnerable to abuse. Their need for sex education and an understanding of appropriate 'touch' is essential because:

- They may rely on intimate care and assistance with using the toilet and getting dressed etc.
- They may have less understanding about 'personal' and 'private' parts of the body through learning difficulties
- They may have less understanding about 'personal' and 'private' parts of the body

through frequent medical examinations where they need to undress or be undressed

- They may have communication difficulties which affect their ability to speak out about abuse

The best way that you as a parent can protect your child from abuse is to have an open and loving relationship based on honesty. You can reassure your child that there is nothing so awful and embarrassing that they couldn't talk to you about it.

Try to make sure that your child understands as much as they can about love and sex and the difference between wanting to touch and kiss someone and being made to do something that feels wrong or scary.

Discuss with them openly how they might handle a situation where they feel uncomfortable, rehearse and role-play – practice shouting 'NO' and calling for help. Be open about discussing who a child or young person might turn to if they are frightened or worried – their parents, a teacher, a policeman, a bus driver, a lifeguard, depending on where they are at the time.

Don't overestimate the risks yourself and overprotect your child as a result. It is still thankfully very rare for children to experience abuse or assault by a stranger. Arm them with the confidence, knowledge and skills to protect themselves and then let them enjoy exploring all that life has to offer.

section four: sex and relationship education at school

A false debate is often presented as to whether parents or schools should be responsible for sex and relationship education. In reality both have an important role.

Whilst special schools usually have considerable expertise in teaching SRE in a way that is inclusive and sensitive to the needs and experience of disabled pupils, children with disabilities increasingly attend mainstream schools.

'Sex and Relationship Education at school was non-existent, they didn't think disabled people should be having sexual relationships...'

Young disabled people have the same rights to education and information, to dignity and respect, as their non-disabled peers. All children and young people have a legal right to education and support that will prepare them for the responsibilities and experiences of adult life. Under the provisions of the Special Educational Needs and Disability Act (2001) schools are

required to ensure that the curriculum (including SRE) is meeting the needs of disabled pupils.

Sex and Relationship Education at school

National guidance from the Department for Education and Skills (Sex and Relationship Education Guidance, published in July 2000) advises schools on the themes that should be covered.

Formal SRE will be taught through compulsory science lessons and during other, specific lessons, often called PSHE (Personal, Social and Health Education). In the early years up to the age of 7, teachers will be helping children to develop the skills of listening and caring as well as talking about feelings and their

relationship with family and friends. Children will learn the names of the body parts, the differences between male and female and the ways in which they will develop and grow. Importantly, they will also learn to recognise unsafe and risky situations, and to ask for help.

From 7 to 18 years they will continue to develop their knowledge and skills. In agreement with parents, children will be prepared for the physical and emotional changes of puberty and learn about reproduction and sexual behaviour. They will also learn about relationships, sexuality, contraception and safer sex, including the importance of marriage and stable long-term relationships for the care and support of children. They will also learn social skills that will help them to be assertive, ask questions, access support, negotiate within relationships, problem solve and make and carry out decisions.

All schools must provide an up to date policy that describes the content and organisation of SRE. The policy should be developed in consultation with pupils and parents and other professionals from the wider community.

Does my child have to take part in these lessons?

Schools have a legal duty to teach the science curriculum and you



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cannot withdraw your child from the sex education that is taught as part of science. However, you do have the right to withdraw your child from other aspects of sex education. Before you exercise this right, you should give careful consideration to whether this is best for your disabled child and you should weigh up whether it might be more damaging for your child to receive (possibly wrong) information in the playground than to receive formal sex education. Taking your child out of these lessons may also make him or her feel different and isolated from classmates. Schools have a duty to discuss your concerns with you and help you to decide what is best.

The Disability Discrimination Act in most cases does not permit the school to refuse your child access to any part of the curriculum or activities or outings on grounds of disability. So if you want your child to receive sex education but the school is withdrawing your child, so that they can receive, for example, physiotherapy or extra coaching in maths, you can take this up with the school and insist that your child participates in the full curriculum.

Preparing your child for sex education

It might be very useful if you could discuss with the teacher beforehand the content of lessons and how it might affect your child. The following is a checklist of questions you might want to ask the teacher:

- Are they aware that they have a disabled pupil in the class?
- Do they know the nature of your child's disability and what issues may arise for them from the lesson content?
- Will your child have an opportunity to speak with a member of staff about any concerns they may



have before the lesson?

- Is there an identified member of staff your child can approach, if they need to speak to someone, after the lesson?

You may wish to make the teacher aware of:

- Your child's thoughts and anxieties about the lessons
- Your child's thoughts and anxieties about a specific area of SRE relating to their disability
- Any support group for your child's condition which might give them more specific information

Consistency in language being used by parents, care workers, teachers and learning assistants is very important where a child needs

intimate care and thus his/her 'private' parts are 'public' property. It may be especially important for pupils with learning disabilities. It may be worth asking the teacher if any particular words are to be used. If your child normally uses a different word, explain to him or her that these words refer to the same part of the body.

Following up SRE at home

For some pupils it may be necessary to have some SRE issues reinforced at home, for example:

- the difference between 'public' and 'private' parts of the body
- reproductive functions of the body
- relationships and responsibility
- realistic expectations/aspirations

If a parent has prior knowledge of what is being taught in PSHE and SRE they are better able to support their children. The following are just some of the personal and individual worries that a child might take home:

- sexual function – How will I be able to have sex?
- sexual orientation – Maybe I am gay
- Body image – Will anybody want to have sex with me?
- Future relationships – Will I ever get a boy/girlfriend?
- Getting married – Will I ever get married?
- Having children – Will I be able to have children?

If you know that your child has covered a topic at school which they may have found difficult or worrying, you may like to ask them how it went and whether they have any follow up questions that they need answering. If you do not have all the answers, don't worry - one of the organisations in the Directory included in this pack may be able to help. The fact that you are seen to be taking your child's worries seriously and trying to find answers will be very reassuring.

How can you be involved in setting the school agenda?

It is very important that there is a strong partnership between the school, parents and the disabled pupil in all areas of school life and this is especially true with SRE and PSHE issues.

It is essential that the governing bodies involve parents, especially parents of disabled pupils if there are children or young people with disabilities at the school, in developing and reviewing their SRE

policy. It is important that communication with them be ongoing. Parents can also look at the resources that are used and test out leaflets and videos at home.

If good communication does not happen, parents may assume that SRE is being covered at school and teachers may assume that it is being covered at home. Parents are far less likely to withdraw their children from SRE if they know how it is being approached and they have been involved in working on, and are aware of, the content.

If your school does not appear to involve parents in this part of the curriculum, you could try contacting the special needs co-ordinator at the school (sometimes referred to as the SENCO) to see if they would like some parental input. Parents have a lot of experience of their child's worries and concerns and if staff and governors understand these, they will be able to better plan a curriculum that is inclusive.

Partnership with other agencies

Most disabled children have professionals from several agencies involved in their lives e.g. social workers, doctors, therapists, community nurse. A good working

relationship with all these agencies is important to ensure a consistency of language, expectations and understanding of the child's needs.

All staff including ancillary staff, physiotherapists, nurses and care workers as well as teachers should follow the school's sex and relationship education policy when working with disabled pupils.

End note

We hope you have found this booklet helpful. Being a parent of a disabled teenager can be a huge challenge. Although it is not always easy talking to your children about growing up or about sex and relationships it is an essential part of parenting and can be highly rewarding for you and your child (even a teenage one!). As young disabled people enter adulthood they need to explore their own needs and voice their own opinions and become themselves rather than their parents' children. To do this they need your continuing love, support, advice, encouragement and understanding.



section five: directory and resources:

The following is a list of organisations and resources for parents, young people and professional workers. Some of the resources are quite expensive, so you might like to see if you can borrow from a library or club together with other parents.

Not sure where to start?

Further information on any aspect of being a parent with a disabled child is available from

Contact a Family

209-211 City Road, London EC1V 1JN
Freephone helpline 10am-4pm 0808 808 3555
Textphone 10am-4pm 0808 808 3556
E mail helpline@cafamily.org.uk
Website www.cafamily.org.uk

Contact a Family welcomes enquiries from families and those working with them. You can order further copies of this pack from Contact a Family as well as other leaflets on topics like benefits, education, community care, fathers, siblings, genetic conditions, play and leisure and many others.

Contact a Family will put you in touch with support groups for hundreds of different disabilities affecting children and young people. For reasons of space we cannot include all of these organisations here, but list the two who have been most closely involved in the production of this pack.

The Arthrogryposis Group

Tel: 01299 825781
www.tagonline.org.uk

Association for Spina Bifida and Hydrocephalus

Tel: 01733 555988 www.asbah.org

Particular topics (in alphabetical order)

Abortion (see also contraception)
British Pregnancy Advisory Service – helpline 08457 30 40 30 (Mon-Sun) www.bpas.org
Clinics offering information and treatment for unplanned pregnancy including counselling to help women choose between options

Brook – helpline 0800 0185 023 (Mon-Fri 9am-5pm)
www.brook.org.uk

Abuse

 (see also bullying)

VOICE UK – helpline – 0870 013 3965 (Mon –Fri 9am-5pm)
www.voiceuk.clara.net
Support, information and publications for people with learning difficulties who have experienced crime or abuse and their families

ChildLine – helpline 0800 1111 (24hrs)
www.childline.org.uk
Helpline for children and young people in who need advice and help or who are in trouble/danger

Ann Craft Trust – helpline 0115 951 5400 (Mon-Thurs 9am-4pm, Fri 9am-12pm)
www.nottingham.ac.uk/sociology/act
Training, publications and advice for staff working in the interests of children with learning difficulties who may be at risk of abuse.

Family Rights Group – helpline 0800 731 1696 (Mon-Fri 1.30-3.30pm)
www.frg.org.uk
Advice and support for families whose children are involved with social services. Can advise on child protection proceedings.

'Developing Personal Safety Skills in Children with Disabilities' by Freda Briggs 1995 £18.95, Jessica Kingsley Publishing, 116 Pentonville Road, London, N1 9JB 020 7833 2307
www.jkp.com/catalogue

Bullying

Anti-Bullying Alliance
020 7843 6315
www.ncb.org.uk/aba
A range of resources on preventing bullying.

Kidscape Campaign for Children's safety - helpline 0845 310 1334 (Mon-Fri 10am -4pm)
www.kidscape.org.uk
Books, leaflets videos, parents' guides on preventing bullying and sexual abuse

Bullying: don't suffer in silence'
Anti-bullying pack for schools, copies are available free of charge from DfES Publications on 0845 602 2260.
www.dfes.gov.uk/bullying/

Contraception

fpa (formerly the Family planning Association) – helpline 0845 310 1334 (Mon-Fri 9am-7pm) www.fpa.org.uk
Books, leaflets, advice on most aspects of sexual health including abortion, contraception and sexually transmitted infections. Book for young people 13+ with learning difficulties 'Talking together about sex and relationships' £14.99
Leaflets 4Boys, 4Girls, Puberty and Abortion

Brook - helpline 0800 0185 023
www.brook.org.uk
Sexual health advice and contraception for young people up to age 25

'A visit to a Brook Centre' Lothian Brook (1999) (Free)
(A fully illustrated booklet for young people with limited reading skills to demonstrate what happens when going to seek advice about contraception) and Thinking about sex? How to use condoms' Lothian Brook (1999)(free)
(A fully illustrated booklet for young people with limited reading skills to explain why, when and how to use condoms)
Both available from Caledonia Youth 5 Castle Terrace, Edinburgh EH1 2DP Tel: 0131 229 3596
www.brookscotland.co.uk

Education

For advice on any aspect of education for a disabled child or young person in England, you can speak to your local parent partnership service. To find your local service see www.parentpartnership.org.uk or phone Contact a Family on 0808 808 3555. They can also put you in touch with other specialist organisations advising on education.

Friendships

'Building friendships' by Jane Fraser and Hugh Firth (1994) £35.00
A resource pack to help young people with learning and other social difficulties

make friendships and develop relationships.

Available from Brook Publications, PO Box 1239, Coventry CV8 3ZB. Tel : 024 7654 5557 www.brook.org.uk

Write Away 0208 964 4225

www.write-away.org

Pen friend scheme for disabled children and young people

Gay and lesbian

Acceptance – helpline 01795 661463 (Tues-Fri 7pm-9pm)

Helpline for parents of gay men and lesbians

Lesbian and Gay Switchboard – helpline 020 7837 7324 (24hrs) www.llgs.org.uk
Support for lesbians and gay men

Growing up (general) (see also Independent Living)

Connexions service – 0808 00 13 219 www.connexions-direct.com – advice and information for young people 13 to 19 on any subject, including careers, health and relationships. Local advisers in each part of England for more in depth support.

'After 16 – What's new – Choices and Challenges for young disabled people' free from the Family Fund, PO Box 50, York, YO1 9ZX Tel: 0845 130 4542 www.after16.org.uk

Comprehensive guide to all aspects of life as a young disabled adult

'Move on Up: Supporting young disabled people in their transition to adulthood' A pack for professionals and young people by Jenny Morris £12 from Barnardo's 0208 550 8822 www.barnardos.org.uk/shop/acatalog/Catalogue_Society_124.html
Guidance on supporting young disabled people in their transition to adulthood.

Health

NHS Direct 0845 46 47 (24 hours) www.nhsdirect.nhs.uk

Advice on any health issue, can put you in touch with clinics in your area

'Keep yourself healthy: a guide to checking your breasts' by Family Advice

& Information Resource £0.75 each (first copy free)

(A fully illustrated booklet explaining why and how you should check your breasts and how to reduce the risk of developing breast cancer – for young women with limited reading skills)

'Keep yourself healthy: a guide to examining your testicles' by FAIR £1.00 each (first copy free)

(A fully illustrated booklet explaining why and how you should check your testicles and how to reduce the risk of developing testicular cancer – for young men with limited reading skills)

Both available from FAIR Multimedia 25-27 West Nicholson Street, Edinburgh EH8 9DB Tel : 0131 662 1962

'Cathy has Thrush' and *'Period problems – what can you do?'* – booklets, free to women with learning disabilities or £1, from Women's Health 020 7251 6333 www.womenshealthlondon.org.uk/order.s.html

'Feeling Grown Up' The Shepherd School, Harvey Road, off Beechdale Road, Nottingham, NG8 3BB Tel: 0115 915 3265

A series of very simple, illustrated booklets (with the addition of widget symbols) for young people with learning disabilities, covering the following :

- Menstruation at home
- Menstruation at the disco
- Female masturbation
- Male masturbation
- Wet dreams
- Using public toilets

'Talking together...about growing up' by Lorna Scott & Lesley Kerr-Edwards (1999)

An activity-based workbook for parents of children with learning disabilities. £9.99 + £2.50 postage and packing from fpa direct PO Box 1078, E.Oxford DO, Oxon, OX4 6JE. Tel: 01865 719 418

'Janet's got her period' An Australian video intended to help young women with learning disabilities cope with menstruation.

£59 + VAT from Boulter Hawker Films Ltd. Tel: 01473 822235

"Books Beyond Words" A series of booklets illustrated in full colour and with no words (or very few) to assist people with learning disabilities to understand health issues, personal relationships or life changes. Edited by Professor Sheila Hollins. £10 each

Available from St George's Hospital Medical School and Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG Tel: 0207 235 2351 ex. 146 www.rcpsych.ac.uk/publications/bbw/index.htm

'Looking after my breasts' Sheila Hollins and Wendy Perez (2000)

'Keeping healthy 'down below' Sheila Hollins and Jackie Downer (2000) (about having a smear test)

'Susan's growing up' Sheila Hollins and Valerie Sinason (2001) (about periods)

'George gets smart' Sheila Hollins, Margaret Flynn and Philippa Russell (2000) (about staying clean)

'Making Friends' Sheila Hollins and Terry Roth (1995)

'Hug me, touch me' Sheila Hollins and Terry Roth (1994) (about when to hug and when not to)

'Falling in love' Sheila Hollins, Wendy Perez and Adam Abdelnoor (1999)

'Jenny speaks out' Sheila Hollins and Valerie Sinason (1992) (about sexual abuse)

'Bob tells all' Sheila Hollins and Valerie Sinason (1993) (about sexual abuse)

'I can get through it' Sheila Hollins, Christiana Horrocks and Valerie Sinason (1998) (about sexual abuse)

'Going to the doctor' Sheila Hollins, Jane Bernal and Matthew Gregory (1996)

'Going to out-patients' Sheila Hollins, Jane Bernal and Matthew Gregory

'All about feeling down' and *'Meeting the emotional needs of young people with learning disabilities: a booklet for parents and carers.'* Foundation for People with Learning Difficulties 7th Floor, 83 Victoria Street, London SW1H 0HW Tel: 020 7802 0302

www.learningdisabilities.org.uk

'Young Disabled People Can...' This is a series of 6 posters and a 16 page booklet on young disabled people and

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relationships, available from London Brook Tel: 020 7787 5024.

Independent Living (see also growing up)

Disabled Living Foundation – helpline 0845 130 9177 www.dlf.org.uk
Advice on equipment for independent living, including clothing and equipment for children. Produce a range of factsheets including choosing a bra.

Disabled Living Centres Council Tel: 0161 834 1044 www.dlcc.org.uk
Have a network of centres across the UK where you can get advice and try equipment.

National Centre for Independent Living – 020 7587 1663 www.ncil.org.uk
Information and advice on independent living, personal assistance and direct payments to pay for care

Living it Up Norah Fry Research Centre, 3 Priory Road, Bristol, BS8 1TX Tel: 0117 923 8137
www.bris.ac.uk/Depts/NorahFry/transition/livingitup1.pdf
CD and magazine written by and for young disabled people – advice about direct payments

Parenting

Parentline Plus helpline 0800 800 2222 www.parentlineplus.org.uk
Information and support to any parent

Disabled Parents Network helpline 0870 241 0450 (Mon-Fri) www.disabledparentsnetwork.org.uk
Support, advice and information to disabled parents

Parents at Work Tel: 020 7253 7243 www.parentsatwork.org.uk
Waving not Drowning project supports working parents with disabled children

Pregnancy (see also abortion)

Disability Pregnancy and Parenthood International helpline 0800 018 4730
Text phone 0800 018 9949 www.dppi.org.uk
UK wide organisation providing information on pregnancy and parenting to all disabled people

Puberty (see health)

Sex and relationships (see also contraception, health)

Most publications on sex and relationships for disabled people are focussed on learning disabilities. There are some publications around physical disability, but these are mostly produced by the relevant disability charity. For example, the Spinal Injuries Association sells 'Sex Matters: A Guide to Sexuality for Spinal Cord Injured People' (£2) via its website www.spinal.co.uk. Contact a Family (0800 808 3555) will put you in touch with the most relevant disability specific organisation.

The Sexual Dysfunction Association Tel: 0870 7743571 www.impotence.org.uk
has useful information about all aspects of male and female sexual dysfunction and can give details of suppliers of vacuum devices to assist men with getting an erection.

Relate helpline 0845 130 4010 www.relate.org.uk
Counselling on relationship difficulties, psychosexual therapy, and specialist bookshop on relationship issues.

Couple Counselling Scotland Tel: 0131 558 9669 www.couplecounselling.org
Co-ordinates a confidential counselling service for couples in Scotland

Sexwise helpline 0800 28 29 30 www.ruthinking.co.uk
Sex and sexual health helpline for young people under 18

Muslim Youth Helpline 020 8795 5321 (Tues 6-9pm and Saturday 10am to 10pm) www.myh.org.uk
Counselling for Muslim youth on any aspect of growing up including sex and relationships.

Your rights about Sex Michelle McCarthy and Paul Cambridge £5
British Institute of Learning Disabilities, Wolverhampton Road, Kidderminster, Worcestershire, DY10 3PP Tel: (sales) 01752 202301
Do's and don'ts of appropriate sexual behaviour for young people with learning disabilities from www.bild.org.uk/publications

'It's Only Natural' by Queens Road Sexual Health Team (1996)
(A video and notes for parents, carers and others involved in the lives of young people with learning disabilities and concerned about the need for PSHE and 'letting go')
£70 (£35 to parents' groups) from Barnardo's, Queens Road Project, Queens Road, Bradford, BD8 7BS. Tel: 01274 481183

"Sexuality – Your Sons and Daughters with Intellectual Disabilities"
by Karin Meiberg Schwier and Dave Hingsburger 2000 £14.95 from amazon.co.uk
ISBN 55766-428-5

'You, Your Body and Sex' 15 minute video for people with learning difficulties £39 plus vat from www.lifesupportproductions.co.uk. Also separate videos for boys and girls

Everything you ever wanted to know about safer sex but nobody bothered to tell you People First. Advice on safer sex for people with learning difficulties. Booklet £4.50 plus £4 for audio-tape. Cheque to People First, 299 Kentish Town Road, NW5 2TJ Tel: 020 7485 6660

Let's Talk about Sex by Robbie Harris and Michael Emberley 1995 – mainstream resource with positive representation of disabled children and adults £7.99 from amazon.co.uk

'Sex and Relationships' – an interactive CD £19.99 from Sense CDs 01732 748664 www.sensecds.com – mainstream resource which has lots of useful information for teenagers and some images of physical disability

Let's talk about sex: growing up, changing bodies, sex and sexual health. Harris, R. H (1995). London: Walker Books
Thorough, frank, up-to-date, responsible and reassuring information about all aspects of growing up, sex and sexuality. Illustrated throughout with amusing but accurate illustrations. Truly inclusive of different sexualities, disabilities, ethnicities and body shapes.

Aimed at 10-14 year olds and their parents and carers.

Teaching resources

Discern provides training for staff supporting people with physical or learning disabilities around areas of sexuality, sexual abuse and bereavement. 01623 623732
www.discerncounselling.org.uk

"Personal, Social and Health Education and Citizenship: planning, teaching and assessing the curriculum for pupils with learning difficulties"

QCA (2001) ISBN 1 858384788
www.qca.org.uk/pubs/mar2001.asp

"Ensuring Entitlement: sex and relationship education for disabled children"

Sex Education Forum factsheet (2001)
Available on: www.ncb.org.uk/sef

Sense: sex and relationships for young people aged 14-16: interactive CD-ROM and teachers support manual. Blake, S and Orpin, L (2003) London: National Children's Bureau
Sex and relationship education CD-ROM designed to support the DfES guidance on SRE, and the Teenage Pregnancy Strategy. The CD-ROM is accompanied either by a comprehensive teachers' manual or by a short booklet for parents and carers. The teachers' manual provides advice on how to develop a whole-school approach to PSHE as well as ideas on how to use the resource.

'I have the right to know: A course on sexuality and personal relationships for people with learning disabilities' by Dean Atkinson, Alison Gingell and Janice Martin (1997) £25.00
A fully illustrated resource for staff to use when teaching about sexual behaviour and personal relationships.

'Exploring your emotions' by Angela Holland, Alison Payne and Lindsey Vickery, (1998) £25.00
A set of 30 full colour photographs illustrating common emotions and situations, which evoke emotional responses, plus an instruction manual for users.

Both available from the British Institute of Learning Disabilities, Wolverhampton Road, Kidderminster, Worcestershire, DY10 3PP. Tel: (sales) 01752 202301
www.bild.org.uk/publications

'Male and Female Cloth Models' Jane Fraser, Sunnybank House, Holly Green, Upton on Severn, Worcestershire WR8 OPG. Tel: 01684 594715. E-mail: clothmodels@revjane.demon.co.uk
£300.00

Anatomically correct, half life-size, clothed male and female models suitable for use with young people with learning disabilities and those with communication difficulties. Available to order at cost price, fully made up and clothed, with guidance notes.

'Picture Yourself' Ann Craft and Hillary Dixon, now available on the web from Hilary Dixon at www.me-and-us.com (complete set £50 plus VAT on CD)
Four sets of A5 cards offering a comprehensive range of line drawings and photographs to stimulate discussion and understanding of sexuality and appropriate behaviour.

How it is – NSPCC - www.howitis.org.uk
visual symbols for use by children to express feelings. Has symbols for body parts useful for discussions around personal safety and sexuality

'Lets Do It: Creative activities for sex education for young people with learning disabilities' by R Johns, Lorna Scott and J Bliss, available from Image in Action, Chinnor Road, High Wycombe, Bucks, HP14 4AJ Tel:01494 481 632 (£20)
A compendium of activities that are drama based or use visual images for use in schools, colleges and day centres for use mainly with people with severe learning disabilities.

'Building on Social Skills' (£15) NASEN, NASEN House, 4/5 Amber Business Village, Amber Close, Amington, Tamworth, B77 4RP www.nasen.org.uk
A programme to enhance the social skills and raise the self esteem of young people between 12-16

'What about us? Sex education for people with disabilities. (£2) NAPE,

University of Leicester, Mouton College, Moulton, Northampton, NN3 7RR Tel: 01604 647 646 www.nape.org.uk

'PHSE Scheme for students with MLD and EBD' £95 also *'People Skills for Young Adults (for students with MLD)'* £25. Chalkface Project, 84a High Street, Stony Stratford, Milton Keynes, MK11 1AH Tel: 0800 781 8858
www.chalkface.com

'Sex Education – the Muslim perspective' (£2.50) Muslim Education Trust, 130 Stroud Green Road, London, N4 3RZ Tel: 020 7272 8502
www.muslim-ed-trust.org.uk/publications.html

WEBSITES

For young disabled people

BBC On Line (year 11 good site for browsing especially problem page)
<http://www.bbc.co.uk/so/trouble/pms.shtml>

Sexwise (useful info on local support, contraceptive advice, infections)
www.ruthinking.co.uk

Sexual Health (years 9,10 and 11 good but a lot on each page)
www.likeitis.org.uk

Sexual Health (year 10 and 11 good for quick information gathering)
www.playingsafely.co.uk

Mind Body and Soul (year 10 and 11 good for quick information gathering)
www.mindbodysoul.gov.uk

Brook Centres (excellent site for year 10 and 11 and post 16 to use for information gathering and fact finding. Very easy to use.)
<http://www.brook.org.uk>

Bullying Online
www.bullying.co.uk

ChildLine
www.childline.org.uk

Gay Youth Online
www.gayyouthuk.org.uk

For teachers of PSHE

Healthy Schools
www.wiredforhealth.gov.uk

Sex Education Forum
www.ncb.org.uk/sef/index.htm

For general information
www.educationunlimited.co.uk/netclass

BBC Schools Online
www.bbc.co.uk/education/id

DfES website for teachers of PSHE
www.teachernet.gov/pshe

Ofsted – the framework for inspection of
PSHE
www.ofsted.gov.uk

Resources for PHSE
www.me-and-us.com

Lead author: Sharon Baker

Sponsored by the Teenage Pregnancy Unit

Editor: Helen Christophers

Designed by twoplus consultants

Library photographs courtesy of www.johnbirdsall.co.uk

All library photos are posed by models

