

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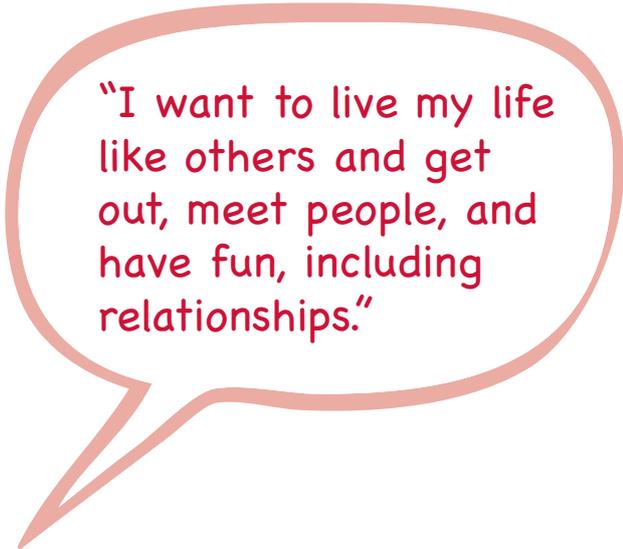
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“I want to live my life like others and get out, meet people, and have fun, including relationships.”

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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 organisations who support us. This guidance allows professionals to support our right to explore sexuality, sex and relationships, by enabling the professionals to know what type and level of support is (and isn't) permitted by law. Sadly, young people like us often encounter misunderstandings of our sexual needs and desire for relationships, they don't understand how important sexuality is for us and why, let alone have the knowledge and support on how to approach conversations about these topics and support us with this aspect of our lives.

Sexuality is not rocket science, it's part of everyday life. We hope that 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, 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 neglected or prevented. Staff need training and support.



This third edition, evidenced based guide is underpinned by standards, has a number of useful sections with quotes from people with life-limiting conditions who contributed to its development. Appendix 3 includes some top tips for living with a life-limiting condition when you are LGBTQ+. 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. There just isn't enough information and support out there, none more so than for young people with complex needs and physical limitations arising from their life-limiting condition. Whilst the internet is a wonderful tool, it doesn't tell you everything and cannot replace continued discussion about these topics from knowledgeable staff who work with us and who can provide us with tailored support and advice specific to our own conditions and needs.

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

The Open University Sexuality Alliance with members of the AdversiTeam have completed on-line education resources about sexuality and people with life-limiting conditions with the OpenLearn Team. There is some synergy between these resources and the on-line education resources, please see <https://www.open.edu/openlearn/talkaboutsex>.

Happy reading!



**Lucy Watts MBE Master of The Open University
Chair of The AdversiTeam
2019**

Introduction

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 et al, 2014) and there are now an estimated 55,000 people age 18-40 years with a LLTC in the UK (Fraser, 2013).

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 a LLTC, sex may not necessarily be about intercourse but simply sharing an intimate relationship with someone else (Blackburn, 2018).

It has been recognised for some time by health, social care and education practitioners (Care Quality Commission, 2019), 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.

The Open University Sexuality Alliance (the Alliance) was formed in 2013 with the key purpose of developing sexuality resources for health, social care and education staff working with young people LLTCs. The Alliance is a collaborative partnership which brings together representatives from public sector organisations, charities, service users and academics with an interest in providing holistic care for young people with LLTCs provide comment, critical feedback, as well as experience from policy, practice and the law on all resources that are developed. The AdversTeam, a group of young adults with LLTCs are co-researchers who support the work of The Open University Sexuality Alliance.

The Open University with Together for Short Lives, working closely with the Alliance, published the first edition of *Talking about sex, sexuality and relationships: Guidance and Standards* in 2015 and this is now the third edition. Both organisations recognise the importance of LGBTQ+ and this will feature more specifically in future work undertaken by The Open University Sexuality Alliance. However, Appendix 3 offers some specific tips about being LGBTQ+ and having a LLTC.

The Standards



Underpinning Principles

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

1. To have the right to privacy, dignity and confidentiality.
2. To be treated in an age-appropriate way, regardless of their developmental stage and mental capacity.
3. To be able to address sexuality, intimacy and relationships with freedom from fear, guilt, shame and taboo.
4. To be appropriately supported from vulnerability to risk or harm.
5. To have the right to discuss, explore and receive relevant information about relationships, intimacy and sexuality, if that is their wish.
6. To have their individual needs and views at the centre of care and support, but with information and support provided to their families too.
7. 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
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 and technological support that they can safely and legally provide to young people.
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.
7. Take responsibility for safeguarding young people in their care.
8. Adhere to their professional body's code of conduct.

Standards for Organisations/Managers

Organisations and service managers should:

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

Part 1: Introduction



The purpose of this document

This third edition of *Talking about Sex, Sexuality and Relationships* aims to provide 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, including some top tips about living with a LLTC when you are LGBTQ+, see Appendix 3 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. In Part 4, there are 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 and voluntary sector agencies, independent organisations as well as professionals who are employed 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 and over.

The guidance is focused on the needs of young people who have life-limiting or life-threatening conditions (LLTCs). These include a whole range of different conditions, which have in common that they are likely to end in a premature death, either in childhood or early adulthood. Definitions of some of the terms used in this guide are included in Appendix 4.

"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 life-limiting conditions 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 fulfill 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 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, identity, culture 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, 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, ethical, legal, historical, religious and spiritual factors”

World Health Organization, 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. The breadth of the World Health Organization (WHO) framing speaks to the diversity of young people with LLTC, their families, and of those who support them. Most importantly, the WHO 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.”



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.

Part 2: For staff

This section of the guide sets out some key information and guidance for practitioners and provides some sentinel standards for them to use to reflect on their own practice. The standards for practitioners 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 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.

The support needs of an individual young person with a LLTC should be considered alongside those of all other children and young people who are being cared for within an organisation (www.sexualrespect.org).

The exception to this is where the law requires the staff member to act in a particular way, or to refer the issue to another staff member.

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 are in conflict with the law.

Standards for Staff:

All members of staff should:

1. Provide a life-long approach to educating and informing 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 their professional body's code of professional conduct.

Information and life-long learning

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. In reality, many young people with a 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 imminent or still some time ahead.

"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..."

Young people are very clear that their sexuality is an important part of their identity and they often want to be able to discuss sex with trusted adults during childhood, their teens and their adult years. 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. New guidance in England related to sex education (SRE) will soon become compulsory in schools for both disabled and non-disabled pupils (DfE, 2019a). Schools will be obliged to meet their responsibilities to enable disabled pupils to access SRE education and prepare them for adulthood (DfE, 2019b).

"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."

Parents and practitioners 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 Organization 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).

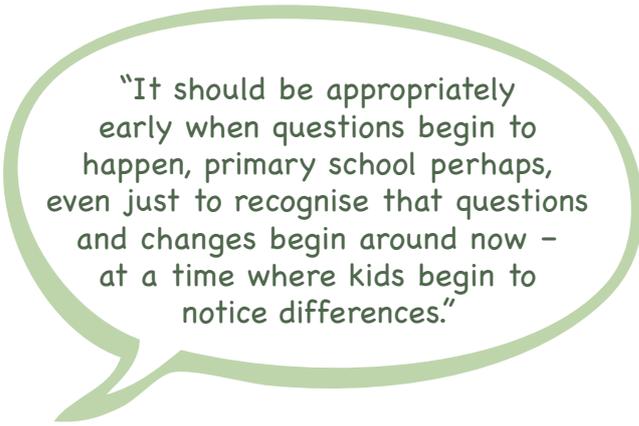
Young people want to have conversations that include the opportunity to acquire information and knowledge, develop skills, and explore their emotions and their values. Much of the education about sex and relationships that young people receive (if they receive any) often only focuses on the biological 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; Scope, 2019). 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.

"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."

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. 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 dangerous 'advice'. Young people with LLTC 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.

Staff should ensure that they use reliable sources of information, so that they can feel confident about their knowledge (see Appendix 1). They should also ensure that young people know how to access information themselves, as well as encouraging them to self-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 and Tegenah, 2013). An updated version of the Mental Capacity Act Code of Practice should be available in late 2019. As stated above, from 2020, schools will be obliged to meet their responsibilities to enable disabled pupils to access Sexual and reproductive education and prepare them for adulthood (DfE, 2019b).

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. 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 (see appendix 4) are met.

The Sexual Offences Act 2003 [Section 14(2) and 14(3)] is very clear that it is not an offence for an adult to communicate with young people about sex and sexuality if they are genuinely acting in the best interests of the young person and intend 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 well-being by the giving of advice

Careful planning by the multidisciplinary care 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.

"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. 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.

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

Practitioners 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-judgemental 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 achieve the most appropriate support.



Staff need training in how to communicate with young people about sexuality, and opportunities to practice having conversations in order that they can offer appropriate support. Organisations should consider having Sexuality and Relationship Champions as volunteer points of contact for people whom they support.

There are a range of tried-and-tested methods and approaches that work well when communicating with young people about sexuality (SCOPE, 2019) (see Appendix 5). Staff should familiarise themselves with these and adapt them into their own communication style so that they feel comfortable when talking to young people.

"... 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 of 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 sexual health trainer worked with a group of professionals supporting young people with disabilities 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 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.

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 well-being. Information about general sexual health is just as important to young people with LLTC as impairment-specific information and support.

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.

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.

"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 LLCs may face with their physical and emotional development."

"Staff should be able to discuss topics like masturbation, basic human needs, embarrassing situations, relationships. It is difficult when you have lost your ability to surf the net. I recognise that there is a lot of useful information out there but it can be challenging to ask for help (from staff) if you need to look at sites with sexual stuff on it."

Practical support

Physical contact is an important aspect of intimate relationships for young people and efforts should be made to improve awareness of this, to ensure that intimacy and touch can be safely and appropriately respected and so 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 only a basic knowledge of the mechanics and health risks involved (Griffith and Tengnah, 2013) for the individual whose capacity is being assessed.

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

"...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."

"...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 but not the best location for the sexual act."

"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 relationships and stuff."



Providing practical support for sexuality includes a number of different aspects, for example:

▶ **Sexual positions**

Knowing how to support and enable young people to get into particular sexual positions, which are manageable and safe, 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 short break unit. Managers should ensure that policies enable staff to support this choice sensitively whilst respecting their 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, whilst respecting the privacy of the young adults as far as possible, 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.

▶ **Catheterization, 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 boy or girlfriend. They may fear they smell because of a urinary catheter or bowel or urinary incontinence. Staff can help them face both the stigma and practicalities of bladder and bowel incontinence (Blackburn, 2000, p.70).

▶ **Menstruation**

Some young women with LLTC may start to menstruate early, at around 7-10 years (precocious puberty). 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 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 (ibid, Blackburn, 2000). Male practitioners may need to also think about 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 more easily live full lives. There are robotic technologies and/or voice activated devices available and in development which have the potential to offer aware of personalized solutions to enable young people to express their sexuality. (See useful resources, page 19). Staff should be the existing and emerging range of sex aids and devices that are available and use their professional judgement 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.

"I am interested in sexual health ... and checking yourself 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!."

Cultural Issues and Diversity

Beliefs are hugely important to many people and there may be occasions when parents and young people have 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 rather than ignoring the subject altogether. It should be recognised that the views of young people (especially those aged over 16) are paramount, but that in some cultures the wider community can have a very influential role on how sex is discussed.



Professional Accountability

For the purpose of this resource, practitioners include doctors, nurses, allied health and social care professionals and teachers. Each practitioner should adhere to their professional code of conduct. For nurses and midwives this is The Code Professional standards of practice of behaviour for nurses, midwives and nursing associates (2019). 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. Failure to comply with the Code may bring nurses and midwives fitness to practise into question. Not all care practitioners are registered nurses but most managers would expect non-registrants to also embrace the principles outlined within the Code.

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 practitioner feels unable to provide this level of support then they should refer the young person to someone who is able to do so.

Safeguarding

Practitioners should be familiar with the organisation's safeguarding policies and procedures for protecting vulnerable children and adults. The key issue to be aware of is the law relating to consent and finding the balance between protecting a young person with a 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.

“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 practitioners

Brook – Resources for young people
www.brook.org.uk/shop/category/resources

CQC guidance on relationships and sexuality in adult social care services (2019),
<https://www.cqc.org.uk/sites/default/files/20190221-Relationships-and-sexuality-in-social-care-PUBLICATION.pdf>

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

Helen & Douglas House, Transition & beyond Toolkit, 2014,
Chapter on Sex and Relationships, pages 61-71
<https://www.helenanddouglas.org.uk/wp-content/uploads/2018/01/hdh-transition-and-beyond-toolkit.pdf>

Image in Action – <http://www.imageinaction.org/>

Makaton – <https://www.makaton.org/>

NSPCC image vocabulary p62-65 – drawings and signs of body part and sexual feelings.

Sexual Health and Disability Alliance (SHADA), www.shada.org.uk

WREX - Introducing Wilmington Robotic Exoskeleton for Quadriplegics, muscular dystrophy, SMA, Cerebral Palsy http://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.

However, the Mental (Amendment) Act 2019 does not implement the Law Commission's recommendations on capacity and disability, instead focusing on deprivation of liberty.

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 is 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 of the individual beliefs of care staff.

Clinical governance is a generic term that relates to activities that help sustain and improve high standards of patient care. Health and social care organisations have a duty to the communities they serve for maintaining the quality and safety of care particularly if that person is at risk of harm or abuse. The Care Quality Commission (2019) and the Royal College of Nursing 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 the Sexuality standards will be reviewed and attained
- ▶ **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 LLTCs



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

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/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.
2. Ensure that care staff are providing care that is within the law, principles of safeguarding and professional codes of conduct.
3. Ensure that 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.”

(Sally and Donaldson 1998, p.61)

Principles of safeguarding and the law

Person-centered safeguarding requires human rights, empowerment and autonomy to be integral parts of support and care. The basis of safeguarding and almost all legislation in the United Kingdom relating to sex is consent. There is a delicate balance between protecting a young person with a LLTC from sexual harm and taking acceptable risks *at the right time, in the right place and in the right capacity*. Providing all of those involved in the sexual activity give their consent, the law generally permits freedom of sexual practice in a private place.

However, that general position might not always apply to young people with disabilities for two important reasons. First, age can be a bar to consent. A young person under 16 years of age cannot consent to sexual contact of any kind (Section 9 of the Sexual Offences Act 2003, “the SOA”). This is because a person under the age of 16 is presumed to lack the capacity to consent to the 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 to lack consent, it must be proved that the person did not have sufficient knowledge or understanding or 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 sophisticated.

It should be acknowledged that disability law is in a state of development, and that duties on practitioners 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 area that the organisation should include in the sexual policy is whether or not trained sex workers are permitted on to their premises. There is a very broad range of intimate and sexual services available from trained sex workers, and 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 whilst staying at a hospice or short break unit. Managers should proactively consider this issue and ensure that robust policies are in place to ensure the privacy and dignity of the individual as well as other residents. In some cases the organisation may decide against supporting this option for a variety of reasons. In such circumstances this should be discussed sensitively with the young adult and he or she should 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

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/legaldefinition-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. 'How should criminal law deal with people who have 'partial capacity'? (2014) in A. Reed, N. Wake, and B. Livings (Eds), *Mental Condition Defences and the Criminal Justice System: Perspectives from Law and Medicine*

Chailey Heritage Foundation (2014) *Safeguarding children and adults at risk (vulnerable adults)*. http://www.chf.org.uk/Safeguarding_Policy.pdf

www.sexualrespect.com/wordpress/law/

www.guardianship.gov.uk

De Than, C and Elvin JD, 'The relationship between capacity and consent' in Reed and Bohlander (Eds), *Consent*, Ashgate, 2016

De Than, 'Three issues of law reform on capacity, consent and disability', *Jersey and Guernsey Law Review*, 2019.

www.rcn.org/https://www.rcn.org.uk/development/practice/clinical_governance/why_it_is_important

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

www.healthyives.stonewall.org.uk/includes/documents/cm_docs/SOGIAG/DH_078351%20brief%2013.pdf

www.scie.org.uk/socialcaretv/video-player.asp?guid=c3f92700-3f9a-4b50-ab5e-13a70c952d73

www.ilgaeurope.org/sites/default/files/Attachments/lgbt_service_users_guidance_for_staff_working_in_mental_health_services.pdf

www.stonewall.org.uk/sites/default/files/older_people_final_lo_res.pdf

www.stonewallscotland.org.uk/sites/default/files/unhealthy_attitudes_scotland.pdf

Part 4: Case examples 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 perhaps 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 case studies will highlight, there is a pressing need for the law to be made clearer in this area, and guidance on the specific policies that prosecutors would use in applying the law. Without this, there is a significant risk that the current legislation will prevent young people and individuals with learning and physical disabilities from exercising fundamental rights in terms of their identity, their right to a private life and to be able to have intimate relationships.

An overview of the law

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 residential care. This often makes issues about sexual expression so complicated that many people don't understand what they can and cannot do.

Young people with 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).

“avoid wrapping [disabled people] up in cotton wool.....The fact is that all life involves risk..... physical health and safety can sometime be bought at too high a price in happiness and emotional welfare.”

(Munby, 2007).



European Convention on Human Rights and the Human Rights Act 1998

The most relevant human rights law in the UK is the European Convention on Human Rights (ECHR). 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 frightened of the law, fearing 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 and, where necessary, make reasonable adjustments for people with disabilities. This could mean, for example, arguing that young people can access information, education and equipment if required at various stages of their life.

Sexual Offences Act 2003 (SOA)

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 child under 18 years (De Than, 2014).

Currently, a child whose disabilities hinder their sexual expression or communication (for example being unable to masturbate) can only be supported in ways which do not involve touching the child in any way which 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 a 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 with a “mental disorder” which may impede choice and where that person is unable to refuse because of an inability to communicate choice and lack of capacity – this can be particularly relevant where care professionals are supporting clients aged over 18.

The SOA sections 30-41 create offences against a person labelled by the law as having a ‘mental disorder’. There are three categories of offence: where a person is unable to refuse sexual activity due to their mental disorder; where inducement, threat or deception is used to achieve agreement to sexual activity from a person with a mental disorder; and where a carer is involved in sexual activity with a person with a mental disorder. See de Than, 2019 ‘A guide to sexual offences against adults with a mental disorder and their implications for social work practice’, (Community Care Inform).

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 it is unlikely that the practitioner would be committing an offence. However 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 (de Than, 2014). The emphasis in some SOA offences on communication about consent means that it is very important to record how a person communicates and to facilitate their communication whenever possible, including by the use of relevant technology.

The Mental Capacity Act 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 and in doing so, there is not necessarily an indication 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 even though sometimes organisations believe they may be able to intervene. However, it has been applied to related matters, such as the ability to make decisions about social contacts with other people.

The Court has stated that the basic requirements for capacity to consent to sex are as follows in (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 and
- c) (if relevant to them) that sex between a man and a woman may result in the woman becoming pregnant.

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:

Most people faced with the decision whether or not to have sex do not embark on a process of weighing up complex, abstract or hypothetical information...There is a danger that the imposition of a higher standard for capacity may discriminate against people with a mental impairment.’ (Baker...)

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, or maybe to reassure or support someone 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 that care professionals might be concerned about are (a) “causing” or “inciting” unlawful sexual behaviour, or (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”

Additionally, care professionals are subject to a specific regime in respect of those labelled by the law as having a “mental disorder” 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), as are certain other matters. See de Than, 2019 ‘A guide to sexual offences against adults with a mental disorder and their implications for social work practice’, Community Care Inform).’

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 professionals 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 relevant to this guidance.



Case example 1

A young woman (age 14) was in a road traffic accident 18 months ago which has rendered her paralysed, although she can communicate orally. She has mental capacity and no acquired learning- disability. She is currently in a hospice and has asked to watch some “porn” on the internet but needs assistance in accessing the material. She does not want you to tell anyone about this request.

Practitioners 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 a 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, then this could be construed as inciting a sexual activity. But someone who is not involved in their care would not commit an offence.

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, hospices, care homes, children's homes and residential family centres.



Case example 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.

Practitioners should consider:

- ▶ How this situation should be safely discussed, for example, at a care team meeting or with a senior care staff member?
- ▶ How to document this request and any management plan in the young man's care notes?
- ▶ The possible use of sexual aids?
- ▶ How to document this request and any management plan in the young man's notes.
- ▶ Sex aids and technology may also be very helpful in this situation.

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 example 3

A young man (age 17) has a number of genetic and neuro-muscular, degenerative, life-limiting conditions. He also has minor learning difficulties. Although he uses a wheelchair, he is still quite adept and independent in moving around the hospice and in the community. His life expectancy is considered to be less than a year. He has told you, his main professional carer for the day in the hospice, that he would like to see a trained sex worker for disabled people. He has never had an intimate relationship and would like to have “a good time” before he dies.

Practitioners 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, 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 on whether to support this request?
- ▶ What are the implications of meeting this request on 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 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. There are laws governing sex work, which though legal in the UK, have many peripheral offences surrounding them which may be relevant and important in this situation. Care professionals should seek advice from the 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 38).



Case example 4

A young couple, both age 16, who have capacity, ask you to support them to have sex together. They both have physical disabilities 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.

Practitioners 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 and 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 case examples above, 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 appear to be prohibited. So, it should not be a carer who applies condoms to a person under 18. If both young people were over 18, had the capacity to, and did consent, then these offences would not apply. Specialist services exist which can assist here (see resources, page 35).¹

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 example 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.

Practitioners 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. Indeed, if they take measures to prevent consensual adult sexual activity taking place in private, they may be sued for breaching human rights law.

If everyone involved in the 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. Specialist advice should be taken.

Key questions for consideration in each of the following case histories

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

Part 5: Appendices

Appendix 1

References

- ACT (2009). *Let's Talk about Sex; Let's Talk about You and Me*. Available at www.togetherforshortlives.org.uk/ (accessed 6th June 2019)
- 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 M C (2018). *Sexuality, relationships and reproductive choices in young adults over 16 years with life limiting and/or life-threatening conditions*. PhD thesis. The Open University Milton Keynes: www.open.ac.uk/oro (accessed 12th July 2019)
- 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 June 2019)
- CQC guidance on relationships and sexuality in adult social care services (2019) <https://www.cqc.org.uk/sites/default/files/20190221-Relationships-and-sexuality-in-social-care-PUBLICATION.pdf>
- 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. *A guide to sexual offences against adults with a mental disorder and their implications for social work practice*. In press, Community Care.
- 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.
- 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 & Tengnah 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-SymbolsBook (accessed on 6th October 2015).

Munby J. *Re MM 2007, EWHC, 2003.*

NMC (2018). *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*, see www.nmc.org.uk.

Open Learn (2019) *Let's talk about sex, intimacy and relationships*
<https://www.open.edu/openlearn/talkaboutsex> (accessed 6th August 2019).

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).

Scally 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 reading

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.clipsargent.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 Katrak 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.

NICE (2017). *End of Life Care Quality Standards*. www.nice.org.uk/guidance/qs13 (accessed 6th July 2019).

The Open University <http://wels.open.ac.uk/research/areas/reproduction-sexualities-and-health>

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-quadriplegicsmuscular-dystrophy-sma_tech

Appendix 2

The Sexuality Journey

The framework below is loosely adapted from www.kidshealth.org/growth/sexual-health/development.html and sets out some of the key milestones of sexual development (physical and emotional).

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

Infancy

- ▶ 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

- ▶ 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

- ▶ 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 (About 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 (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 develops.
- ▶ Body and self-image, particularly skin appearance, body weight, how one is seen by others.
- ▶ Peer group pressure.
- ▶ May express ambivalence between dependence and independence.
- ▶ Challenge parental intervention whilst also seeking their support.
- ▶ Possible sexual ambivalence which may deepen questioning about gay, lesbian and bisexuality.

Appendix 3

Top tips for LGBTQ+

Disabled people are often desexualised by others, and expressing a sexuality or gender outside the 'heteronormative' framework becomes quite a statement – not only do you have desires, but they're different from those of the people around you. In practice, there's no contradiction between being disabled and being LGBTQ+, and there's lots of us out there. Here are five things for you to know:

1. Disabled people don't just have sex, we have sexualities

People often assume that just because we're disabled, we don't have any sexuality, or any interest in sex whatsoever. It's a form of infantilising us – treating us like children – in which we're not understood to be the teenagers and adults we are. Even when people accept that we might want to date, the assumption is that we'd be straight. In fact, there are lots of disabled lesbian, gay, bi and queer (LGBQ) people out there, and we find partners and love the same way everyone else does.

2. Other people's responses are not your responsibility

When, or if, you decide to 'come out' and tell the people in your life that you're LGBTQ+, remember that you're not responsible for how they react. Family members sometimes want to grieve for the future that they'd assumed you'd have, but you're not responsible for their future dreams or their feelings. The only thing you can do is focus on making yourself happy.

3. Take your time working things out

Finding out what you desire can be difficult – and this is made a lot harder if you were brought up with the people around you assuming that you didn't have any desires! Remember that there's no rush. Taking the time to know yourself is really worthwhile, and will help you establish happy relationships in the future.

4. Labels are there to support you, not constrain you

If you've found a label that describes you and helps you communicate yourself to other people, then that's brilliant – but if that label no longer fits, don't feel trapped in it. Labels work as a kind of social shorthand, but they shouldn't become a prison. If one set of words don't fit, you'll find others that do.

5. You can be disabled and trans

There are lots of disabled trans people out there. If you think you might be trans and want to discuss it with someone, talk to your GP, and, if you so desire, ask for a referral to a counsellor and/or a Gender Identity Clinic. While some aspects of transition might be harder (I couldn't complete the surgeries I wanted because anaesthetic became too risky), being disabled shouldn't stop you exploring this part of your identity, and finding language and gender that fits you.

By Jamie Hale

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Appendix 4

Glossary of terms

A child is defined as 'a young person aged up to their 19th 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 with similar but separate legislation. They are given to both 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. <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/direct-payments-personal-budgets.aspx>

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 twenties and sums up the period of ongoing transition into adulthood (Beresford, 2013): Making a difference for young adult patients: research prompts, 2.)

End of life care the end-of life phase begins when 'a judgement 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 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'.

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.

Fraser Guidelines. *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 June 2019).

LGBTQ+. LGBTQ+ is an “inclusive” way to represent different sexual identities

L – lesbian: a woman who is attracted to other women

G – gay: a man who is attracted to other men or broadly people who identify as homosexual

B – bisexual: a person who is attracted to both men and women

T – transgender: a person whose gender identity is different from the sex the doctor put down on their birth certificate

Q – questioning: a person who is still exploring their sexuality or gender identity

I – intersex: a person whose body is not definitively male or female. This may be because they have chromosomes which are not XX or XY or because their genitals or reproductive organs are not considered “standard”

A – allies: a person who identifies as straight but supports people in the LGBTQIAAP community

A – asexual: a person who is not attracted in a sexual way to people of any gender

P – pansexual: a person whose sexual attraction is not based on gender and may themselves be fluid when it comes to gender or sexual identity

The above terms cover the different ways people define their gender and sexuality, including those with disabilities. The list is not exhaustive. Some people may identify with more than one of these descriptions. <http://www.bbc.co.uk/newsbeat/article/33278165/we-know-what-lgbt-means-but-heres-what-lgbtqiaap-stands-for> (Accessed 6th July 2019)

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.

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 above definition is preferred.* ([://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/))

Sexual health is “...a state of physical, emotional, mental and social well-being 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 is: “...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 (1). "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 recognized in international and regional human rights documents and other consensus documents and in national laws.

Rights critical to the realization of sexual health include:

- ▶ Rights critical to the realization 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)

Appendix 5

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-25's 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

Contact

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 family's circumstances, and for their right to be included and equal in society. www.contact.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

Disability Rights UK

A charity led by disabled people who are working for equal participation for everyone. <https://www.disabilityrightsuk.org/about-us>

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.dwac.demon.co.uk

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. They have now completed 'Educate and protect from sexual abuse' a project to train people with learning disabilities to support the delivery of training on sexuality and relationships. www.enable.org.uk

Enabled Lives

Enabled Lives offers training and consultancy to those working and living with people who are vulnerable. This includes adults and children with learning disabilities or difficulties, looked-after children and others. www.enabledlives.co.uk

Foundation for People with Learning Disabilities

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

Foundation for People with Learning Disabilities (Scotland)

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/our_work/inspecting_and_regulating_care.aspx

Healthcare Inspectorate Wales (HIW)

The independent inspectorate and regulator of all health care in Wales. www.hiw.org.uk/about-us

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

MENCAP

Mencap is a UK charity for people with a learning disability, including autism and Down's syndrome. It supports families and carers. www.mencap.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 Outsiders Trust

The Outsiders Trust offers support on relationships, sexuality, dating and sexual services, to all disabled people and a wide range of their therapists and health and social care professionals. This work is featured widely in Jessica Kingsley's book Supporting Disabled People with their Sexual Lives. www.outsiders.org.uk

People First

Independent self-advocacy for people with learning difficulties. www.peoplefirstltd.com

Planned Parenthood

Planned Parenthood is a nonprofit organisation that provides sexual health care and information in the United States and globally.

<https://www.QIA.plannedparenthood.org>

Rare Diseases UK

Works with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, including assessment of genetic risks.

www.rare-disease.org.uk

Respond

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

www.respond.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 Nursing (RCN)

Represents nurses and nursing, promotes excellence in practice and shapes health policies and represents the interests of nurses and nursing and be their voice locally, nationally and internationally. www.rcn.org.uk

The Royal College of Paediatrics and Child Health (RCPCH)

Responsible for training and examining paediatricians in the UK. The College has members both in the UK and overseas, and sets standards for professional and postgraduate medical education of paediatricians.

www.rcpch.ac.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.

www.sexeducationforum.org.uk

Sexual Health and Disability Alliance (SHADA)

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

www.shada.org.uk

Sexwise

Sexwise provides information about having sex as well as contraception.

<https://www.sexwise.fpa.org.uk/contraception>

SCOPE

This is a disability, equality charity in England and Wales. It provides practical information and emotional support when required. It campaigns to create a fairer society.

<https://www.scope.org.uk/about-us/>

Scottish Commission for Learning Disability

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. They offer a training course entitled Relationships and Sexuality, which is an accredited module. www.sclld.org.uk

The Teenage Cancer Trust

Around seven young people aged between 13 and 24 are diagnosed with cancer every day in the UK. They require expert treatment and support following cancer diagnosis. The Teenage Cancer Trust supports teenagers with cancer and their families.

<https://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. We support families, professionals and services, including children's hospices. Our work 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.uk

Appendix 6

Members of The Open University Sexuality Alliance

- ▶ Sharon Ballingall, Social Worker, Children's Hospices Across Scotland (CHAS)
- ▶ Dr Maddie Blackburn Research Fellow and Chair of the Open University Sexuality Alliance, Faculty of Wellbeing, Education & Language Studies, The Open University
- ▶ Lucy Brumpton, Practice Development Manager/ Young Persons' and Transition Lead, East Anglia's Children's Hospices (EACH)
- ▶ Colin Bowker, Bank Inspector, Care Quality Commission
- ▶ Lizzie Chambers, Director of Programmes, Together for Short Lives
- ▶ Mark Chapman, DMD Pathfinders
- ▶ Alison Cooke, Research Fellow, The Open University
- ▶ Professor Claire de Than, Deputy Director of the Institute of Law, Jersey and Co-Director of the Centre for Law, Justice and Journalism, City University London
- ▶ Dr Sarah Earle, Director, Health & Wellbeing Priority Research Area, Faculty of Wellbeing, Education & Language Studies, The Open University
- ▶ Simon Hardcastle Diana Team Leader, Clinical Lead for Transition, East Midlands Strategic Clinical Network & Senate, NHS England, Leicestershire Partnership NHS Trust
- ▶ Dr Jon Rey- Hastie, CEO, DMD Pathfinders
- ▶ Laura Klepping, Nurse and Care Team Leader, Helen & Douglas House Hospice
- ▶ Dr Susie Lapwood Senior Associate Specialist Emeritus, Helen & Douglas House, Honorary Clinical Fellow, Oxford University Hospitals NHS Trust, GP Appraiser, NHS England (Thames Valley)
- ▶ Dr Kirsty Liddiard, Research Fellow, the School of Education, University of Sheffield
- ▶ Manjula Patel, Manager, Disabilities Team, Murray Hall
- ▶ David Raeburn, Interim Head of Strategic Programmes, MENCAP
- ▶ Phillipa Sellar, Transition Lead and Clinical Nurse Specialist, St Christopher's Hospice
- ▶ Dr Carole Walford, Chief Clinical Officer, Hospice UK
- ▶ Richard Whateley, Chief Executive Officer, The Myriad Centre Ltd, Worcester

The AdversiTeam

Lucy Watts MBE, Master of The Open University: Chair AdversiTeam and member of The Open University Sexuality Alliance

Katherine Watts: AdversiTeam member (Parent)

Jimoh Hameed (Jimoh): AdversiTeam and Open University Sexuality Alliance member

Leah Booth: Vice Chair AdversiTeam and Open University Alliance member

Chloe Print-Lambert: AdversiTeam member

Jordan Print-Lambert: AdversiTeam member

Amy Frouks: AdversiTeam member

Chelsea Corbett: AdversiTeam member

Lauren West: AdversiTeam member

Rebecca Toricelli: AdversiTeam member

Charlotte Hardwick: AdversiTeam member

Tom Hardwick: AdversiTeam member

Sam Milden: AdversiTeam member

Anjali Solanki: AdversiTeam member

Molly Smith: AdversiTeam member



50
YEARS



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