

Talking about sex, sexuality and relationships: GUIDANCE AND STANDARDS

For those working with young people with life-limiting or life-threatening conditions



Talking about sex, sexuality and relationships: Guidance and Standards

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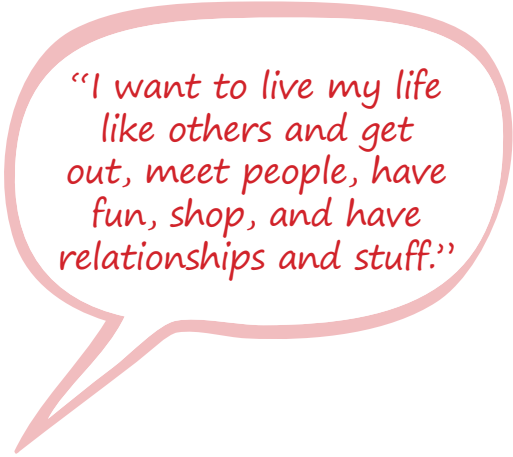
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“I want to live my life like others and get out, meet people, have fun, shop, and have relationships and stuff.”

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Foreword

“As young people with life-limiting conditions, we commend these sexuality guidance and standards for health and social care staff and the organisations who support people like us. We are particularly lucky to receive support and care from individuals who are very professional and not shy in discussing topics of importance to us, such as relationships, intimacy and sexuality. However, this is not always the case and certainly some staff and organisations supporting people with life-limiting conditions are coy, nervous, “*just don’t get it*”, or don’t have the skills to spend time talking about sex when they believe that they may have more important matters to attend to in their everyday work. But this IS important; so please don’t ignore our needs.

Sexuality is not rocket science, it’s part of everyday life. So hopefully staff using this guidance will understand some of the issues that they may need to address in their daily work, and consequently feel more comfortable, more confident and able to discuss sexuality with young people. Yes, talking about sex, intimacy and providing practical support for young people like us can be challenging, but such discussions shouldn’t be ignored and swept under the carpet. Staff just need training and support.

This well-illustrated guide, which is underpinned by standards, has a number of short, useful sections with quotes from people with life-limiting conditions who contributed hugely to its development. It also includes case histories with discussion points, information about the law, lists of useful resources and guidance. This guide discusses the importance of being able to access sex education as well as information about sex, relationships and intimacy throughout life and includes topics like masturbation, basic human needs, embarrassing situations, and relationships. Yes, it is difficult to do this yourself when you have lost your ability to surf the net. We recognise that there is a lot of useful information out there on the net but it can be challenging to ask for help if you need to look at sites with sexual stuff on them.

It’s regrettable in the 21st Century that sex and sexuality is still perceived as a taboo topic but this guide certainly aims to dispel those myths.

Happy reading! ”

**Hameed Jimoh (Junior) and Lucy Watts MBE
2016**

Executive summary

Until recently young people with a life-limiting or life-threatening condition (LLTC) were not expected to live into adulthood. Science and technology have helped improve life expectancy (Beresford & Stuttard, 2014) and there are now an estimated 55,000 people aged 18-40 with an LLTC in the UK (Fraser, 2014; Fraser, 2012).

As many young people with LLTCs are now living well into adulthood, it is not surprising that many want to know more about how their bodies develop and change over time and how this may impact on opportunities to have an intimate relationship in future. For many young people with an LLTC, sex may not necessarily be about intercourse but simply sharing an intimate relationship with someone else (Blackburn, 2002).

It has been recognised for some time by health, social care and education practitioners (Chailey Heritage Foundation, 2014; Helen & Douglas House, 2014) that professionals find it very difficult to effectively support disabled young people with sexuality issues, and that this is even more difficult for staff who are supporting young people with life-limiting or life-threatening conditions and their families.

ACT (now Together for Short Lives) had produced guidance and standards in 2009, but these had not been updated since their initial publication. In 2012, a national conference *Let's Get Back to Basics* hosted by Helen & Douglas House and Rainbows Hospice for Children & Young People explored the legalities and practicalities of supporting young people with LLTCs with sexuality and intimate relationships. It concluded that there was a dearth of specific and up-to-date guidance and standards relating to sexuality for this group of young people.

The Open University Sexuality Alliance was formed in 2013 as a result of this conference, with the key purpose of developing sexuality guidance and standards for health, social care and education staff working with young people with LLTCs. The Alliance is a collaborative partnership that brings together representatives from public sector organisations, charities, service users and academics with an interest in providing holistic care for young people with LLTCs.

Following a favourable opinion from The Open University's Human Research Ethics Committee (HREC) in 2014, a full review of the literature was undertaken and the contents and design of the guidance and standards were discussed with four groups of young adults with LLTCs and some parents (N=25) in Scotland and England in 2014 and 2015. Participants at the focus groups greatly informed the design, content and final production of the guidance. Following the young people's consent, their input was anonymised and analysed for key themes using NVIVO data analytical software to determine the issues that matter most to them.

Members of The Open University Sexuality Alliance provided comment, critical feedback, experience from practice and legal expertise to the drafts of this document. Anonymised quotes are used throughout.

The Standards



UNDERPINNING PRINCIPLES

All young people with a life-limiting or life-threatening condition should expect:

- ◆ To have the right to privacy, dignity and confidentiality
- ◆ To be treated in an age-appropriate way, regardless of their developmental stage and mental capacity
- ◆ To be able to address sexuality, intimacy and relationships with freedom from fear, guilt, shame and taboo
- ◆ To be appropriately supported from vulnerability to risk or harm
- ◆ To have the right to discuss, explore and receive relevant information about relationships, intimacy and sexuality, if that is their wish
- ◆ To have their individual needs and views at the centre of care and support, but with information and support provided to their families too
- ◆ To be able to approach professionals to discuss issues of sex, sexuality and intimacy without being judged
- ◆ To have support relating to sex, sexuality and intimacy throughout their life, including early discussions in childhood, as needs change and at the end of life

STANDARDS FOR STAFF

All members of staff should:

1. Provide a life-long approach to providing information and education for young people, ensuring that they have access to developmentally appropriate information to enable them to explore and develop their own sexual identity, irrespective of gender or sexual orientation
2. Prepare parents/carers to be able to support young people with their emerging sexuality, intimacy and relationship issues
3. Feel confident about communicating with young people about sexuality and relationship issues, undertaking training as necessary
4. Be informed about practical support that they can safely and legally provide to young people, including the use of technology
5. Be aware of cultural and religious beliefs of young people and how these may impact on young people's sexual development and sexual expression
6. Take professional accountability for ensuring that young people are supported with sexual issues, with awareness that avoidance of this can cause distress for young people
7. Take responsibility for safeguarding young people in their care
8. Adhere to codes of professional conduct (see page 18)

STANDARDS FOR ORGANISATIONS AND MANAGERS

Organisations and service managers should:

1. Ensure that there are robust clinical governance procedures in place, and that staff are fully aware of them and know how to use them
2. Ensure that staff are providing support that is within the law and principles of safeguarding, and that complies with professional codes of conduct (see page 18)
3. Ensure there is a sexuality policy in place to support both staff and young people, which is regularly reviewed
4. Provide training to enable their staff to support and advise young people and their families safely and effectively in a culture that welcomes open discussion about sexuality

Part 1: Introduction



The purpose of this document

Talking about sex, sexuality and relationships aims to provide some key standards for health, social care and education staff working with young people who have life-limiting or life-threatening conditions (LLTCs). It provides information about how best to support young people, and their families, in addressing sexuality, sexuality expression, relationships and intimacy, providing signposts to useful resources and examples of the law applied to practice. It is not a comprehensive 'how to' guide covering every aspect of sex, intimacy and relationships but aims to highlight some of the key issues that may arise and build confidence in how to approach the issue of sexuality with young people.

It also sets out some of the key governance issues that need to be considered by organisations and service managers and provides useful case examples that highlight some of the legal and safeguarding issues.

The guidance is not setting-specific, but has been designed for use by statutory, voluntary and independent agencies, as well as professionals who are employed directly through Direct Payments in the UK. The guidance may also be useful for parents, carers and partners.

Who are the young people?

For the purpose of this guidance the term 'young people' is used as a generic term to include children, teenagers and young adults. Where the term 'young adult' is used this refers to people aged 18-40.

The guidance is focused on the needs of young people who have LLTCs. These include a range of different conditions that are likely to end in death either in childhood or early adulthood. Definitions of some of the terms used in this guide are included in Appendix 3 (see page 35).

"The main things I see as important within the guidance is puberty, adolescence, reproduction, local laws plus Q and A section."

“Yeah changes to body and things, also a bit about how to chat to adults not like children. I’m 20, some professionals still chat to me like I’m 12. It’s about not judging people on their stature but as adults.”

There are particular issues faced by young people with LLTCs with regards to their sexuality, not least because their health conditions can have a serious impact on their physical development and their lives as a whole. So often their lives have been dominated by hospital appointments, procedures and treatments, making it difficult to maintain friendships and develop intimate or sexual relationships as they get older.

There is also the added pressure of many conditions being degenerative, which means that many young people can have an uncertain life-course



with reducing physical ability and sometimes also cognitive ability as they get older. Their needs for support to fulfil their wishes and aspirations as end-of-life approaches can make it all the more pressing to ensure that young people are supported to feel valued, loved, desired and to have meaningful relationships or sexual experiences.

Some people with an LLTC have a learning disability. Historically, it has been assumed that people with a learning disability may not understand sex (Hollomotz, 2009) and as such have had social and cultural norms imposed upon them to restrict and at times prevent development of their sexuality. This can make some people with learning disabilities very vulnerable, particularly to abuse, stigma or prejudice. Such negative attitudes and expectations may be detrimental to an individual’s perceptions of their own sexual identity, and consequently their opportunity to learn about and develop a positive, safe and healthy approach to sexuality and relationships. Equally, this sometimes results in discussions relating to sexuality being neglected or overlooked by those involved in caring for people with learning disabilities.

There is sometimes a tendency when supporting young adults with profound learning disabilities to infantilise them – engaging with them as if they are young children. It should be recognised that young adults, whatever their developmental age, should be treated as adults and that sexual expression is an important part of their overall identity as a human being.

Recently, there has been a marked shift towards inclusive, person-centred approaches, and a move to overcome negative attitudes, improve understanding and awareness, and ensure each young person and those around them is able to engage with the development of a sexual identity in whatever way is meaningful to them, regardless of their gender, culture, religion or sexual orientation.

“Over 18s are classed as adults so we should be able to be treated like adults, you know, and we have to make our own choices in life. We will learn from our mistakes...”

What is sexuality?

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.”

World Health Organisation, 2006a

There are many ways of interpreting sexuality. Human sexuality is how people experience and express themselves as sexual individuals. For the purposes of this document, The Open University Sexuality Alliance adopted its understanding of sexuality from the World Health Organisation (WHO). The breadth of the World Health Organisation framing speaks to the diversity of young people with LLTCs, their families, and of those who support them. Most importantly, WHO’s definition reiterates that all people have the capacity to be sexual if they so choose.

“... there are lots of different people out there with different needs, body shapes and developments. However the challenge is to share your sexual needs when people seem to think we are not interested in sex or question our ability to have sexual relationships, in fact any meaningful relationship. I guess it would be a massive step to recognise my unique sexual needs when they tend to ask my carer my needs, i.e. does he want sauce with that?”

“Staff need to be aware of ‘privacy’; respect and choice where sex is concerned.”



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- ◆ To be appropriately supported from vulnerability to risk or harm
- ◆ To have the right to discuss, explore and receive relevant information about relationships, intimacy and sexuality, if that is their wish
- ◆ To have their individual needs and views at the centre of care and support, but with information and support provided to their families too
- ◆ To be able to approach professionals to discuss issues of sex, sexuality and intimacy without being judged
- ◆ To have support relating to sex, sexuality and intimacy throughout their life, including early discussions in childhood, as needs change and at the end of life

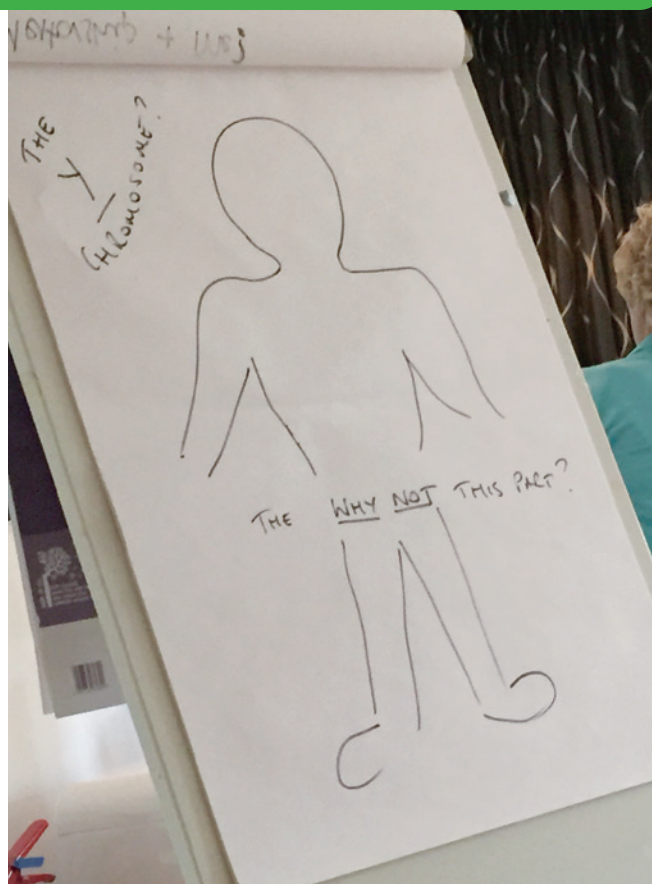
Part 2: For staff

This section of the guide sets out some key information and guidance for staff and provides some sentinel standards for them to use to reflect on their own practice. The standards for staff should be read in conjunction with the underpinning principles.

Sexuality can be a challenging and sensitive discussion area for many people and not least for those supporting young people with life-limiting or life-threatening conditions (LLTCs) and their families. However, staff should be aware of and be prepared to discuss the sexual needs of the young people they are supporting in a non-judgmental way.

While all young people should expect an open, non-judgmental, non-prejudicial approach from professionals, wherever they work, it should also be recognised that the rights of individual members of staff should be respected, so that they are not forced to compromise their religious or cultural beliefs.

In addition, the support needs of an individual young person should also be considered alongside those of other young people who are being cared for within an organisation (www.sexualrespect.com).



STANDARDS FOR STAFF

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2. Prepare parents/carers to be able to support young people with their emerging sexuality, intimacy and relationship issues
3. Feel confident about communicating with young people about sexuality and relationship issues, undertaking training as necessary
4. Be informed about practical support that they can safely and legally provide to young people, including the use of technology
5. Be aware of cultural and religious beliefs of young people and how these may impact on young people's sexual development and sexual expression
6. Take professional accountability for ensuring that young people are supported with sexual issues, with awareness that avoidance of this can cause distress for young people
7. Take responsibility for safeguarding young people in their care
8. Adhere to codes of professional conduct (see page 18)

ETHICS

It should be noted that law and ethics are inextricably linked but different. Ethical principles are founded on maximising benefit and protecting people, particularly more vulnerable people, such as young people with LLTCs, from any risk of harm. This does not always run in parallel to the law and staff may find it difficult when their own moral or ethical values do not seem to be supported by the law.

“I am interested in how things work regarding a carrier of a condition, can it skip, will it skip etc? The few times I have tried to ask more, the conversations have been shut down – not really sure why. It’s not a blame thing, it’s for my understanding.”

Information and life-long learning

Young people are very clear that their sexuality is an important part of who they are and their overall identity. They often want to be able to discuss sex and relationships with trusted adults during childhood, their teens and their adult years (Liddiard, 2013; Liddiard, 2014). Comprehensive sex and relationships education involves learning about the emotional, social and physical aspects of growing up from an early age and throughout life, however uncertain the life-course may be. This includes learning about bodies and how different bodies develop, puberty, gender differences, relationships, sex, sexuality and sexual health.

“I get the feeling that some people (family and professionals) don’t feel I need to know about genetic information, partly due to their perception that I am not sexually active so no need and also because I have a short life span and won’t need info as I won’t have children – go figure...”

Parents and staff should ensure that they can provide a safe and appropriate environment in which conversations can happen, taking into consideration the young person’s age, condition and ability to understand. Given the breadth of the World Health Organisation definition (WHO, 2006a), it can feel overwhelming to know where, and at what point to start discussing sex, but it is important that these discussions do take place and that consideration

is given to whether communication aids may be required, such as the Makaton Sex Education Symbols Book (2008).

Due to advances in medicine and related technologies, many children and young people with LLTCs are now living beyond adolescence, although life expectancy for many may still be uncertain (Fraser et al, 2014). In reality, many young people with an LLTC will die in early adulthood and may want to experience sex and intimacy, whatever that means for each individual, within the short time that they have. For those young people with an uncertain life-course who are contemplating parenthood, the importance of professional signposting to appropriate genetic screening and counselling (if desired) can offer support. This will be important whether end-of-life is soon or still some time ahead.

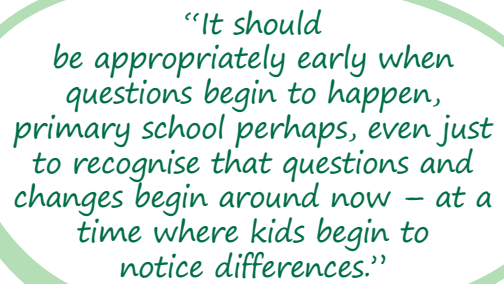
Young people may obtain information and advice about relationships and sexuality from many sources and different types of media, including from their peers, parents, carers, personal assistants (PAs), professionals, books, leaflets, magazines, phone apps and online, and so on. However, this information may not always be up to date or reliable and can be bewildering. Staff and indeed parents/carers should exercise caution about the use of the internet and guard against young people being exposed to damaging material or

“It would be good to capture some sexual health things within standard learning, like disability, body image, connections and sexual beings within primary and secondary education.”

dangerous 'advice'. Young people with LLTCs may be particularly vulnerable because their sexuality has not been recognised and they may not have had appropriate guidance. For those young people who are questioning their sexual orientation and/or gender identity, reliable information may be even more difficult to access.

Young people want to have conversations that include the opportunity to acquire information and knowledge, develop skills, and explore their emotions and their values. Much of the education about sex and relationships that young people receive (if they receive any) only focuses on the biological aspects of sex. Young people have repeatedly said – in our focus groups and in the literature – that they want a more holistic approach to their sexuality and want meaningful conversations with professionals, parents/carers and with their peers (Brook, 2014). For example, some young people with LLTCs may want information about the challenges that they could face with their physical or sensory development and how their condition may impact on their sexuality and sexual functioning.

Staff should ensure that they use reliable sources of information, such as those with the Department of Health Information Standard Certification and those listed in this guide, so that they can feel confident about their knowledge. They should also ensure that young people know how to access information themselves, as well as encouraging them to evaluate whether the information is trustworthy.



“It should be appropriately early when questions begin to happen, primary school perhaps, even just to recognise that questions and changes begin around now – at a time where kids begin to notice differences.”

WHAT DOES THE LAW SAY ABOUT SEX EDUCATION AND INFORMATION?

The Mental Capacity Act 2005 requires that all practicable steps should be taken to help a person make a decision and this includes providing sex education to those who lack capacity to engage in sexual activity (Griffith & Tengnah, 2013).

The right to freedom of expression under Article 10 of the European Convention on Human Rights also requires people to be given access to information which they need in order to make decisions about their own lives.

Professionals must work within the remit of current legislation, seeking support as needed to ensure safety. Requirements will differ depending on the person's age, and professionals should remain mindful of an individual's capacity to consent to particular decision-making or risk-taking situations in the context of different stages of their transition from childhood to young adulthood and beyond. This must include strategies to assess an individual's ability to understand, retain and communicate information relating to an issue. Careful planning by the multidisciplinary team may be of benefit, for example considering the use of an advocate or an interpreter, and there may be local resources to be aware of such as education groups or dating agencies.

The law says that young people are entitled to receive confidential sexual health advice and/or treatment, even if they are under 16, provided that certain criteria, known as Fraser Guidelines are met (see page 35).

The Sexual Offences Act 2003 [section 14(2) and 14(3)] is very clear that it is not an offence to communicate with young people about sex and sexuality if the adult is genuinely acting in the best interests of the young person and intends to:

- a) Protect the young person from a sexually transmitted infection
- b) Protect the physical safety of the young person
- c) Prevent a young person from becoming pregnant
- d) Promote the young person's emotional wellbeing by the giving of advice

For the purpose of this guidance, the term 'young person' is used as a generic term to include children, teenagers and young adults. Where the term 'young adult' is used, this refers to people aged 18-40.

“I’d quite like brothers and sisters to have access [to information] too, if they knew more about things they might feel easier chatting to me.”

Supporting parents, carers and partners

Parents play an important role 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 that sexual maturity brings. It can be difficult for some parents to find the confidence to deal with their child’s emergent sexuality and to find that their child may no longer want them to provide personal care in their teens and beyond.

Staff should ensure that parents are provided with information and support to enable them to respond to their child’s questions and reassure them, as well as feel confident about enabling their child to build and maintain their privacy and personal dignity.

Some young people will have partners, or may be engaged or married. It is important that partners are involved in discussions so that they are part of open and honest communication and learn about the practicalities of having a safe and enjoyable sexual relationship.

Communication

Both staff and parents need training in how to communicate with young people about sexuality, and opportunities to practise having conversations in order that they can offer appropriate support. Parents may have their own perceptions, prejudices and fears about their child’s sexuality and it may be helpful for both young people and their parents to have support from professionals to talk about these.

There is a range of tried-and-tested methods and approaches that work well when communicating with young people about sexuality (FPA, 2015). Staff should familiarise themselves with these and adapt them into their own communication style so that they feel comfortable when talking to young people.



Staff should recognise the broad scope of support that may be required to communicate well with young people, including those with learning disabilities. Their organisations or managers should encourage them to do so safely and effectively through the use of policies, guidance and opportunities for regular training and reflection. Promotion of positive perceptions of sexuality within the care environment will translate into a confident and non-judgmental approach to supporting sexuality, which in turn will ensure young people have the freedom to express their needs in an open and honest way to help achieve the most appropriate support.

“I find it difficult to know who I can ask for information and practical help. At present I feel that I can only chat with very few people and I’m totally embarrassed about the prospect, about even thinking about sexual activity and the ripple of wider discussions.”

“Some health professionals thought that I would just sit around the house and watch TV all day. They didn’t take into account I want to live my life like others and get out, meet people, have fun, shop, and have relationships and stuff.”

“Yeah it would be good to have relationship and sex information. I mean I struggle to find the right age of person to chat with or who I would even consider asking for help; someone too old or too young, my own age of carer, might have different challenges or repercussions.”

“People need to know that we do appreciate the chance to share our thoughts, but it’s a bit tricky to share thoughts around sexual things when you are at a clinic appointment with a range of medics and your parent. That is just wrong, bit of common sense is needed, I would not be comfortable to discuss things in this spotlight situation.”

GOOD PRACTICE TIPS FOR COMMUNICATION

A trainer from the Family Planning Association worked with a group of professionals supporting disabled young people and introduced a simple five-step framework for responding to young people’s questions as follows:

1. “I’m glad you felt able to talk to me about that...”

This encourages the young person to talk to you and also gives you some thinking time.

2. “Where did you hear about...?”

This helps to give you the correct context for the discussion and also helps you to check whether the young person is being harmed or at risk of harm.

3. Give a short, factually correct, age-appropriate answer to the question

Try to answer the question in one sentence, if possible, no matter what the age of the young person. If you do not know the answer, say so straight away but let the young person know that you will find out, or you can find out together.

4. “Does that answer your question?”

This gives the young person a chance to check their understanding or ask you more questions if they still don’t understand or if they want more information.

5. “Remember, you can talk to me and ask me questions any time.”

Even if you have felt a bit embarrassed or uncertain while you were answering the question, saying this gives the young person the idea that you are willing to listen and respond, even if you sometimes find it a bit difficult.

It is important to establish a rapport with someone in order to effectively support their sexuality, and modified communication strategies for those with learning disabilities may be needed to achieve this. Honest, clear and consistent communication may enable individuals to communicate their needs and aspirations, and this will assist in assessing the help that is needed. Examples of support could include encouraging attention to sexual health needs, facilitating individual choices about personal appearance, and ensuring there are opportunities for social interaction and developing friendships and relationships, if desired.

Some young people can find it difficult when forming a relationship with someone to tell them that they are going to die young. This can impact on decisions about having a relationship at all and some young people have said that they struggle with decisions about when or whether to tell a prospective partner. They may feel that they are not being honest with the other person if they don't share information about their short life expectancy from the start. This may be something that they would find helpful to discuss with a trusted professional.

"Staff need to be able to discuss things around puberty, sexual urges, normal morning routines (in regards to erections etc.) and things to do with the law."

"I think we should be talking about the challenges young people with LLTCs may face with their physical and emotional development."

A staff culture of recognising and respecting a person's privacy should be established. There may be a need to seek or provide sexual health education. Some people with learning disabilities need help to understand about privacy and appropriate sexual behaviour. This may be a process of learning that occurs over time (Wills, 2011).

This support may just be needed for the young person, or may extend to important others in their life, such as partners or family.

Practical support

Physical contact is an important aspect of intimate relationships for young people and efforts should be made to improve awareness. This ensures that individual practitioners can feel confident that they are providing safe and lawful support. Assessment of capacity to consent to sexual activity is specific to the sexual act and requires a basic knowledge of the mechanics and health risks involved (for further information, please see Griffith & Tengnah, 2014).

"All environments bring up their own challenges, no pun intended, home – parents can be tricky, taboo discussions plus recognition that I'm sexually developing – embarrassing for everyone; hospital – well enough said clinical and very, very medical; and hospice – great place to chat, time for people to listen, but, eh, a hospice... So good for information, discussions, peer support and answers to embarrassing questions."

Discussions about sexuality, intimacy and relationships often pose challenges for professionals working with young people who have LLTCs, many of whom may also have a significant physical or learning disability. This can cause emotional anxieties or frustration for the young person, and care staff may feel inadequately equipped to support them. Staff may also have their own beliefs and values, which can impact on their feelings about whether and how they should work with young people to manage such matters, or may make them feel embarrassed and reluctant to discuss this subject, so they focus on other aspects of care. Staff may also feel uncertain about the legal framework and be hesitant or unwilling to provide support, in case they are subject to allegations of improper behaviour or abuse. Taboos surrounding sex and intimacy can inhibit acknowledgment of the needs of an individual and lead to avoidance, all of which can create barriers to the support of young people, having a detrimental effect on their overall health and wellbeing (Blackburn, Earle & Komaromy, 2014). Information about general sexual health is just as important to young people with an LLTC as condition-specific information and support.

Young people told us that practical support was vital for having a “normal life”, and sex and sexuality are part of this normality. They wanted to meet people outside of their home and the hospice and this sometimes meant that support was needed to enable this. Practical support to have a “normal life” also meant being treated like an adult or age appropriate adult wherever and whenever possible.

“...we are sexual beings with needs like everyone else, we might need some practical help to reach our goals but it does not make us any less human.”

“I am interested in sexual health... and checking myself out, but it is a challenge just to see my goods! I certainly don't have the ability to lay my hands on them. Who can you ask to check them out and how comfortable would I feel asking others to have a feel? Seriously!”

“We have to make our own choices. We will learn from our own mistakes.”



Providing practical support for sexuality includes a number of different aspects which may be discussed, for example:

- **Sexual positions**

Where appropriate, knowing how to support and enable young adults to get into particular sexual positions, that are manageable, safe and pleasurable, particularly when the young person has pain or mobility issues.

- **Pornography**

Young adults may wish to view pornography, either at home or when visiting a hospice or other residential or short break unit. Managers should ensure that policies enable staff to support this choice sensitively while respecting the young person's privacy and dignity, and that of others.

- **Use of trained sex workers**

Some young adults may decide to use the services of a trained sex worker. Requests for this type of support should be referred to the service manager, as there may be issues of law and safety that need to be considered.

- **Medication and the impact on sexual function**

Some medications can impact on sexual desire and sexual function. It is important that young people are encouraged to seek information about any medication they are on and, if needed, supported to speak to health professionals about any unwanted side effects.

- **Catheterisation, continence and sex**

Some young people may use continence devices and be shy about discussing this with care professionals, let alone discussing it with a sexual partner. They may fear they smell because of a urinary catheter, or bowel or urinary incontinence. Staff can help them discuss both the stigma and practicalities of bladder and bowel incontinence (Blackburn, 2007).

- **Menstruation**

Some young women with LLTCs may start to menstruate early, at around 7-10 years (precocious puberty, see glossary – page 35). Practitioners will require particular skills in explaining how or why a young girl will need to use a sanitary towel or tampon and where the blood flow comes from, at a point in time when the girl may not yet have received any information about her menstrual cycle. This may require more sensitivity if the girl has a learning disability. Male practitioners or carers may need to also think about and find out whether they and the young person are comfortable with them inserting tampons or changing sanitary towels.

- **Checking sexual health**

Some young people may need support in the standard practicalities of sexual health: checking their body for sexually transmitted infections (STIs) and other health problems (e.g. genital/reproductive cancers) and accessing and safely using contraception.

- **The use of technologies**

Developments in technology are supporting young people with LLTCs to live full lives more easily. There are robotic technologies and/or voice activated devices available and in development which have the potential to offer personalised solutions, enabling young people to express their sexuality (see useful resources and additional references, pages 19 and 33). Staff should be aware of the existing and emerging range of sex aids and devices that are available and use their professional judgment about whether a particular piece of equipment is appropriate, taking into consideration the views and wishes of the young person whose needs are to be met.

Cultural issues and diversity

Beliefs are hugely important to many people and there may be occasions when parents and young people express different interpretations or understanding. In order for discussion to take place, it is important to recognise the differences and to respect diversity. If the differences seem too great, it may be important to identify someone trusted by the young person and their partner or family who can help with a conversation, instead of ignoring the subject altogether. It should be recognised that the views of young people (especially those aged over 16) are all-paramount, but that in some cultures the wider community can have a very influential role.



Professional accountability

It is important to recognise that addressing issues about sex and sexuality is both appropriate and legitimate and that staff have a professional and clinical responsibility to do so within the boundaries of their individual cultural, religious and social beliefs and the law. If a member of staff feels unable to provide this level of support then they should refer the young person to someone who is able to do so.

Safeguarding

Staff should be familiar with both national and their organisation's safeguarding policies and procedures for protecting vulnerable children and adults (see page 19 for useful resources). The key issues to be aware of are the law relating to consent, mental capacity and finding the right balance between protecting a young person with an LLTC from harm and taking acceptable risks. As long as those involved in the sexual activity give their consent, the law generally permits freedom of sexual expression.

Adherence to codes of professional conduct

For the purpose of this guidance, the term 'staff' is used to embrace a range of practitioners, including doctors, nurses, allied health and social care professionals and teachers. Each practitioner must adhere to their professional code of conduct. For nurses and midwives this is the Nursing & Midwifery Council's (NMC) Code, 2015. This presents the professional standards that nurses and midwives must uphold in order to practise in the UK. It is based on four themes – prioritising people, practising effectively, preserving safety and promoting professionalism and trust. The Code is necessary to ensure that nurses and midwives are professionally accountable. Not all care practitioners are registered nurses but most managers would expect non-registrants to embrace the principles outlined in for example, the NMC Code, 2015, and the Code of Ethics for Social Work, the British Association of Social Workers (BASW) 2012.

"I have so many questions around the sexual act, the reality of getting into position, knowing what a safe position is. I mean who you would ask for advice, whose role is it to assess the safety of different sexual positions?"

SIGNPOSTING TO USEFUL RESOURCES FOR STAFF

Action Duchenne

www.actionduchenne.org/takin-charge-and-robotics-at-the-institute-of-child-health-saturday-4-july

British Association of Social Workers (BASW) – Code of Ethics for Social Work: Statement of Principles 2012

cdn.basw.co.uk/upload/basw_112315-7.pdf

Brook – Resources for young people

www.brook.org.uk/shop/category/resources

Contact a Family – Growing up, sex and relationships: a booklet for young disabled people

www.cafamily.org.uk/media/379646/growingupsexrelsyoungeople.pdf

FPA – Sex and relationships education (SRE) resources

www.fpa.org.uk/resources/leaflet-and-booklet-downloads

FPA book – Speakeasy: talking with your children about growing up

www.fpa.org.uk/product/speakeasy-talking-your-children-about-growing

FPA – Talking together about sex and relationships

www.fpa.org.uk/product/talking-together-about-sex-and-relationships

Helen & Douglas House – Transition & beyond Toolkit, 2014, Chapter on Sex and Relationships, pages 61-71

www.helenanddouglas.org.uk/get_information/healthcare-professionals/healthcare-resources

Image in Action

www.imageinaction.org

Macmillan Cancer Support (2014) Sexuality and Cancer – information for women: 1st edition. MAC 14768

For further information please see www.macmillan.org.uk

Makaton

www.makaton.org

NSPCC & Triangle – An image vocabulary for children about: feelings, rights and safety, personal care and sexuality (2002)

www.nspcc.org.uk/services-and-resources/research-and-resources/how-it-is

Sexual Respect Toolkit

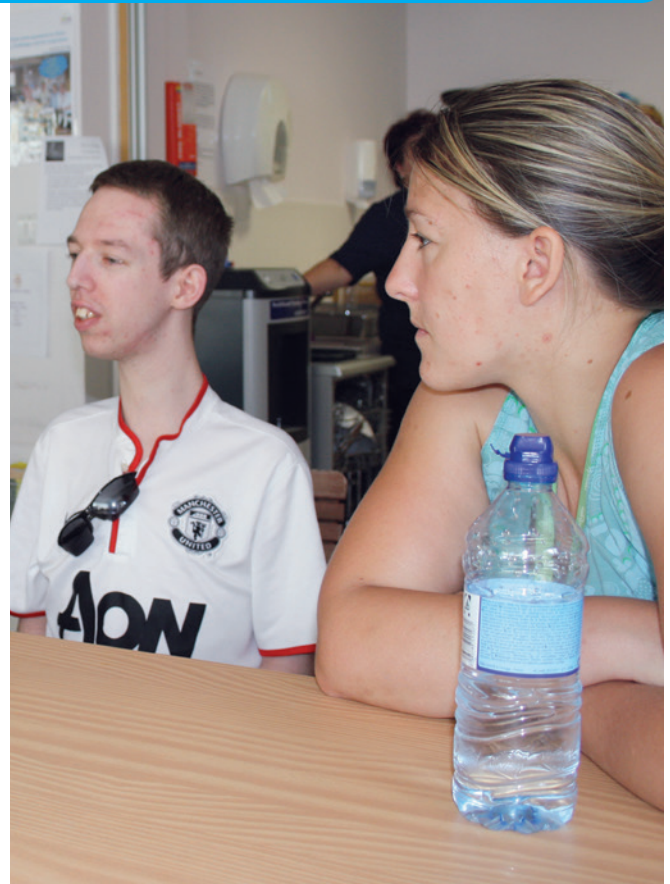
www.sexualrespect.com

Part 3: For organisations and managers

Organisations and managers of teams or services in the statutory, voluntary and private sector should ensure that up-to-date and robust policies, governance, training and guidance are available to their staff, so that they are able to appropriately support young people with sexuality issues. Staff should be able to provide support that can be flexible to the young person's needs and wishes, but also protects their safety and reduces their risk of harm. This should be done in a way that is mindful of the health, safety and comfort of other children, young people and families who are using the service and takes into consideration the individual beliefs of care staff.

Clinical governance is a generic term that relates to activities that help sustain and improve high standards of care. Health and social care organisations have a duty to the communities they serve for maintaining the quality and safety of care, particularly if a person in that community is at risk of harm or abuse. The Care Quality Commission (2010) and the Royal College of Nursing (2014) suggest that there are five key considerations in clinical governance. This guidance suggests that they may be applied to sexuality issues as follows:

- **Young people** – how services are based on young people's needs, including their sexuality
- **Information focus** – how sexuality information is discussed and presented
- **Quality improvement** – how these particular sexuality standards will be reviewed and maintained
- **Staff focus** – how staff are developed, in this case, to be able to address sex, intimacy and



relationships in their daily professional duties with people with life-limiting or life-threatening conditions (LLTCs)

- **Leadership** – how improvement efforts are planned to reduce taboos, and improve the knowledge, confidence and competence of all staff

Organisations and managers should ensure that appropriate governance arrangements are in place and regularly reviewed, in order to support both staff and young people in the workplace.

STANDARDS FOR ORGANISATIONS AND MANAGERS

Organisations and service managers should:

1. Ensure that there are robust clinical governance procedures in place and that staff are fully aware of them and know how to use them
2. Ensure that staff are providing support that is within the law and principles of safeguarding, and that complies with professional codes of conduct (see page 18)
3. Ensure there is a sexuality policy in place to support both staff and young people, which is regularly reviewed
4. Provide training to enable their staff to support and advise young people and their families safely and effectively in a culture that welcomes open discussion about sexuality

CLINICAL GOVERNANCE

“Clinical governance is a system through which NHS organisations [and also the private and third sector throughout the UK] are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.”

Scally & Donaldson, 1998

Principles of safeguarding and the law

The basis of safeguarding, and almost all legislation in the UK relating to sex, is consent. There is a delicate balance between protecting a young person with an LLTC from sexual harm and taking acceptable risks at the right time, in the right place and in the right capacity. Provided that all of those involved in the sexual activity give their consent, the law generally permits freedom of sexual practice in a private place for young adults who are able to give their consent.

However, that general position might not always apply to disabled young people for two important reasons. First, age can be a bar to consent. Any young person under 16 years of age cannot consent to sexual contact of any kind (section 9 of the Sexual Offences Act [SOA] 2003). This is because a person under the age of 16 is presumed to lack the capacity to consent to sexual contact. Because care professionals will generally be in a position of trust, the age of consent for the purposes of the various types of sexual offences found in the SOA is increased from 16 to 18. Second, certain disabilities can be a bar to consent. Section 74 of the SOA defines “consent” as an agreement by choice where the person “has the freedom and capacity to make that choice”. In other words, the consent must be voluntary, without influence or pressure. The person must be informed of all of the risks and the benefits. Where capacity is concerned, the person must be capable of giving consent, which means that they must understand the information given to them and be able to use it to make an informed decision.

For a person not to consent, it must be proved that the person did not have sufficient knowledge or understanding to comprehend the nature and potential consequences of the act that is to take place and that it has a sexual character.

The knowledge or understanding need only be rudimentary and not complete or sophisticated.

It should be acknowledged that disability law is complicated and sometimes may appear confusing. Disability law is in a state of development and the duties of staff to support choice and decision-making may well increase in future.

Sexuality policy

Organisations and service managers should be responsible for developing a clear and robust policy about how their staff should support young people who want to explore their sexuality. This should set out clear reporting lines, be clear about what is within legal frameworks and be informed by research and evidence. Organisations and services should consider identifying someone from the care team to lead on sexuality and who can be responsible for supporting other staff. This might be, for example, the person who leads on transition or safeguarding within the organisation.

One particular area that managers should consider in their sexuality policy is about the use of trained sex workers. Training should be in place to enable staff to confidently discuss the implications of this with the individual with particular reference to issues of law and safety. There are a number of challenges for young adults who are unable to access such services independently and some may request to do so while staying at a hospice or short break unit. Managers should proactively consider this issue and ensure that robust policies are in place to protect and respect the privacy and dignity of the individual, as well as other residents. If the organisation decides against supporting this option, this should be discussed sensitively with the young adult so they can be supported to find an alternative option.

Training

Managers and organisations should work towards achieving a culture in which sexuality issues can be openly discussed within the staff team and in which young people are encouraged and supported to talk about their sexuality and sexual needs. Provision of training for staff is one way that can help to achieve this. Staff should be provided with training that covers a whole range of issues relating to communication with young people and families about sex and sexuality and providing practical support to young people. Such training should be reviewed regularly to ensure that practice is up to date.

KNOW THE LAW IN THE UK

England and Wales

The Care Act 2014

The Children Act 1989

The Children and Families Act 2014

The Deprivation of Liberty Safeguards (www.cqc.org.uk)

The Equality Act 2010 (only applies in England, Scotland and Wales)

The Equality Act 2010 (Specific Duties) Regulations 2011

The Human Rights Act 1998

The Mental Capacity Act 2005

The Sexual Offences Act 1956, 1967, 2003, 2006, 2009

Gillick v West Norfolk and Wisbech AHA [1985] UKHL

Gillick competency and Fraser guidelines, www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines

Scotland

The Adults with Incapacity (Scotland) Act 2000

The Age of Legal Capacity (Scotland) Act 1991

The Equality Act 2010

The Human Rights Act 1998

The Prohibition of Female Genital Mutilation (Scotland) Act 2005

The Protection from Abuse (Scotland) Act 2001

The Protection of Children (Scotland) Act 2003

The Protection of Children and Prevention of Sexual Offences (Scotland) Act 2005

The Sexual Offences (Scotland) Act 2009

Northern Ireland

The Children (Northern Ireland) Order 1995

The Disability Discrimination Acts 1995 & 2005

The Female Genital Mutilation (England, Wales and Northern Ireland) Order 2003

The Human Rights Act 1998

The Safeguarding Vulnerable Groups (Northern Ireland) Order 2007

The Sexual Offences (Northern Ireland) Order 2008

International

The European Convention on Human Rights, particularly Articles 8, 10 and 14

The United Nations Convention on the Rights of Persons with Disabilities



SIGNPOST TO RESOURCES FOR ORGANISATIONS

De Than C & Elvin J (2014). How should criminal law deal with people who have 'partial capacity' in Reed A; Wake N & Livings B (eds), *Mental Condition Defences and the Criminal Justice System: Perspectives from Law and Medicine*

Elvin JD & de Than C (01 Dec 2014). Mistaken Private Defence: The Case for Reform, in Reed A & Bohlander M (eds), *General Defences in Criminal Law: Domestic and Comparative Perspectives*

The Equality Network

www.equality-network.org/wp-content/uploads/2015/04/Resources-for-intersectional-LGBT-people.pdf

Family Planning Association (FPA)

www.fpa.org.uk/sites/default/files/northern-ireland-sex-and-the-law.pdf

The Royal College of Nursing

www.rcn.org.uk/clinical-topics

The Sexual Respect Toolkit

www.sexualrespect.com/wordpress/law

Social Care Institute for Excellence (SCIE)

www.scie.org.uk

Stonewall

www.healthyives.stonewall.org.uk

Part 4: Case histories and the law



Sex and sexuality is a very complex area that involves a number of legal issues. In this section we provide case examples which provide typical scenarios that may pose a challenge to staff and their managers. We have provided some points for consideration and discussion for both staff and managers, with a view to these being used to prompt discussion within a training session. For each scenario we have provided information about some of the key legal issues to be considered.

As the following case histories will highlight, there is a pressing need for the law to be made clearer in this area, and guidance on the specific policies prosecutors would use in applying the law. Without this, there is a significant risk that the current legislation will prevent young people with learning and physical disabilities from exercising fundamental rights, for example in terms of their right to a private life, to be able to have intimate relationships and to form families.

An overview of the law

Young people with life-limiting or life-threatening conditions (LLTCs) should have the same right to relationships, fun and sexual expression as anyone else as long as no harm will be caused (De Than, 2014).

“... wrapping [disabled people] up in cotton wool... the fact is that all life involves risk... physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare.”
(Munby, 2007).

CARE STAFF

Care staff must recognise their professional and legitimate responsibilities in providing personal care, such as washing a young person's genital area because the young person cannot do this by themselves, while acknowledging and understanding that this is an essential part of a carer's role and is not in itself a sexual act. However, sometimes a young person may become sexually aroused during this level of personal care. This may be embarrassing for both the young person and/or care practitioner. This should be managed sensitively in a way that respects the dignity of both the young person and the member of staff. Should the young person indicate that they wish to discuss this situation, they should be given an opportunity to do so. It may also be appropriate to make arrangements for a more structured conversation to take place at a later time following personal care. Non-verbal communication aids may be required where the young person is unable to speak, such as the *Makaton Sex Education Symbols Book* (see references, page 32).

European Convention on Human Rights (ECHR) and the Human Rights Act 1998

The most relevant human rights law in the UK is the European Convention on Human Rights. Currently, under Article 8 of that convention and incorporated into the Human Rights Act 1998 in England and Wales, everyone has the right to respect for their privacy, family life, home and correspondence. The ECHR indicates that Article 8 protects sexual autonomy, confidentiality, dignity, forming and maintaining personal relationships and allowing them to develop normally (*Pretty v UK 2002*). So often staff caring for young people fear reprisal and are anxious that they may risk committing an offence or colluding in a crime. Human rights may only be limited by the State if it needs to do so in order to achieve an aim such as preventing crime or upholding the rights of others. So there should be an equal right for all adults to have consensual sexual

activity in private, alone or consensually with others, to have a relationship of their choice, be intimate and have a child, if they so wish (De Than, 2014).

The Equality Act 2010

The Equality Act 2010 imposes a duty on public authorities to promote equality for disabled people by treating them more favourably and, where necessary, making reasonable adjustments for people with disabilities. Its primary purpose is to codify anti-discrimination law. In relation to disability, it requires equal treatment in access to employment, as well as to private and public services, with employers and service providers under a duty to make reasonable adjustments to their workplaces to overcome barriers experienced by disabled people. This could mean, for example, making adjustments to ensure that disabled young people can access the information, education and equipment they need at various stages of their lives.

A key issue in the UK is that different rules and laws are based on age, mental capacity, the nature of the disability, and whether a disabled person lives at home or in a residential setting. This often makes issues about sexual expression so complicated that many people don't understand what they can and cannot do.

Sexual Offences Act (SOA) 2003

The SOA 2003 criminalises underage teenage sexual behaviour, and those who assist it, even when they act in the best interests of that teenager. Young people under 16 years cannot consent to sex or sexual touching or being touched sexually. It is also a crime for people in a position of trust, such as care staff and teachers, to have sexual contact with a young person under 18 years.

Currently, a young person whose disabilities hinder their sexual expression or communication (for example being unable to masturbate) can only be supported in ways that do not involve touching the young person in any way that may be interpreted as sexual. Here the criminal law conflicts with the human rights of the young person. Naturally there is a delicate balance between protecting a young person from harm and respecting their human rights, particularly their right to sexual expression.

When a young person has an LLTC which may affect communicating consent, such as hearing and speech difficulties, the SOA 2003 presumes that person does not consent to sexual activity and anyone who has sex with that young person cannot guarantee that there was consent. This would then

be presumed to be a sex crime. Campaigners argue that this is an issue in need of legal reform.

The SOA 2003 potentially criminalises people in long-term relationships when one person develops or suffers brain injury, has multiple disabilities or develops a mental illness. There is case law where judges have decided that a disabled person lacked capacity to make informed decisions about sexual expression and prevented that person from continuing their relationship with another person.

The SOA sections 30-33 creates offences against a person labelled by the law as having a 'mental disorder' (see glossary of terms, page 35). This may impede choice, particularly for clients over 18 who are unable to refuse because of a lack of capacity and an inability to communicate their wishes.

Many staff are understandably concerned that sexual activity might occur during their work shift. Unless the practitioner was actively encouraging sexual activity to take place, arguably the practitioner would not be committing an offence. If a practitioner or organisation knew that sexual abuse was taking place and did nothing to prevent it, they could be sued for compensation – but not if consensual sexual activity was thought to be taking place (De Than, 2014).

The Mental Capacity Act (MCA) 2005

The premise of this Act is that everyone is presumed to have mental capacity to make decisions about their own lives, unless and until it is proved that they lack capacity. The Act recognises that everyone has the right to make unwise decisions, which does not necessarily indicate that a person lacks capacity. The Act does not and cannot apply to sexual matters as no one can consent to sex on behalf of another person.

The Court has stated that the basic requirements for capacity to consent to sex are as follows (*Re AB* 2011 Court of Protection, *EWHC 101*):

A person has capacity to consent to sex if they understand on a simple level:

- a) The mechanics of the act
- b) That there are health risks involved, particularly the acquisition of sexually transmitted and transmissible infections
- c) That sex between a man and a woman may result in the woman becoming pregnant (if relevant to them)

If there is anything that can enable a young person to have that basic understanding, then it should be

facilitated. It is not lawful to prevent an adult from having consensual sexual expression in private, alone or accompanied, unless they have already been found to lack capacity to make decisions about sex.

General legal principles in the area of sexuality

Touching clients

Generally clients should not be touched without their permission; doing so may be judged as an assault. There may be exceptions when it may not be possible to obtain consent, such as in a medical emergency. Qualified health professionals, such as doctors, dentists, nurses, physiotherapists may touch their patients within these boundaries but not in a sexual way. Sometimes the law implies consent, such as touching someone to gain their attention, and for washing, or maybe to reassure or support them if the young person is distressed. Care staff who breach consent could be convicted of one or more criminal offences.

Sexual offences and care professionals

The types of potentially criminal behaviour found in the Sexual Offences Act 2003 that care professionals might be concerned about are:

- (a) 'Causing' or 'inciting' unlawful sexual behaviour
- (b) 'Aiding, abetting or counselling' that behaviour

It is important to consider what is meant by each type of offence.



'Causing or inciting'

A care professional would commit a criminal offence by intentionally causing or inciting a young person under 16 to engage in sexual activity (see section 10 of the SOA). Section 31 of the SOA has a similar effect in respect of a person with a 'mental disorder' impeding choice. However, it is important to understand what 'causing' and 'inciting' mean. A care professional would only 'cause' an act if controlling or influencing the person in their care to do it. It is not enough that the care professional assisted the person in their care. Similarly, to 'incite' is to urge or encourage and not to merely assist at the request of the person in care.

'Aiding, abetting or counselling'

The criminal law always recognises that it is an offence to assist another to commit an offence. However, care professionals may benefit from a number of statutory exceptions in the SOA in respect of liability for aiding, abetting or counselling the commission of sexual offences against children. These apply where the aider or abetter does not act for the purposes of sexual gratification or causing or encouraging the activity, but to protect the child from sexually transmitted infection, to preserve the child's physical safety, to prevent the child from becoming pregnant or to promote the child's emotional wellbeing by the giving of advice.

Clients with 'mental disorders'

Care professionals are subject to a specific regime in respect of those labelled by the law as having a 'mental disorder' (see page 35) in their care, whether or not that mental disorder has the effect in practice of restricting choice. The intentional sexual touching of a person with a 'mental disorder' is an offence (section 38 of the SOA) as is causing or inciting sexual behaviour (section 39 of the SOA).

A WORD OF CAUTION

It must be noted that this is a complex area of law. While these general principles apply, their application will vary depending on the specifics of a situation. Care staff should seek legal advice to clarify how the law will apply in a specific situation.

Case histories

This case history, and the following four examples, have been examined and interpreted by legal advisors, in order to address the legal and safeguarding considerations given in this guidance.

CASE HISTORY 1

A young person (age 14) was paralysed in a road traffic accident 18 months ago. S/he can communicate orally, has mental capacity and no acquired learning disability. S/he is currently in a hospice and has asked to watch some porn on the internet but needs assistance in accessing the material. S/he does not want you to tell anyone about this request.

Staff should consider:

- ◆ How would you manage this request in a hospice setting?
- ◆ Should you discuss this request with anyone else?
- ◆ Should you inform the client's parents?
- ◆ What are your responsibilities, legally, morally and in terms of your professional accountability?

Organisations and managers should consider:

- ◆ Is access to online pornography included within the organisation's policy on sexuality?
- ◆ Does the organisation's policy on confidentiality provide adequate guidance for staff for this type of scenario?

What are the legal and safeguarding considerations?

Section 12 of the SOA 2003 states that a person over the age of 18 commits an offence if, for the purpose of obtaining sexual gratification, they intentionally cause another person to watch someone else engaging in a sexual activity, or an image of a person engaging in sexual activity.

If a carer was asked to assist in searching for pornographic material on behalf of a child this should not come within this definition, as the carer would not be doing the internet search in order to 'obtain sexual gratification'.

However, a problem arises by virtue of section 17 of the Act, which covers the situation where someone in a position of trust intentionally causes or incites someone under 18 to engage in a sexual activity.

Strictly speaking, if (as the carer of someone under 18) you assist them to access pornography in the knowledge that they will then be masturbating, this could be construed as inciting a sexual activity and therefore would be illegal.

A position of trust will apply where someone looks after a person under 18 who is accommodated and cared for in a range of settings, including hospitals, care homes, children's homes and residential family centres.

CASE HISTORY 2

A young man in his late teens is having a respite break in a young adult hospice. He tells his care staff member that he needs to masturbate. Due to muscle weakness in his upper body, the young man struggles to use his hands, so cannot masturbate. He has an erect penis and is clearly embarrassed, but has expressed the need for assistance to relieve himself.

Staff should consider:

- ◆ Who to discuss this situation with, for example, at a team meeting or with a senior staff member.
- ◆ How to document this request and any management plan in the young man's care notes.
- ◆ The possible use of sexual aids.
- ◆ The personal care that should be provided by staff following the young man's masturbation.

Organisations and managers should consider:

- ◆ Whether the organisation has detailed, robust policies in place regarding sex and relationships.
- ◆ Appropriate staff ratios in order to safeguard both staff and young people.

What are the legal and safeguarding considerations?

Among the key issues here are the age of the young man and whether the carer is appropriately following the necessary policies put in place by their employer.

Generally, a person at the age of 16 is no longer considered to be a 'child' for the purposes of a number of sections in the SOA 2003. However, as noted in case history 1, where a person is being cared for in certain settings, their carer would be acting in a 'position of trust'. In this scenario, assisting a patient who is under 18 to masturbate would likely result in committing the offence of an abuse of a position of trust to intentionally cause or incite sexual activity (section 17 SOA 2003). Within this offence, there is no exception or defence on the basis of consent by the patient. Where the young man is under 18, despite the carer's function and purpose being one of care, the wording of the legislation (section 78 SOA) is likely to class the act as 'sexual activity' and therefore would be illegal.

If the young man were 18 or older, consent is the key issue. Providing that the young person had the capacity to consent, did give consent and did not have a 'mental disorder', a carer assisting a patient to masturbate would not necessarily be committing an offence under the SOA. That said, this is still a difficult area for practitioners as they may leave themselves open to prosecution if the young person was to later say that they did not in fact give their consent. Organisations would need to ensure that strict policy guidelines were in place detailing, among other things, exactly what 'assistance' means and what appropriate safeguarding measures would need to be in place to protect the young man and carer in such situations.

CASE HISTORY 3

A young person (age 17) has a number of genetic and neuro-muscular degenerative conditions. S/he also has mild learning disabilities. S/he uses a wheelchair and is quite adept and independent in moving around the hospice and in the community. His/her life expectancy is considered to be less than a year. S/he has told you, his/her main professional carer for the day in the hospice, that s/he would like to see a trained sex worker for disabled people. S/he has never had an intimate relationship and would like to experience sex before s/he dies.

Staff should consider:

- ◆ How would you respond to this request?
- ◆ Should you discuss this request with anyone?
- ◆ Would your advice differ if the client was 19 or 25 years old?
- ◆ What are your responsibilities to the client and to yourself?
- ◆ What are your legal duties?

Organisations and managers should consider:

- ◆ Is there clear guidance for staff about confidentiality for this kind of scenario?
- ◆ What is the organisation's process for deciding whether to support this request?
- ◆ What are the implications of meeting this request for other service users?
- ◆ How can the individual member of staff and the wider staff team be supported to manage this scenario?

What are the legal and safeguarding considerations?

The definition of consent is if a person agrees by choice and has the freedom and capacity to make that choice. The issue here is that section 17 of the SOA 2003 (abuse of a position of trust causing or inciting a child to engage in sexual activity) does not include references to consent. In effect, this may mean that a carer would be guilty of the offence of inciting the young person to engage in sexual activity despite having been instructed to do so, namely by consent having been given by the young person.

Abuse of a position of trust applies to patients under the age of 18 so this would not be relevant where the young person was over 18.

Of course, there is law governing sex work which though legal in the UK has many peripheral offences surrounding it, which may be relevant in this situation. That said, it is not necessarily illegal for a care home to arrange for a sex worker to visit a disabled client (who is over 18 and with the capacity to consent), though this is a grey area and care professionals should seek advice from their health and social care inspectorate before proceeding, to ensure that they comply with the national regulator's standards – for example, the Care Quality Commission (see useful organisations, page 37).

CASE HISTORY 4

A young couple (both age 16) ask you to support them to have sex together. They are both physically disabled and neither of them have the motor skills required to put on a condom or to insert a female condom. You have already explored other forms of contraception but they are adamant that they want to use either male or female condoms, as these also offer some protection from sexually transmitted infections. The couple have discussed it and want you to be the person who helps them directly with condom use.

Staff should consider:

- ◆ Who should make the decision about whether this request can be met?
- ◆ How can the support be provided effectively and safely?
- ◆ How can the couple be afforded privacy, dignity and respect?
- ◆ What are the risks?
- ◆ How should this be noted in care records?

Organisations and managers should consider:

- ◆ What is the legal position for the carer?
- ◆ Is the legal position different if the couple involved are both 18 or over?
- ◆ Are there any environmental considerations?
- ◆ Are there any staff health and safety considerations?

What are the legal and safeguarding considerations?

One difficulty with the law in relation to this scenario is the possible overlap between sections 17 and 73 in the SOA 2003.

Generally, section 73 provides an exception which means that a person is not guilty of aiding, abetting or counselling an offence against a child where they act for the purpose of protecting them from sexually transmitted infection or preventing them from becoming pregnant.

However, this exception does not cover all of the offences in the SOA 2003. As discussed in the previous case histories, section 17 covers the offence of abusing a position of trust where causing or inciting a person under 18 to engage in sexual activity. The section 73 exception does not apply to this offence so could not be relied on in this example.

Despite the purpose of the action, because the patient is under 18, the act of applying or inserting the condom would result in the care worker committing an offence. Were both young people to be over 18 and fully consenting, this offence would not apply in this situation.

It should be noted that the law is very unclear here. Generally speaking, a person does not cause the voluntary actions of another person who has capacity. The age of consent to sex is 16, unless there is a position of trust between those involved in the sexual behaviour. If a carer is not involved in the sex in any way, then buying condoms at the request of a person over 16 should not be an offence.

CASE HISTORY 5

One of your colleagues went into the bedroom of one of the adult clients thinking it was empty but found the (male) client having oral sex with another male resident. Both men have a learning disability. The staff member wants to initiate safeguarding procedures immediately and put them in separate residential units as it is not clear whether both of the clients have capacity to consent to sex. It is known that both of the men spend a lot of time together socially and have a very warm and friendly relationship with each other.

Staff should consider:

- ◆ Is the colleague's reaction due to their own personal moral beliefs?
- ◆ Is there a conflict that needs to be raised with a manager?
- ◆ How can it be established whether or not both young men gave consent?
- ◆ How can the young men be supported to understand the need for consent?

Organisations and managers should consider:

- ◆ What is the legal position if the two men continue to spend private time with each other given that it is not clear yet whether they both have capacity to consent to sexual activity?

What are the legal and safeguarding considerations?

The key issue here is what is meant by 'causing or inciting' sexual activity. By not placing the two adult clients into separate nursing homes, in terms of criminal law, the care worker is not 'causing or inciting' sexual activity in relation to section 39 of the SOA 2003. Unless care workers were actively encouraging the sexual behaviour to take place, they would not be committing an offence.

There is a possibility of the practitioner or organisation being sued for compensation if they knew at the time that sexual abuse was taking place and did nothing to prevent this, but not if consensual sexual activity was thought to be taking place.



If everyone involved in sexual activity:

- is an adult;
- is not a carer;
- has capacity to consent to sex;
- can communicate about consent;
- consents;

and the sexual activity is being conducted in private, then it is generally lawful.

If any one of these criteria is not met, it may not be lawful.

KEY QUESTIONS FOR CONSIDERATION IN EACH OF THE ABOVE CASE HISTORIES

- ◆ What do you **want** to do?
- ◆ What **must** you do?
- ◆ What should you definitely **not** do?

References

- ACT (2009). *Let's Talk about Sex; Let's Talk about You and Me*. Available at www.togetherforshortlives.org.uk/ (accessed 6.10.2015)
- ACT & Triangle (2011). *The Whole Picture: Exploring disability and sexuality*. DVD.
- Beresford BA & Stuttard L (2014). *Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions*. *Clinical Medicine*, vol 14, no 4, p 404-408.
- Blackburn MC, Earle S & Komaromy C (2014). *Relationships and Sexuality in Young Adults with Life-Limiting Conditions in the UK*. *BMJ Support Palliat. Care*, 4, A27 doi:10.1136/bmjspcare-2014-000654.74
- Blackburn MC (2007). *Safeguarding Children and Young People with Continence Difficulties*: in *Effective Management of Bladder and Bowel problems in Children*. Ch1 p5-24; eds. Bonner L & Wells M: Class Publishing, London, ISBN 13: 9781859591659.
- Blackburn MC (2002). *Sexuality and Disability*. Butterworth/Heinemann: Elsevier Science, ISBN: 7506-2252-0.
- Brook (2014). *Sex and Relationships Education (SRE) for the 21st Century*, London: Available at Brook www.brook.org.uk/your-life/category/relationships (accessed 6th October 2015)
- Care Quality Commission (2010). *Guidance about Compliance: Summary of Regulations, Outcomes and Judgment Framework*.
- Chailey Heritage Foundation (2014). *Safeguarding children and adults at risk (vulnerable adults)*. Available at www.chf.org.uk/Safeguarding_Policy.pdf (accessed 6th October 2015).
- De Than C (2014). *Sex, Disability and Human Rights: Current legal and practical problems* in Owen & De Than, *Supporting Disabled People with their Sexual Lives; A clear guide for health and social care professionals*: Jessica Kingsley Publishers, ISBN: 978-1-84905-369-9.
- Family Planning Association (2015). Online sex and relationships education resource for primary schools. Available at www.fpa.org.uk/schools-and-teachers/online-sre-and-pshe-primary-schools?ems= (accessed 7th October 2015).
- Fraser LK (2014). *Prevalence in young adults with life-limiting and life threatening conditions*. Report available from Together for Short Lives.
- Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA & Parslow RC (2012). *Rising national prevalence of life-limiting conditions in children in England*, *Pediatrics*, vol 129, no 4, p e923-e929, 10.1542/peds.2011-2846. Available at pediatrics.aappublications.org/content/129/4/e923 (accessed 6th October 2015).
- Griffith R & Tegnah C (2014). *Assessing capacity to consent to sexual relations: a guide for nurses*, *Br J Community Nurs*, Apr, vol 18, no 4, p198-201.
- Helen & Douglas House (2014). *Transition and Beyond Toolkit for professionals working with young people who have palliative care needs*.
- Hollomotz A (2009). *Beyond 'Vulnerability': An Ecological Model Approach to Conceptualizing Risk of Sexual Violence against People with Learning Difficulties*, *The British Journal of Social Work*, vol 39, no 1, p99-112.
- Liddiard K (2013). *Reflections on the Process of Researching Disabled People's Sexual Lives*, *Social Research Online*, vol 18, no 3, p10.
- Liddiard K (2014). *The Work of Disabled Identities in Intimate Relationships* in *Disability and Society*, vol 29, no 1, p115-128.
- Makaton: *Sex Education Symbols Book* www.makaton.org/shop/shopping/stockDetails/Sex-Education-Symbols-Book (accessed on 6th October 2015).
- Sir James Munby. *Re MM 2007, EWHC, 2003*.
- Nursing & Midwifery Council (2015). *The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives*. www.nmc.org.uk/standards/code (accessed on 6th October 2015).
- Qualitative Software International: NVIVO www.qsrinternational.com (accessed on 6th October 2015).
- Royal College of Nursing (2014). *Core Knowledge. Sexual Health for Non-Experts*. CPD Online Learning www.rcn.org.uk/clinical-topics (accessed 6th October 2015).
- Sally G & Donaldson LJ (1998). *Clinical Governance and the Drive for Quality Improvement in the New NHS in England*, *British Medical Journal*, vol 317, no 7150, 4 July, p61-65.

Wills C (2011). *Obtaining Consent to help a Young Man with Difficulties Masturbating*, Learning Disability Practice, vol 14, no 6.

World Health Organisation (2006a) *Sexual and Reproductive Health*. www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/ (accessed on 6th October 2015).

Additional references

Abbott D, Carpenter J & Bushby C (2012). *Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy: Research from the UK*, Neuromuscular Disorders, 22, 445-456.

Abbott D & Carpenter J (2012). *Talking about Tricky Transitions with Young Men with Duchenne Muscular Dystrophy and their Families* BMJ Supportive & Palliative Care, 2 (2) 17.

Care Quality Commission (2014). *From the Pond into the Sea: Children's transition to adult health services*. www.cqc.org.uk/content/teenagers-complex-health-needs-lack-support-they-approach-adulthood (accessed 6th October 2015).

CLIC Sargeant (2015) Sexual Identity www.clicsargent.org.uk/content/sexual-identity (accessed 2 December 2015)

Elvin JD & de Than C (2014). *Mistaken Private Defence: The Case for Reform*, in Reed A and Bohlander M (Eds), *General Defences in Criminal Law: Domestic and Comparative Perspectives*.

Earle S, Komaromy C & Layne L (2012). *Understanding Reproductive Loss: Perspectives on Life, Death and Fertility*. Ashgate.

Earle S, Foley P, Komaromy C & Lloyd CE (2008). *Conceptualising Reproductive Loss: A Social Sciences Perspective*, Human Fertility, vol 11, no 4, p259-262, ISSN: 1464-7273.

Earle S, Komaromy C, Foley P and Lloyd C (2007). *The Social Dimensions of Reproductive Loss*, The Practising Midwife, June, ISSN: 1461-3123.

Fanstone C and Ktrak Z (2003). *Sexuality and Learning Disability* see www.fpa.org.uk (accessed October 6 2015).

Goldman A, Hain R, and Liben S (2012). *Adolescents and Young Adults*, in The Oxford Textbook of Palliative Care for Children, ISBN: 978-0-19-959510-5.

Komaromy C, Earle S, Foley P & Lloyd C (2007). *Reproductive Loss and the Moment of Death* in The Practising Midwife, ISSN: 1461-3123.

Komaromy C, Earle S, Lloyd C & Foley P (2007). *A Social Insight into Bereavement and Reproductive Loss* in The Practising Midwife, ISSN: 1461-3123.

Liddiard K (forthcoming). *The Intimate Lives of Disabled People: Sex and Relationships*. Ashgate Publishing Limited, ISBN: 978-1-4094-6090-9.

NICE (2011, revised 2013). *End of Life Care Quality Standards*. www.nice.org.uk/guidance/qs13 (accessed 6th October 2015).

The Open University www.open.ac.uk/health-and-social-care/research/sexuality-alliance

Sinason V (2010) *Mental Handicap and the Human Condition, An Analytic Approach to Intellectual Disability*, (Revised 2nd edition) Free Association Books.

Together for Short Lives (2015). *Stepping Up: A Guide to Enabling a Good Transition to Adulthood for Young People with Life-Limiting and Life-Threatening Conditions*, ISBN: 1 898 447 330.

Together for Short Lives (2013). *A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions*, third edition.

WREX – Introducing Wilmington Robotic Exoskeleton for Quadriplegics, muscular dystrophy, SMA, Cerebral Palsy www.dailymotion.com/video/x2wpawu_wrex-introducing-wilmington-robotic-exoskeleton-for-quadriplegics-muscular-dystrophy-sma_tech

The Law Commission Consultation is proposing significant changes to the Mental Capacity Act 2005 and linked laws:

<http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>

And the interim Government response is at: <https://www.gov.uk/government/publications/deprivation-of-liberty-standards-dols-consultation-response/departments-of-health-response-to-the-law-commissions-consultation-on-mental-capacity-and-deprivation-of-liberty>

The sexuality journey

The framework below is loosely adapted from The Sexual Respect Toolkit, www.sexualrespect.com and KidsHealth kidshealth.org/parent/growth/sexual_health/development_foyer.html

Typical milestones of sexual development for young people. The stages may differ for a young person with a life-limiting, life-threatening condition

Infancy (up to approximately 18 months)

- Children become sexual from birth
- Males may have erections in the womb
- Babies develop their sexuality by suckling, touching and being appropriately touched, and responding to positive and appropriate interaction with family
- The tenderness and love that a baby or child receives may enable the child to reciprocate appropriate love and affection to others

Toddlerhood (approximately 18 months – 3 years)

- Toddlers usually develop language and movement
- They start to name body parts and differences between boys and girls
- They may become curious about their body and may touch their own genitals
- Girls may begin to experience orgasm if they touch their own genitals
- Boys don't usually ejaculate until puberty
- Children will observe human interactions and mimic

Pre-school (approximately 3 – 5 years)

- Children are interested to discover that the bodies of opposite gender parents or siblings differ
- They develop interest in sexual content in the media
- They want to know where babies come from
- Often affectionate, hugging, holding hands with other children

Pre-adolescence (approximately 8 – 13 years)

- Transition from childhood to adolescence
- Puberty begins in most children
- Self-conscious about their bodies
- Increased preoccupation about physical appearance
- Often shy about undressing in front of others
- Masturbation may increase as a form of pleasure
- Often have 'crushes' on older adults
- Group dating/parties may begin at the end of this period
- Process of sexual identity develops

Young people (approximately 14 – 18 years)

- Menstruation in girls, early morning erections in boys
- Physical growth, pubertal and psycho-social development
- Timing of puberty, early or late onset may impact on behaviour
- Identity and sexual identity develops
- Awareness of body and self-image, particularly skin appearance, body weight concerns, how one is seen or perceived by others
- Identifies with peer group pressure
- May express ambivalence between dependence and independence
- Challenge parental intervention while also seeking their support
- Possible sexual ambivalence which may deepen questioning about being gay, lesbian, transsexual or bisexual (LGBT) – see glossary, page 35

Glossary of terms

A child is defined as a young person aged up to their 18th birthday.

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both the child and their family – physical, emotional, social and spiritual – through a range of services.

Complex or continuing care is a bespoke package of care beyond what is available through core and universal services. It is provided to children and young people with high levels of complexity or intensity of nursing care needs.

Direct payments and personal budgets are offered by local authorities to enable more flexibility over how care and support is arranged and provided throughout the UK. They are delivered through a new system of Self-Directed Support in Scotland (SDSS) with similar but separate legislation. They are given both to people with care and support needs, and also to carers. A personal budget or direct payment will be created after an assessment by social services.

Disability or a disabled person. A person is disabled under the Equality Act 2010, if they have a physical or mental impairment that has a substantial and long-term negative effect on their ability to do normal daily activities.

Emerging adulthood is a distinct developmental stage spanning late adolescence to mid/late 20s and sums up the period of ongoing transition into adulthood (Beresford, 2014).

End-of-life care. The end-of life phase begins when a judgment is made that death is imminent. It is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support, and support for the family into bereavement.

Gillick competency and Fraser guidelines refer to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under-16-year-olds without parental consent. Since then, they have been more widely used to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions. www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines (accessed 6th October 2015).

LGBT or **GLBT** are initials that stand for lesbian, gay, bisexual and transgender.

Life-limiting/life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

Long-term means 12 months or more, e.g. a long-term breathing condition that develops as a result of a lung infection.

Mental disorder. The Sexual Offences Act 2003 uses the definition of mental disorder from section 1 of the Mental Health Act 1983. Section 1 of the Mental Health Act sets out that mental disorder includes any 'disorder or disability of the mind'. A person with a learning disability is not normally considered by reason of that disability to be suffering from a mental disorder unless the disability is associated with abnormally aggressive or seriously irresponsible conduct. Dependence on alcohol or drugs is not considered to be a disorder or a disability.

Extreme pornography. Sections 63-67 of the Criminal Justice and Immigration Act 2008 makes it an offence to possess extreme pornographic images that depict acts which threaten a person's life; which result in or are likely to result in serious injury to a person's anus, breasts or genitals; bestiality; or necrophilia. The Act also provides for the exclusion of classified films and sets out defences and the penalties for the offence. Section 68 and Schedule 14 of the Act are in place to ensure that the operation of the extreme pornography offence is consistent with the UK's commitments under the E-Commerce Directive (Directive 2000/31/EC) with regard to services provided by the internet industry.

Precocious puberty is the onset of signs of puberty before age 7 or 8 in girls and age 9 in boys. In girls, this may include any of the following before 7 or 8 years of age: breast development, pubic or underarm hair development, a rapid growth in height, start of menstruation, acne, a mature body odour. In boys, signs before 9-years of age include: enlargement of the penis or testicles, pubic, underarm or facial hair development, rapid growth in height, deepening voice, acne, a mature body odour.

Sex refers to the biological characteristics that define humans as female or male. While these sets of biological characteristics are not mutually exclusive, as there are individuals who possess both, they tend to differentiate humans as males and females. In general use in many languages, the term sex is often used to mean 'sexual activity', but for technical purposes in the context of sexuality and sexual health discussions, the former definition is preferred

www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/ (accessed 6th October 2015).

Sexual health is "a state of physical, emotional, mental and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO, 2006a)

Sexuality: "A central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." (WHO, 2006a)

Sexual rights. "There is a growing consensus that sexual health cannot be achieved and maintained without respect for, and protection of, certain human rights. The working definition of sexual rights given below is a contribution to the continuing dialogue on human rights related to sexual health. The fulfilment of sexual health is tied to the extent to which human rights are respected, protected and fulfilled. Sexual rights embrace certain human rights that are already recognised in international and regional human rights documents and other consensus documents and in national laws.

Rights critical to the realisation of sexual health include:

- the rights to equality and non-discrimination
- the right to be free from torture or to cruel, inhumane or degrading treatment or punishment
- the right to privacy
- the rights to the highest attainable standard of health (including sexual health) and social security
- the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage
- the right to decide the number and spacing of one's children
- the rights to information, as well as education
- the rights to freedom of opinion and expression, and
- the right to an effective remedy for violations of fundamental rights.

The responsible exercise of human rights requires that all persons respect the rights of others. The application of existing human rights to sexuality and sexual health constitute sexual rights. Sexual rights protect all people's rights to fulfil and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination." (WHO, 2006a, updated 2010)

Useful organisations

Action Duchenne

A UK charity dedicated to funding research into a cure for Duchenne Muscular Dystrophy and improving the lives of people affected by DMD.

www.actionduchenne.org

The British Association of Social Workers (BASW)

The largest professional association for social work in the UK, with offices in England and Northern Ireland.

www.basw.co.uk

British Institute of Learning Disabilities (BILD)

Information and publications, training and consultancy.

www.bild.org.uk

Brook Advisory Services

Dealing with under 25s sexual health and wellbeing, with a range of leaflets, resources and teaching aids on sexuality and relationships, including for people with learning disabilities and their teachers.

www.brook.org.uk

The Care Quality Commission

The independent regulator of health and social care in England. It makes sure health and social care services provide people with safe, effective, compassionate, high-quality care and encourages care services to improve.

www.cqc.org.uk

The Challenging Behaviour Foundation

The UK charity for people with severe learning disabilities whose behaviour challenges. It works to improve understanding of challenging behaviour, empower families with information and support, and help others to provide better services and more opportunities to make a difference to the lives of children and adults across the UK.

www.challengingbehaviour.org.uk

CLIC Sargent

This is the UK's leading cancer charity for children/young people, and their families, providing support from diagnosis, during treatment and bereavement.

www.clicsargent.org.uk

The Council for Disabled Children (CDC)

The umbrella body for the disabled children's sector in England, with links to other UK nations. CDC aims to make a difference to the lives of disabled children and children with special educational needs. It aims to influence Government policy, working with local agencies to translate policy into practice and producing guidance on issues affecting the lives of disabled children.

www.councilfordisabledchildren.org.uk/what-we-do

Contact a Family

A national charity that provides information, advice and support for families with a disabled child. It brings families together so they can support each other. It campaigns to improve their families circumstances, and for their right to be included and equal in society.

www.cafamily.org.uk

Disability Wales

The national association of disability groups in Wales works to promote the rights, inclusion, equality, and support of all disabled people in Wales.

www.disabilitywales.org

DMD Pathfinders

A user-led charity which promotes choice and control and quality of life for teenagers and adults with Duchenne Muscular Dystrophy in the UK. It campaigns for improved standards of health and social care and provides advice, guidance and support to teenagers and adults with DMD on issues such as independent living, housing, employment and welfare rights.

www.dmdpathfinders.org.uk/about

ENABLE Scotland

A membership organisation for people with learning disabilities and their family carers in Scotland.

www.enable.org.uk

Family Planning Association (FPA)

A sexual health charity, providing training and resources on sexuality and learning disability, including easy read booklets on contraception and sexually transmitted infections.

www.fpa.org.uk

Foundation for People with Learning Disabilities (FPLD)

Works with people and their families to ensure they can use effective services, play a fuller part in communities and society, and enjoy equal rights.

www.learningdisabilities.org.uk

The General Medical Council (GMC)

Helps to protect patients and improve medical education and practice in the UK by setting standards for students and doctors. It supports them in achieving and exceeding those standards, and takes action when they are not met.

www.gmc-uk.org/about/index.asp

Healthcare Improvement Scotland (HIS)

The national healthcare improvement organisation for Scotland and part of NHS Scotland. It works with staff who provide care in hospitals, GP practices, clinics, NHS boards and with patients, carers, communities and the public. By inspecting care, HIS helps to ensure that healthcare services are meeting the required standards of care, that good practice is identified and areas for improvement are addressed.

www.healthcareimprovementscotland.org

Healthcare Inspectorate Wales (HIW)

The independent inspectorate and regulator of all health care in Wales.

www.hiw.org.uk/about-us

Hospice UK

A national charity supporting over 200 hospices in the UK. It believes that everyone matters throughout their life right up until they die, and that no one should die in avoidable pain or suffering. It aims to ensure that everyone with a life-limiting or terminal condition receives the very best care, and believes that hospices are critical to achieving this. Collectively hospices in the UK care for around 360,000 people every year. Hospice UK works closely with hospices to support them in their vital work and to create a stronger voice for hospice care. Hospice UK also supports the development of hospice and palliative care worldwide.

www.hospiceuk.org

The Institute of Psychotherapy and Disability (IPD)

Exists as an organisation to develop, accredit and regulate psychotherapists who work with people with disabilities. Established in May 2000, their initial focus was on the needs of people with learning disabilities. Over time, their perspective has

broadened to include individuals who have physical disabilities.

www.instpd.org.uk

LawWorks

A registered charity which enables access to justice to individuals in need of advice, who are not eligible for legal aid and are without the means to pay for a lawyer. It brokers legal advice to small not-for-profit organisations, to support the continuation and expansion of their services to people in need for free in England and Wales.

www.lawworks.org.uk

Macmillan

A national charity supporting people with cancer and their families from the moment of diagnosis, through treatment and beyond.

www.macmillan.org.uk

Marie Curie

A national charity providing care and support for people living with any terminal illness, and their families.

www.mariecurie.org.uk

The National Council for Palliative Care (NCPC)

This is the umbrella charity for all those involved in palliative, end-of-life and hospice care in England, Wales and Northern Ireland. It believes that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition.

www.ncpc.org.uk

The Nursing & Midwifery Council (NMC)

Regulates nurses and midwives in England, Wales, Scotland and Northern Ireland. It exists to protect the public. It sets standards of education, training, conduct and performance so that nurses and midwives can deliver high quality healthcare throughout their careers. It makes sure that nurses and midwives keep their skills and knowledge up to date and uphold professional standards.

www.nmc.org.uk

The Open University (OU)

The Open University's mission is to be open to people, places, methods and ideas. It promotes educational opportunity and social justice by providing high-quality university education to all who wish to realise their ambitions and fulfil their potential. Through academic research, innovation

and collaborative partnership it seeks to be a world leader in the design, content and delivery of supported open learning. The Open University is incorporated by Royal Charter, an exempt charity in England & Wales and a charity registered in Scotland.

www.open.ac.uk

People First

Independent self-advocacy for people with learning difficulties.

www.peoplefirsttld.com

Respond

Provides counselling and therapy for people with learning difficulties, their families and carers and professionals who work with them.

www.respond.org.uk

Scottish Consortium for Learning Disability (SCLD)

SCLD is a charity and an independent company made up of partner organisations who have joined together with funding from the Scottish Executive to become the Scottish Consortium for Learning Disability.

www.sclld.org.uk

Sex Education Forum

Advice and publications on developing sex and relationships education policies, working with parents and carers in delivering sex and relationship education. Their factsheet 32 is *Sex and relationship education for children and young people with learning difficulties*.

www.sexeducationforum.org.uk

Sexual Health and Wellbeing Programme (WISHH)

The Scotland-wide Sexual Health and Wellbeing Network will help by drawing on skills base, knowledge and experience; sharing various approaches and our experiences of them; and developing ways of effectively sharing information.

www.healthscotland.com/SHW

Sexual Health and Disability Alliance (SHADA)

SHADA was started by the charity Outsiders in 2005. SHADA produces policy guidelines for GPs, surgeons, therapists, residential homes, colleges, disability agencies, including information on sex and learning disabilities.

www.shada.org.uk

Stonewall

Aims to provide help, advice, information and support for lesbian, gay, bisexual and trans communities (LGBT) and their allies.

www.stonewall.org.uk

The Regulation and Quality Improvement Authority (RQIA)

Northern Ireland's independent health and social care regulator. RQIA encourages continuous improvement in the quality of health and social care services through a programme of inspections and reviews.

www.rqia.org.uk

The Royal College of Paediatrics and Child Health (RCPCH)

Responsible for training and examining paediatricians in the UK. RCPCH has over 16,000 members in the UK and internationally, and sets standards for professional and postgraduate medical education of paediatricians.

www.rcpch.ac.uk

The Royal College of Nursing (RCN)

The RCN promotes excellence in practice and shapes health policies and represents the interests of nurses and nursing locally, nationally and internationally.

www.rcn.org.uk

The Teenage Cancer Trust

The Teenage Cancer Trust supports teenagers with cancer and their families.

www.teenagecancertrust.org/about-us

Together for Short Lives

Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. It supports families, professionals and services, including children's hospices. It helps to ensure that children and young people can get the best possible care, wherever and whenever they need it.

www.togetherforshortlives.org.uk

Triangle

Triangle is an independent organisation working directly with children and young people with complex needs. They give expert opinion to the courts and teach and advise parents and professionals.

www.triangle.org

Members of The Open University Sexuality Alliance



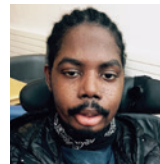
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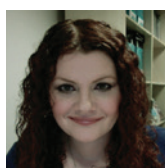
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Talking about sex, sexuality and relationships: Guidance and standards is endorsed by the Royal College of Nursing (RCN)

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This document will be reviewed at the end of December 2018