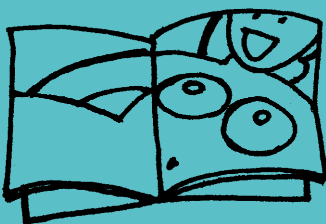
batteries not included

a sexuality resource pack for working with people with complex communication needs



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What this pack offers

An exploration of sexuality for people with complex communication support needs – dreams, ambitions and realities.

A framework for considering a number of issues related to sexuality for people with complex communication needs.

Solutions to some of these sexuality issues where possible.

Discussion of the current dilemmas in relation to sexual expression for people with complex communication needs within current legal and policy frameworks.

Underpinning of the rights of people with complex communication needs to be sexual citizens and be included in the sexual health agenda.

The pack does not aim to be

A definitive guide to sex and relationships education for all people with complex communication needs.

A tablet of stone – it should be seen as a starting point for developing and discussing the dilemmas raised.

The answer to all concerns about the legal, ethical and moral questions that arise for people with complex communication needs in relation to sexuality and sexual health.

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Many people have contributed to the development of 'Batteries not Included'.

The pack has been developed over a period of time and many aspects have been enriched by the many conversations, arguments and debates the subject of sex and sexuality in relation to people with complex needs engenders. Susan Douglas-Scott (PHACE Chief Executive) and Paul Hart (Principal Officer (Practice Development) SENSE Scotland) would like to extend their thanks to everyone they spoke to, as you are too many to list here.

Thanks to the following people who read and commented on the pack as it developed and those of you who attended the consultative symposium we had to explore the content of this pack. This was a useful way to ensure that an appropriate range of issues were covered in this publication.

Thanks in particular to:
Anne Robson, Sarah Andrews, Georgie McCormack, Jackie Nicholson, Adrienne Hannah

About the commissioners and authors

This pack was commissioned by Common Knowledge, a Glasgow based partnership organisation between people with learning difficulties, families, statutory and voluntary sector organisations, further education colleges and Social Inclusion Partnerships. Common Knowledge is about change. It is designed to help change the way Glasgow includes and supports people with learning difficulties through a series of linked learning activities. It aims to create learning for individuals, learning for different services and learning in local communities. Part of this is achieved by providing inter-agency training for staff helping them to work in a more inclusive and person centred way. The project is managed by SHS Trust and is jointly funded by the European Social Fund, Glasgow City Council and the NHS in Glasgow.

Common Knowledge facilitates a cross organisation sexuality working group and through discussion recognised that staff who work with people with complex communication needs had little or no access to information about how to offer sexuality support. In recognition of this gap, fpa and Sense Scotland were commission to write 'Batteries not Included'.

Paul Hart has worked for Sense Scotland since 1987, 2 years after completing a Bachelor of Music degree. Prior to working for Sense, he worked in a school for children with emotional and behavioural difficulties and in a project for homeless men. In the past 16 years he has held a number of posts with Sense, including support worker, manager of residential services, manager of day services and Head of Services (West of Scotland).

Paul has been Principal Officer (Practice Development) since April 1998, where he spends much of his time developing and delivering training courses, supporting the development of communication strategies with individuals and thinking about new ways to support deafblind people.

Paul delivers training and practice support both within Sense Scotland and for many other statutory and voluntary organisations throughout the UK. He also speaks regularly at conferences and seminars on the themes of assessment, communication, staff development and sex education.

Susan Douglas-Scott was the Director of fpa Scotland from September 2000 until July 2003, during which time she developed a strong network of colleagues in both the statutory and voluntary sectors with the aim of expanding the horizons of fpa's work in Scotland.

In July 2003 Susan moved to PHACE Scotland as their new Chief Executive. Promoting Health and Challenging Exclusion, PHACE Scotland is a national, Scottish sexual health organisation committed to HIV advocacy, advice, support and wider sexual health equalities issues. She is passionately committed to continuing her work in sexual health and extending this to a wider HIV role. Susan continues to work in partnership with fpa wherever possible, contributing jointly to the voluntary sectors network of sexual health expertise.

Prior to moving into the sexual health field, Susan enjoyed a nineteen-year career within disability services in both the statutory and voluntary sectors, latterly with Sense Scotland. This, along with her personal experience as a disabled woman, gave her the opportunity to develop her theoretical, academic and political ideas on disability. Since 1989 she has developed and presented disability equality training as one of the pioneers of this work in Scotland.

She has a particular interest in sex and sexuality in relation to disability and in the challenge homophobia presents in sex and relationships education for everyone. As part of the 2003 expert reference group to the Scottish Executive for the development of a National Sexual Health Strategy for Scotland, Susan championed these issues among other sexual health inequalities.

Both Paul and Susan have enjoyed the opportunity to rekindle their working relationship through the development and writing of 'Batteries not Included'. The production of this pack means they have finally had the time to cogitate, debate and write about the issues that they have been discussing since they first began working together in 1998.

fpa (formerly the Family Planning Association) wants to see a society with positive and open attitudes to sex, in which everybody enjoys sexual health and where sexual and reproductive rights are respected. Its mission is to enable people in the UK to make informed choices about sex and to enjoy sexual health free from exploitation, oppression and harm.

fpa's objectives in relation to disability are to highlight barriers to sexual health and to promote the sexuality and sexual health needs of people with impairment and with learning difficulties. fpa uses the term 'disability' to describe the social oppression (of which poor access to sexual health services is an important and under-recognised element) experienced by individuals as a result of their physical, sensory or medical impairment and/or learning difficulties.

fpa believes that service providers should be sensitive to the ongoing training and support needs of staff and those responsible for caring for disabled people. Training for those working with or caring for disabled people should be ongoing and include the physical and cognitive aspects of impairment if and where appropriate but more importantly, address the social impact of disability, the barriers

experienced and how they can be overcome. It should seek to reassure staff, families and carers who may feel anxious or uninformed about the sexual health needs of disabled people, and enable them to address the sexuality of individuals in their care with confidence.

SHS Trust and the work we do

Scottish Human Services Trust (SHS) is a values led training, consultancy, research and development company. All of our work is driven by a strong belief in social inclusion and the view that everyone is entitled to the supports they need to be a part of and play a part in community.

SHS believes that many individuals and groups in our society are at risk of social exclusion. These include older people, people with learning difficulties, people with physical and/or sensory impairment, people who have or are suffering from mental ill health, young people in care, and other disadvantaged groups.

The work we do brings us into contact with:

- individuals and families on a one to one basis
- user led groups and community organisations who want to change things at a local or national level
- staff from service providers working in the statutory, private or charitable sectors – for example: social workers, care managers, support and care staff, nurses and health associated professionals, advocates, day centre staff, supported employment workers
- policy makers at local and national government level

As part of our work we design and run training courses, conferences and seminars. We publish articles, research papers, books and policy statements and we undertake a range of development work in fields such as advocacy, user involvement, person centred service design, and capacity building in local communities.

SHS is an independent, not-for-profit organisation. We do not receive core funding or subsidy from any source and all of our income is generated from the work we are commissioned to do. Any profit generated by the company is passed back to the Trust to enable them to further their aims.

Why this pack about sex?

> "Every single one of us was put here in order to be close and intimate with another person, whether it's the same person for the rest of your life or whatever. Without intimacy there is no connection."
> O'Callaghan in Deveney, 2003

What does this tell us about the support generally offered to people with complex communication support needs? If we consider intimacy as the key, then we encapsulate sex, sexuality and relationships in a holistic way that should mean each aspect is addressed. By defining sexuality in a wider context, it also allows us to see that as supporters, we have a role to play in the creation of learning opportunities.

Over the years of working with a range of disabled people, in particular people with complex communication needs, the commissioners and authors of this pack had many discussions about the realities and dilemmas about sexual rights versus the duty of care and protection of vulnerable adults from sexual abuse. We have debated these issues and are concerned that although there have been a range of publications in this area over the years (Neff 1979, Ostli 1987; Bunck 1989; Shelton 1992; Von Malachowski 1994; Downs and Craft 1997; Longhorn 1997; Brandenburg 1998; Scott and Kerr-Edwards 1999; Moss and Baha 2001) these have not encouraged live debate that impacts positively on practice, nor do carers and professionals feel more confident in tackling the full range of sexuality issues.

In particular we are concerned for people who use touch as their main form of communication. The rest of the world imposes a set of boundaries about what constitutes acceptable touch that effectively restricts the individual involved from learning and communicating.

In public and with most others around us, socially acceptable touch is generally non-sexual, with sexual touch constrained to private moments alone or with a significant other. Unacceptable touch is also defined by these social mores and relates to touching of ourselves or others bodies in ways which are considered either sexual or just plain inappropriate to the majority. This places those who rely on touch to learn and communicate in a difficult position, which generally results in one of two things. Either we urge them not to use this sense because others have defined it inappropriate, or we push at the boundaries of what is acceptable, to create opportunities for a minority of people with specific needs. It is saddening that often the former happens – what the writers and contributors of this pack would like to see is, instead, the boundaries being moved, challenged and changed.

When considering sexuality and how we extend support to people with complex communication needs, the following four routes are likely to reflect attitudes and actions towards people's sexuality. We can:

- eliminate their sexuality
- tolerate their sexuality
- accept their sexuality
- cultivate their sexuality

(Johnson and Kempton 1981 in Scott and Hovey 1991)

Although there are significant challenges in the latter, this is where as authors of this pack we position ourselves, and in carrying out research for this pack, it has become clear to us that cultivation of sexuality for people with complex communication needs remains a significant challenge in many places.

So, all of the above provides us with the key reasons for writing this pack, which can be summarised as follows:

- a number of people with complex communication needs have real gaps in their sexual knowledge
- people with complex communication needs can find themselves in very vulnerable sexual situations along with those who support them
- people can engage in harmful sexual behaviours
- people miss out on full exploration of the sexual potential in their lives

> 'Nina does not communicate using words. Over three years, staff had supported her relationship with her boyfriend. The question of Nina's 'capacity' to enter into this relationship never came up: it was clear Nina wanted to be in the relationship. However, when Nina's boyfriend asked her to marry him, staff panicked and called in a nurse from the community learning disability team. The nurse, who did not know Nina at all, did not know if Nina could consent. Her advice to staff was 'to leave it all alone'. This withdrawal of support effectively ended Nina's relationship.'
> Edge 2001

Sexuality is a multifaceted process of biological factors and cultural behaviours, influenced by internalisation of social norms. However, in order to be influenced we need input from those around us, messages from peers, family, books, media, society in general. Imagine for a moment how you arrived at an understanding of yourself, your place in the world and your relationship to those around you. There will have been thousands of moments of incidental as well as direct learning.

Most of us understand differences between boys and girls and men and women from when we are very young.

As teenagers, we notice the process of physical maturation of ourselves and others. Our understanding of this is informed by our parents, friends, books, magazines, television, films and school.

As adults, we also learn from the world around us, making sense of all the available information, often informed and influenced by societal values. It can be a long and sometimes tortuous process to understand your sexuality and how it helps us to relate to others. It is no surprise then that some disabled people with multi-sensory and/or intellectual impairments have difficulty gathering, let alone understanding, the type of information most of us take for granted. Many of the people we support do not have access to the tools people usually use to build a picture of who they are sexually and how they should behave. For further reading in this area, Bunck (1989) and Hamilton (1979) explore the impact that vision and hearing can have on the development of self-image and Hayes (1995) considers how everyday activities are used by the average child, from the very earliest years, to build pictures of their world.

In the absence of efficient communication, visual cues and auditory stimulation how does sexuality manifest? How does the individual know what their body is going through as it grows and develops, and how it impacts on other people? If you have an itch, your automatic response is to scratch. Is masturbation the same response to sexual arousal? If so, how do we learn where and when it is appropriate? And there is the question of how to learn to do it effectively. These questions and others like these will be tackled in 'Batteries not Included'.

Whether we acknowledge it or not, one thing we all have in common is sexuality and many people would argue that sexuality is a central

part of our very being (Longhorn 1997; Stewart and Ray 2001; Steele 1998; Hinsburger et al 1999, Craft 1987). How we express this aspect of ourselves is as diverse as human behaviour can be, ranging from celibacy through to being prolifically sexually active. There are also rules. Some of these are created by society and are culturally influenced. Breaching these can result in rejection, isolation and feelings of difference. The law also defines what and what is not acceptable in terms of sexual behaviour, particularly in public. One of the reasons for writing this pack is to explore how these messages are conveyed to those who have difficulty understanding or interpreting cultural norms and cannot understand the complex nature of the law.

Young people's experiences show us that the more information and support a person has about sex and relationships, the more likely they are to make informed choices and feel comfortable about expressing their sexuality. This is the basis for sex and relationships education, information, training and services. The authors and commissioners of this report believe that all people need access to information about sex and sexuality and that more needs to be done to assist those who cannot easily access the knowledge they need. Our argument is that none of us can fully develop as human beings without sufficient knowledge of our sexual identity (Miller 1994, Ostli 1987; Bunck 1989; Hinsburger and Tough 2002).

> "To be a human being is to be a sexual being. Although there may be a range of intensity, varying over time, we all have sexual needs, feelings and drives......Although we can shape (and mis-shape) sexual expression, sexuality is not an optional extra which we in our wisdom can choose to bestow or withhold according to whether or not some kind of intelligence test is passed".
> Craft 1987

This publication aims to look at the particular issues sexuality raises for people who do not communicate easily due to multiple impairments, including dual sensory impairment. With impairment of hearing, sight and complex communication support needs, the transference of information about any subject is challenging. Sex and sexuality information is even more challenging because of constraints highlighted earlier, but also due to fear. People with complex communication needs have not been considered as sexual beings with associated rights until very recently, therefore this rights based approach has a young agenda, with implications for services.

If the wider population of people with learning difficulties were offered regular and comprehensive sex and relationships education, then this would positively influence the same agenda for the even more marginalized group we are considering in this pack. Hinsburger (2001) describes it as a tragedy that people with learning difficulties do not receive adequate sex education. Our research for this pack has shown us that not only is it tragic, but entirely avoidable. Many of the ethical, moral and legal questions that we encountered simply do not arise for people with learning difficulties, without complex communication needs. By the time you reach the end of this resource you might not have all the answers for people with complex communication support needs, but will recognise that there is no reason why today, in all of our schools and support services across the UK, we cannot regularly offer support and teaching that will allow people with learning difficulties to fully develop and understand their sexuality.

Despite this, in general, people with learning difficulties do not routinely access good quality support with sexual health, sex education and relationships skills. This underpins our concerns, as by comparison to people with more complex communication needs, it is straightforward to address these issues with people who can see and hear.

Those people who have learning difficulties without the challenge of additional impairments can and should be supported to use their other abilities – hearing, sight, mobility – to compensate for the intellectual challenge created by much of the social and written information on sex and sexuality. The types of intervention we outline in this pack should be directly useful for a wide service user group.

So, in relation to people with complex communication needs, how do we know if they understand sex and sexuality? The simple answer is to say it is too difficult to find out. In this pack, we want to help overcome such barriers by examining how communication impacts upon the delivery of sex education. We also give examples of how this work links to practice and holistic support, by sharing what has worked and suggesting a number of responses that are possible within our current legal and ethical frameworks.

The million-dollar question seems to be how pro-active we should be and can we make a distinction between sex education and sex guidance in the way that they do in Denmark, for example? If someone does not know something, is it because they are not interested or because they are unaware? In the context of sex and relationships education, if a person with complex needs has shown no interest in developing a sexual relationship is this because they do not want to, or because they have not yet learned that such a thing is possible (Hayes 1995)?

In the policy and practice section of 'Batteries not Included', we expand on this theme and give some guidance. Many schools, resource centres and voluntary organisations will have policies in place that state that we should not simply wait for a problem to arise before providing an individual with sex and relationships education – that we should provide support and education that will avoid difficulties arising in the first place. We agree with this approach, but as will be seen as you work through this pack, it is easy to state such a position and much more difficult to fully achieve it.

We need to consider that adults with complex communication needs may have had some sex education, but we cannot always be sure what learning has taken place. Some adults will have sexual experience but again we might not know if or how this came about, what knowledge the person had beforehand and how they felt about it. Some people with complex communication needs will engage in masturbation in public so staff will know this is an issue for them. Others may only do this in private and therefore the fact remains unknown. In short, we are unlikely to be supporting adults who have no sexual experience or knowledge.

However, it is our view that the quality and quantity of sex education currently on offer to children and adults with complex communication support needs is not sufficiently comprehensive and so it will be equally true that we are supporting adults who will have significant knowledge gaps. We will offer some advice and guidance on ways to assess the level and types of knowledge currently held by an individual with complex communication needs.

We are particularly interested in this area because of our experience that some of the people we support mature at different rates, and others, due to use of certain medications, have issues with sexual development and desire. This means that for those individuals questions do not become apparent until later than is usual in human sexual development.

One of the key concerns we have deliberated over is that inaction in the area of sex and relationships education may be harmful for some people and so, despite the dilemmas and difficulties, and in the absence of solutions for all of these, one of the central aims of this pack is to take a proactive approach, linked to the specific learning needs of the individual (Carson 1992).

As authors, we were also influenced directly by good practice considerations, the legal context and the views of staff teams and families. One strong message is that if we get too drawn into deep philosophical questions about ethics and morality, then it is easy to avoid doing anything at all. Before we take any first steps, supporters are often convinced that the destination is impossible to reach. In order to try and address this there is a discussion towards the end of this pack that confronts the key dilemmas that arise.

Before we get there we have made numerous suggestions about responsive and responsible first steps that can be made. There are many areas in which support, guidance and teaching can be offered to people with complex communication support needs and we hope to dispel the myths and break down the barriers that prevent us from acting. We have no desire for this resource to clutter up shelves, but instead be viewed as a working tool that can both give answers and ask difficult and awkward questions to ensure we continue to progress this important agenda.

In many respects, we hope that this pack serves as a gatekeeper to other resources. There are sex and relationships materials on the creation of support programmes, policies and procedures, there are books that list relevant models, pictures and videos that can be used, there are publications that detail innovative ways of maximising sensory input and we would urge readers to gather together such materials. Our pack outlines a process that can allow you to consider the issues in as wide a sense as possible, to allow diverse and creative use of the materials available.

To this end, throughout this pack, we will be directing people to other resources that currently exist. We felt there was nothing to be gained in re-inventing the wheel and while this means that not all answers are included in this pack – hence the title, 'Batteries not Included' – we consider that a greater understanding of the topic as a whole can be

achieved by working across various resources that are currently available.

We also highlight areas for future consideration, believing this helpful, because many of the difficult obstacles and boundaries are simply not written about or discussed. In order to start addressing these issues we need to be clearer about what they are in the first place. This is what we hope 'Batteries not Included' will achieve.

Sex and the law

The law gives us guidance on what we can and cannot do sexually. It defines people with learning difficulties and their ability to consent. There is also the law around the duty of care and it is the interpretation of this which complicates things regarding peoples rights to take risks and what these constitute. Policies can also cause conflict as they may pull against each other rather than harmonise in order to fully support adult life.

The Human Rights Act 1998 was implemented in the UK in October 2000. It brought a number of human rights issues to the fore and, in law, supports other pieces of legislation to ensure that people are treated fairly. At no point does it suggest that some people are exempt. It does not say that the Act only applies to non-disabled people. This means that it applies equally to people with any impairment you can think of, including dual sensory impairments and learning difficulties.

The Human Rights Act makes it unlawful for public authorities to behave in a way that is incompatible with the rights laid down in the European Convention of Human Rights. Within the European Convention, Article 8 covers a number of issues including “the freedom to privacy”, article 12 says that men and women of marriageable age have the right to marry and to found a family, and article 14 prohibits discrimination on the basis of sex, race, ethnicity, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. There is nothing specifically about same sex relationships, mainly because it was written in 1950 when there was little recognition of lesbian and gay rights. However, the legislation is now being interpreted as broadly rights based and it now acknowledges and acts for the benefit of same-sex-attracted people.

So, what does this mean for the group of people we are concerned with? Our interpretation is that it does mean that all disabled people are entitled to basic information upon which to make life choices about sex and relationships. The complexity of how people access this information due to impairment and the methods of delivery available are what we need to explore. To do this we want to look at the sharing of sexual health and relationships information on a number of levels and hopefully give some insight into what is possible without change, what is possible with change in some approaches and what is more of a challenge for us in the UK today.

To start with it will be useful to consider what the law tells us with regard to people with learning difficulties. An important precursor is the fact that Scot's law is by nature influenced by case law over time. This means that recent developments in cases heard and policy and practice can and do have positive impacts. The Lord Advocate oversees criminal prosecutions in Scotland and s/he is bound to take into account recent developments and advances to assist people with learning difficulties to live ordinary lives.

Rather than quoting large and at times complex chunks of legislation the following questions and answers are designed to help us examine some relevant aspects over a range of different acts.

> **Under the Mental Health (Scotland) Act 1984 it is an offence for a man to have sex with a woman with learning difficulties.**
> **Answer: True and False**

The term 'unlawful' within this Act means outside of marriage, so if a man were married to a woman with learning difficulties then sex would not be illegal. For unmarried women it depends on an assessment on the level of the woman's impairment of intelligence and social functioning. The question of her consent is irrelevant and

the answer for each individual woman is based on whether or not she comes under this definition. Therefore if she were assessed as “having arrested or incomplete development of mind including significant impairment of intelligence and social functioning” then it would be illegal for a man to have sex with her. If she were deemed “capable” then it would not be an offence.

The challenge for support staff is to empower disabled people to express their wishes and live ordinary lives in community settings. We need to expand the definitions of “intelligence” and “social functioning”. People with learning difficulties have the same range of sexual drives, desires and needs as the rest of the population.

Under the Mental Health (Scotland) Act 1984 it is an offence for a male or female member of staff to have unlawful intercourse with a patient/service user.
Answer: True

Section 107 of the Mental Health (Scotland) Act 1984 was designed to protect “mentally disordered” people from abuse by staff and others with authority over them. This includes learning difficulties and mental health problems. In hospitals and nursing homes it is an offence for staff to have sex with a woman or “homosexual acts” with a man receiving “treatment” or support. Here the degree of learning impairment is irrelevant. The law is less clear about a woman member of staff having sexual relations with a male service user. However, the duty of care issue would extend this to protect vulnerable men.

This is an issue of abuse rather than ordinary development and expression of sexuality and sex behaviour, with the law recognising the vulnerable position of a person receiving care. This is highly likely to apply to residential care and supported accommodation.

Which of the following is still an offence for consenting adults:
a) Homosexual activity that takes place in public
b) If either of the partners in a homosexual act is unable to live outside institutional care
Answer: both a and b

a) Any sex in public is an offence. Heterosexual people could be charged with breach of the peace whereas gay men are more likely to be charged with gross indecency.

In relation to inappropriate masturbation in public, this is also an offence and individuals with learning difficulties may need support to learn where they can and cannot do this with regards to the law.

b) The partners do not have to be living independently but must be capable of doing so. The interpretation of capability here is wide, as the law originally related to hospitals and did not have the vision of people with learning difficulties living in supported, community based settings. However, capacity is now considered as something that can develop under the definitions within the Adults with Incapacity Act 2000.

Staff need to build a picture of how the individual communicates sexual choices and that relationships are supported to develop in a way that is considered consensual. Then there is a strong foundation to say that the person is expressing free choice. This can be done by recording and discussing with other appropriate people eg practice development staff, care managers and parents.

What is the age of consent to sexual acts between people of the same sex?
For men: 14,16,18 or 21? For women: 14, 16, 18 or 21?
Answer: 16 years for men and women

The age of consent for gay men was equalised on the 1st January 2001. There is no recognition in law concerning lesbian sex. However, if a woman is under 16 she cannot consent to an act that is considered indecent assault, which a woman having sex with a female minor would constitute. This would apply to sexual relationships between men where one was below the age of consent.

With regard to people with learning difficulties, the Criminal Justice Act 1980, section 80 makes "homosexual acts" with a man with learning difficulties an offence if he cannot consent. As with vulnerable women, an assessment of capacity would be needed and should also be informed by the Adults with Incapacity Act 2000 in partnership with Human Rights legislation.

The main issue relating to same sex relationships is lack of awareness. Disabled people receive very limited information about heterosexual sexual relationships and even less about same sex relationships. What needs to be considered here is that disabled people are as likely to be lesbian, gay or bisexual as the rest of the population and generally this is estimated at about 10%. Disabled people, like everyone else, need access to information and support to understand and express their sexuality. There is also the transgender issue to consider.

Sterilisation can be performed on an adult without his or her consent:
Answer: True

If a person is unable to give consent then a Guardian can make the decision on behalf of the person. A court ruling would be required to decide if sterilisation was in the best interests of the individual. The Adults with Incapacity Act 2000 requires an assessment of capacity in relation to medical treatment. Article 8 of the Human Rights Act 1998 limits the extent to which a public authority can do things without permission, which invade your right of privacy and this has been interpreted to the body.

Here we see two pieces of legislation building on each other and both should be taken into consideration before any sterilisation is approved. Other than the breach of Human Rights of forced sterilisation, it is not an effective sexual health approach as it only prevents pregnancy and does not protect women from sexually transmitted infection. Developing skills to avoid both unplanned pregnancy and infection is a better solution for both men and women with learning difficulties.

Abortion can be performed on an adult woman without her consent.
Answer: True

Abortion is only lawful if it meets the grounds set out in the 1967 Abortion Act which states that abortion is illegal beyond 24 weeks gestation unless there is evidence to suggest that there will be substantial risk to the mother's health (mental or physical) or that the child will be born with severe foetal abnormality. If the former is evidenced then a termination can be carried out up to term. With regards to consent, the issues are similar to those relating to

sterilisation where a Guardian can give consent if the woman is considered incapable.

Disabled people are not considered as potential parents as they can be dependent on care themselves. Being dependent on care does not mean that a person cannot be a good and capable parent. They might just need help with some aspects of it. What needs to be established, as with any woman, is that the pregnancy is what she wants and that it is not unduly endangering her health.

If a person with learning difficulties (over 16) wishes to get married, s/he must:
a) Obtain the court's permission
b) Obtain permission of the responsible medical officer
Answer: False

The Officiate has a duty to check the understanding of both parties who must have a basic understanding of the meaning of marriage and be able to consent to it. If the capacity of either person is in question, medical evidence may be required to determine capacity and understanding. Under article 12 of the European Human Rights Convention, men and women have the right 'to marry and found a family'. Article 14 of the same says that people are entitled to equal access to rights, therefore people with learning difficulties are protected from discrimination from a human right perspective. However, the law says that they will need to show that they are capable of giving consent.

It can be argued that marriage is a socially constructed phenomenon that does not apply equally to everyone, as it is important to some and not so to others. We need to consider if marriage is actually meaningful to people who communicate and relate to others differently, as is the case with people with complex communication difficulties. Perhaps for some, marriage is not the issue but expressing themselves sexually is. This concept applies equally to how and with whom people with complex communication needs form a variety of relationships.

A member of staff is likely to be prosecuted if s/he teaches a people with complex communication needs to masturbate.
Answer: True and False

This is true if a support worker acts on his/her own without consultation. If this is the case they may need to defend a charge of indecent assault.

The opposite is the case where teaching masturbation has been discussed and agreed as part of the support plan and work is recorded and monitored. It is important that organisations are aware of this and have written policy and procedures to support this work. (See Policy and Practice section).

Without help to masturbate effectively people who find it difficult can put themselves at risk either by becoming increasingly frustrated or by hurting themselves physically by using inappropriate objects to help achieve pleasurable feelings and/or orgasm. This is why it is a very important area to tackle and help the disabled person find a solution. A vibrator can sometimes be the answer to such a dilemma and

used in the context of a support plan is a feasible option (See Useful Resources for ideas). This links to the section on sex and masturbation in public places. Given that these are offences, staff have a duty of care to give information to the individual that can help minimise this issue.

However, organisations and staff need to be clear that support in this area does not extend to a member of staff observing or overseeing masturbation, as this would be considered voyeurism and as such is illegal.

Another key dilemma in relation to masturbation is not that simple – we cannot forget those who are not masturbating. Perhaps they do not know that this avenue for pleasure exists. It is generally considered that most adults masturbate to a lesser or greater degree, depending on fluctuations of their libido. If so, this should also logically apply to people with complex communication needs. What needs to be considered is how to deal with sharing this information in a proactive rather than in the usual reactive way.

In conclusion, it is vital to remember that organisations should ensure that they adhere to the law with regard to their policies and practice, while achieving the delicate balance needed to ensure that "they do not exaggerate the risks involved or seek to protect themselves by taking away the rights of people with learning difficulties to form loving relationships" (McKay 1991).

Myths abound

Not only do we need to consider aspects of law, but also that sexuality in adults who have intellectual and communication impairments is also clouded by myths. These are as long standing and as seemingly intractable in terms of public opinion as those that plague generations of teenagers – 'if you have sex standing up you won't get pregnant', 'no one gets pregnant first time' and so on. Where do these come from? In relation to disability, myths are founded on the major myth that disabled people are not sexual beings. Let's consider some of these in relation to people with complex communication needs.

Myth: People with complex communication needs do not have sexual feelings like the rest of the population

Nonsense! Of course people with people with complex communication needs have sexual feelings: they show signs of arousal, express sexual desire, masturbate and have sexual intercourse.

The expression and intensity of those feelings will vary as they do in the rest of the population. In some cases the environment may actively discourage expression of sexual feelings and their recognition by others.

There are also many myths and fears surrounding the sexuality of people with complex communication needs perpetuated by the public, the media, carers and parents who tend to all see and treat severely disabled people as permanent children.

Myth: Sterilisation of a man or woman with people with complex communication needs will reduce their sexual desire

Sterilisation only stops conception. There is no physiological reason why it should change sexual desire in anyone. However, parents may request sterilisation in the erroneous belief that it will stop all signs of sexual interest and activity.

Anyone who is sexually active or likely to be needs safer sex advice and support. The only method of contraception that helps us reduce our chances of contracting sexually transmitted infections is condoms. These are available for different sexual activities; flavoured for oral sex, a wide variety for vaginal sex and extra strong ones for anal sex. While the extra strong ones can be used for oral and vaginal sex, the others are only suited to the purpose for which they are designed.

Myth: Sterilisation of a woman with learning difficulties will remove the problem of heavy periods.

A woman will continue to have periods after sterilisation, which only involves cutting or tying the Fallopian tubes. Sometimes a hysterectomy (removal of the womb) is performed under the guise of sterilisation. It is a much more major operation, and following this, a woman will no longer have periods nor be able to conceive a child.

The injectable form of hormonal contraception (Depo Provera) eliminates or drastically reduces menstruation. This is often used to manage disabled women's menstruation more easily. However, it needs to be prescribed by a family planning practitioner and be the best choice for the woman rather than being used solely as an easier way to manage her menstruation.

Myth: People with learning difficulties are more fertile than the general population.

Fertility has two aspects:
a) The biological capacity to reproduce,
b) Effective reproduction, or the numbers of children actually produced.

With regard to the first aspect, while there are some exceptions, most people with learning difficulties are fertile at a biological level. This belief is linked with fear about people with learning difficulties being overly sexual and is primarily confusion between virility (the need for sexual expression) and fertility (the ability to conceive a child). It may also be linked with the eugenics movement earlier this century, which discouraged pregnancy in those thought likely to lower the quality of the population gene pool. With regard to effective reproduction, it is more likely that social status often reduces disabled peoples' chances of having children.

With the group we are considering in this pack, we need to review our constructs of relationships and choice. Having children is not every woman's wish, for some it is and it does not happen, for others they are careful to avoid pregnancy because it is not something they choose for themselves. With people who have complex needs, it will be similar and some women will love children and others will not. For those individuals who have limited interaction with others this may not be a choice that they would relish for themselves and support staff, parents and carers need to try their best to interpret the persons messages without imposing their own beliefs or values. This needs to happen within a context of adult sexuality and recognition of those needs alongside reproduction and contraception.

Another consideration with regard to fertility and virility for people with complex communication needs is prescription drugs. Many of these can have an effect on sexual activity such as interest, arousal or orgasm. These include:

- beta blockers
- anti-depressants
- tranquillisers
- epilepsy drugs

With some drugs the effects are predictable and well documented, with others individual response may vary greatly. It is important that support staff are alert to the possible effects of a particular drug. It is sometimes difficult to know whether the effect on sexual activity is due to the drug or the condition necessitating drug therapy. In the case of people with complex communication needs, drugs are sometimes prescribed to control challenging behaviour and decrease sexual interest/activity. People with complex communication issues, particularly those who have experienced long term hospital care, can be at increased risk of being prescribed drugs to manage aspects of their behavior. Many organisations are now challenging this practice; it is still an ongoing issue that needs to be considered.

Policy and Practice Background

This section of the pack will look at a number of practice considerations and approaches that are familiar to parents and professionals in this field of work and explore how we can apply these general principles to sex and relationships education for people with complex communication support needs. First, let's look at the context that impacts on policy.

In February 2000 a number of young people attending a seminar run by the Sex Education Forum developed a charter for good sex and relationships education. [1]They listed three principal objectives:

- every child has the right to sex education in all areas (gay, lesbian, straight and bisexual)
- every child has the right to express their opinion
- every child has the right to specific information, advice, counselling and support

In April 2002, Children in Scotland and fpa Scotland brought over 60 young people from 17 different regions across Scotland to examine what sexual health information and support young people say they need. (Sexpression 2002) The young delegates worked with a facilitator to set the agenda for the day, examining issues they felt were important. From the topics they chose to discuss they identified the following as key issues:

- equality of access – young deaf people in particular feel very excluded from comprehensive sex education
- the need for accurate, accessible information on all aspects of sexual health and in particular regarding emergency

[1] This charter is available from the Sex Education Forum website

contraception, abortion, lesbian and gay relationships, Sexually Transmitted Infections and HIV

- the need for values led teacher training in the delivery of sex education to develop skills and knowledge. Young people stressed that this needs to have a balance of information about same sex relationships.
- the need for support for parents in their role in sex education with regard to knowledge and skills

In general young people want society to be more open about sex education, for parents to be less embarrassed, and for parents, teachers and other professionals to be given support to develop skills.

Young people also identified areas where they need information including real-life dilemmas, peer pressure, friendships, being gay or lesbian, contraception, HIV, STIs, when is the right time to have sex, what are the pros and cons of sex, and so on.

This set an overwhelming challenge for parents and professionals to ensure all children's right to sex education. Human Rights Legislation at no stage suggests that profound impairment means the person is not considered to be in that group of "all children" or "everyone"? The next logical conclusion is that everyone is entitled to the relationships of their choice, which also sets an overwhelming challenge for parents and professionals. At what stage does an adult cease to be sufficiently human that we can simply dismiss these rights? This context is further underpinned as the Disability Discrimination Act now applies to educational services. At what stage does a young person's communication become so complex that we can ignore the sex and relationships questions they are asking us?

These are profound challenges that we cannot ignore, and they set the context for the policy and practice procedures that are needed to

support sex and relationships education. Central to this work there needs to be a commitment to the rights we have discussed here, applying equally to everyone, no matter the level of communication difference that may exist. Our current knowledge in the field of sex education for people with complex communication support needs and the current views held by wider society might make the realisation of some of these rights difficult and indeed problematic (Swain and Thirlaway), but rights they are nevertheless (Craft and Downs 1996). As parents and professionals we must continue to ask ourselves, how could I make sure this information is conveyed to this person? How can we replicate the learning that takes place more easily for other people? Key to this is that any such work is based on a foundation of supportive organisational policy, which leads us on to exploring the policy background against which all sex and relationships education and sexuality support must operate.

Policy considerations

We do not propose in this resource pack to provide a detailed account of how to put together a policy, as there are other publications that give clear guidance in this area (Craft and Downs 1997, BILD 2001, Hinsburger and Tough 2002). We though it best to make overall observations about the key elements that must be in place. It is vital that managers support both staff and service users by endorsing organisational policy to enable staff and services to operate within a policy context. For individuals to offer support in this area outwith organisational policy and guidelines is foolhardy at best and at worst leaves everyone vulnerable.

We have provided an example of a policy at the end of this resource (appendix 3), but this is primarily so that we can highlight some key elements. We recommend that staff teams and services follow the types of processes that are outlined in the various publications available on the market.

Sex in Context (Craft and Downs 1997) provides practical guidance and advice on creating policies and guidelines and is a useful starting point for any organisation. They highlight the fact that children and adults with profound and multiple impairments 'will always need other people to be involved in almost every aspect of their lives'. With that involvement, they suggest, comes risk and that is a significant reason why a policy framework is essential. They go on to summarise some of the benefits of having such policies in place:

- bringing sex and sexuality into the open
- providing an opportunity for staff to discuss and share their – often differing – beliefs on a topic seldom aired
- ensuring accountability
- providing a framework for staff
- reinforcing the notion that sex and sexuality are an integral part of being human

They give examples of questions that should be addressed under each of these headings. In particular, they stress that sexual needs are linked to emotional health and not designed to 'thwart staff' or be 'a source of problems'. This approach will place an appropriate person centred emphasis on policy building in this area.

Although 'Batteries not Included' is aimed at supporting adults, we would also recommend readers to consult the Scottish Executive guidance Sex education in Scottish Schools. Part of this guidance relates to consultation and is supported by a leaflet, 'Effective Consultation with Parents and Carers'. This provides information on the principles and aims of sex education that can inform your policy development.[2] The principles endorsed by the Executive stress a positive, natural and lifelong approach to sex education as follows:

[2] The Scottish Executive published 'Sex Education in Scottish Schools – Summary of National Advice' March 2001

> “Sex Education can be defined as a lifelong learning process whereby children and young people acquire knowledge, understanding and skills, and develop beliefs, attitudes and values about their sexuality and relationships within a moral and ethical framework.”

The key principles are as follows:

- sex education should be viewed as one element of health education, set within the wider context of health promotion and health-promoting ethos of the school
- sex education should contribute to the physical, emotional, moral and spiritual development of all young people within the context of today’s society
- education about sexuality and relationships should reflect the cultural, ethnic and religious influences within the home, the school; and the community
- sex education should be non-discriminatory and sensitive to the diverse backgrounds and needs of all young people
- sex education starts informally at an early stage with parents and carers and continues though to adulthood both within the home and at all stages of school life

There are two further publications worth referencing during your sex and sexuality policy development process. The first is ‘Sexual health resources for young people who are blind or partially sighted’, which is a publication by the Royal National Institute for the Blind (RNIB 2000). In its appendix there are details of a stage-by-stage process in developing a sex education policy, finishing by providing a model policy framework.

‘Social and Personal Relationships: Policy and Good Practice Guidelines for staff working with Adults with Learning Disabilities’ (BILD 2001) goes further and provides examples of policy statements in a wide range of topic areas.

Put together, all of these publications provide a structure for creating a policy for any agency with relevant advice on content. We would stress again at this stage that the existence of a policy is an essential requirement for carrying out any work in sex education. Workers should not consider implementing any of the activities that follow in this resource pack if their use is not sanctioned by your agencies policy and procedures.

In concluding this section on policy considerations, we have identified the elements from our Exemplar Policy that we have included at the end of this resource pack. We would remind you that this is not a finished product but one which you can modify for use in your own agency following the types of processes outlined in the publications above and also in Ostli (1987) Von Malachowski (1994) and Hendy (2002).

The Exemplar Policy (see appendix 3) has a number of key elements:

- it starts from a position of being ‘sex-positive’, a policy that gives a clear message that people should be able to develop lifestyles of their choice, including having sexual relationships
- it states that the organisation’s role is to offer support, information and guidance
- support offered should be proactive – we should not always wait for a problem to arise
- support should be offered within the context of an individual’s preferred communication approaches and learning styles

- support should be agreed in collaboration with others and central to this is the individual
- it tackles the issue of consent and offers guidance to staff how to conclude that consent is/is not being given
- it establishes a link with organisational policies on protection
- it gives clear guidance on the decision making process and recommends the establishment of a 'Personal Planning Group' so that individual staff are not acting alone
- it spells out the roles and responsibilities that are played by all concerned, giving clear guidance about the nature of any support of an intimate or sexual nature. This includes the responsibility of the organisation to offer support and training to its staff
- it encourages monitoring and review, with clear accountability and a record-keeping process

Practice Considerations

There are a number of practice approaches that underpin this resource pack that we will explore in this section. First we will consider how people learn, then we will explore some aspects of communication. Leading from this we will highlight what the behaviour of people with complex communication needs might be telling us and how this can then be linked to the development of specific learning objectives in the area of sex and relationships education and sexuality support. To achieve this we will initially look at a number of principles around learning and education.

Our first broad principle flows from the concept of experiential learning. In our experience it is important that the people we support learn by doing. It is vitally important that they learn by doing real life

activities, with associated real life objects. For example, a young child in a mainstream nursery school may learn about some of processes tea-making by using toy tea-making sets, all in miniature using cold water. Generally the child will relate this to the real life adult activity of making tea. That involves a degree of abstract and imaginative thinking that is not always available to people with complex communication support needs. Similarly, many of us will have learned something about shopping through play and by giving other objects representational qualities. The play bricks we had when we were young were sometimes a pound of butter, other times a Ferrari, depending on how extravagant that day's shopping trip had been!

Much of this type of learning is unavailable to people with complex communication support needs and as a result they miss out on much of the information we pick up on a day-to-day basis. How can you pretend to buy a fast car that is really a brick with a drawing of a million pound note if you do not have access to the information your imagination needs to do so? From this understanding it seems safe to conclude that learning by concrete experience is a vital element for people with complex communication needs.

A second broad principle is to do with accessing these experiential learning opportunities. When many of us learned how to make a pot of tea, we did it with supervision from adults around us. A parent will probably stand over you giving verbal instructions: 'Right, fill the kettle with water. Just wait for it to boil. Now you'll need to put the tea bag in the in pot' and so on. This type of learning is often of limited use to a person with complex communication support needs and needs to be modified. The experiential learning, the act of doing the activity often has to involve direct physical assistance from another person. Somebody will assist you to lift the kettle, someone will help you to fill it with water, and someone will help you to find the tea bag. Involving the person with complex communication needs requires a lot of hand-over-hand assistance. It is a time-consuming process, but one

that allows the individual to grasp all of the processes involved. For the people we support there is little to be gained from a second hand account of a process.

A third broad principle relates to the often passive nature of some people with complex communication support needs. In schools and resource centres, staff engage in the process of bringing the world to people. By this, we do not mean that people are not able to access community resources but we do mean that without appropriate intervention from others, some people are not necessarily aware of the world beyond their immediate reach. Neither will they be aware of activities and opportunities that are outwith their normal day–to–day routines. We must provide support to access new opportunities for people and help open up the world with all its exciting possibilities. If someone has never been horse riding, swimming or flying, we should help them explore why they might wish to be introduced to this opportunity.

The fourth principle is about life long learning. An open approach to life long learning helps us to grow and develop throughout our life span and where we recognise and support this the fuller our experiences will be. Although this resource is aimed at supporting adults who may have significant gaps in their learning, we must stress that early intervention and learning is hugely important in the area of sex and relationships education (Miller 1994, Bunck 1989, Hayes 1995, Brandenburg 1998).

For almost any activity you could think of right now, these four broad principles can work alongside one another and provide a potent educational mix which opens up a great range of new learning opportunities for people. To explore these concepts more fully, let's consider swimming in more detail.

If somebody you are supporting has never been swimming before, can you give some prior concepts, some introduction to what they might expect? If it were somebody with some residual vision, we could visit the pool and say: 'Do you fancy a go at that?' We could use photographs or pictures to forewarn the person about what to expect. If the person is deafblind, then you could perhaps build up visits gradually – normal bath, splash pool, hydrotherapy pool, swimming pool. There is other preparatory work you could do: visit the changing rooms, have showers etc. However, the first time in that big pool is exactly that – the first time in that big pool. In all of this process, it might be the staff member or parent who is taking the lead, even though we are moving at the pace set by the individual. At all stages throughout this introduction, there would be much physical support and it is obvious that the swimming will take on no meaning until the deafblind person is in the water for the first time.

So, is it simple taking these principles and applying them to sex education? Sex is a fundamental activity that millions of people all over the world regularly engage in, at various stages in their lives. If we view sex simply as another activity to offer people, then are we able to chart out a series of lesson plans using our broad principles?

1. We need to deliver the required information and education in a real-life setting. Learning should be experiential.
2. Where an individual has significant sensory impairments and cannot access information through their vision or hearing, we may need to adopt a 'hands-on' approach to supporting their learning, using physical prompts where necessary.
3. We should look for new opportunities, new experiences, new activities and we should actively introduce these to the people we support.
4. We should continue to offer new opportunities throughout a person's life.

Unfortunately it is not that simple, and without a comprehensive consideration of each point listed above, and how it relates to sex education and sexuality support, we would be countenancing acts that could be in breach of legal, ethical and socially constructed codes. However, we need to bear in mind that those codes will principally have been created by and for people who can hear and see and for whom touch is not the single most important method of accessing information. In order not to exclude people with complex communication needs we need to find resolutions to these dilemmas because people with complex communication support needs are still asking us on many occasions for information, they do find themselves in vulnerable situations and they do engage in behaviours and activities that can cause harm to themselves or others.

Activity design – moving from abstract to concrete

What we suggest as an approach to learning and education in terms of sex education should help move us from abstract ideas to more concrete methods and in subsequent sections of this resource pack we will help you to know where along this continuum you should direct support for any one individual and which learning methods to use.

We are aware that this approach is the opposite to ways in which we would normally facilitate learning with people with complex communication support needs and opposite to the examples we gave previously. There are particular reasons why we are suggesting this. Principally, it safeguards vulnerable individuals and asks us to satisfy ourselves that more abstract ways of learning will not work for an individual before moving on to more concrete and direct approaches; this fits with the advice given by Downs and Farrell (1996) that the least invasive intervention should be employed. We are not

necessarily suggesting that this is ideal for each individual that we might support, but there are issues of protection and rights to information that we must carefully balance. This is one of the dilemmas that we will return to towards the end of 'Batteries not Included'.

Communication

In our consultation around sex education and sexuality, central themes emerged. Parents ask questions such as:

> ‘How do we know if John wants information about his body?’
>
> ‘My daughter seems to be struggling with masturbation but I’m not sure if I can offer her any advice or support – would she thank me for this? ‘
>
> ‘Could I ever tell if my son wants to have a relationship with somebody?’

‘Listening to Children with communication support needs’ (Aitken and Millar 2002) is a publication aimed at people who are interested in listening to and consulting children. The publication came about within the context of moves towards people increasingly being consulted and this approach is important in our deliberations about sex education and sexuality support for adults with complex communication needs.

The central questions asked by Aitken and Millar (2002) can be adapted to consider how we might address the involvement of people in accessing information on sexuality and sex education and helps us get to the heart of consent issues:

- what is the person able to express at present about this topic?
- how do we know that s/he is asking us for more information?
- how does this person relate to people in life at present?
- how can we tell that s/he is consenting to a sexual relationship?
- how can we ask questions about the lifestyle s/he wants to lead?

Aitken and Millar (2002) provide numerous suggestions for developing and sustaining communication partnerships with people with complex communication needs and they point out ways of building up a sense of how such a person may live their life. They highlight the work of Clark and Moss (2001) who developed a way of consulting with very young children called 'the Mosaic approach'. This involves many aspects, but includes walking with the person, trying to "be in their shoes". For example, walking around a building with a young person observing what they seem to gravitate towards, talking to them as you go, taking photographs and noting what seems to be important for that person. It is a bit like being a detective, making sense of all the clues that you have in front of you and building a picture of

- how that person seems to see their life
- what and who is important to them
- what do they particularly like and dislike
- what seem to be their thoughts and feelings

These will be similar to existing approaches to communication and making sense of behaviour that is applied in some schools, resource centres, voluntary organisations and family homes (Downs and Farrell 1996). Such models can also be used to facilitate learning about sex and sexuality.

Behaviour as a communication tool

Our starting point is to understand that behaviour patterns shown by most of us are forms of communication. People will behave in ways that seem logical to them, so even if someone hits their head to indicate that they want to go to the toilet, we would suggest that for them it is the most logical and clear way to ask for the toilet. When supporting people with complex communication needs our job centres around recognising and responding to such attempts at communication. So, if someone walks down the street and begins to masturbate, what are they trying to tell you? Here are a few possible reasons:

> 'I'm bored and I want to go home'
>
> 'I've just seen someone I find attractive'
>
> 'Am I allowed to do this here?'
>
> 'I've noticed some changes in my body – can you tell what's happening to me?'
>
> 'I've no idea where we are going, so I'll just amuse myself'
>
> 'I feel aroused so think its OK to touch myself'

How do you go about establishing what is in the mind of the person each time s/he masturbates? How are you supposed to respond at each time?

If s/he is telling you s/he is bored and you dismiss it as a behaviour with no real message, discourage her from masturbation and carry on with the shopping trip, then you will have made the situation worse. Or

if you think s/he does want to masturbate and you take her to the nearest toilet, but s/he wants to go home, then you've created an enormous amount of confusion. Why have I been brought to this toilet?

If s/he is asking for someone to explain puberty changes that have been happening and you take her straight home because that's what you thought she wanted, then she's going to be reluctant to ask again.

None of this is easy, but we must make sense of the messages people are giving us if we are to have any chance of giving them the type of information they need.

This 'communication detective' role becomes a central tool in our quest to discover if someone is giving consent, both to sex education as well as the possibility of sexual relationships.

This applies equally to passive behaviours. If someone is not interacting much with the world around them, again, this will be what seems reasonable to them as an individual. We need to ask ourselves why someone has given up interacting with the world around them and not simply see this behaviour as the definitive comment on how someone wants to live their life.

We have to remember that the world in which someone lives has a clear influence on their behaviour. If someone has grown used to not being responded to, then that can explain a lack of interaction. If someone is not regularly offered information and support, then this explains why they stop asking questions.

By exhibiting challenging or passive behaviour, as professionals it is inappropriate to respond with "what is it that I need to 'fix' in them?" Instead we should be asking "what is it that I need to do to make the

situation different for the other person?" It is not the impairment that is the problem as we cannot expect to change the way people see and hear, move and understand. It is the communication barriers that we need to address and these are things that we can continue to develop and change, in partnership with the individual.

This way of working allows us to move forward with learning and development opportunities, together with everyone involved in the person's life, rather than others being in control making decisions on behalf of the disabled person. This is challenging but allows us to see that we have a role to play in repairing communication breakdowns and creating opportunities for new communication routes.

How the person gets involved in communication partnerships will directly influence how you respond to communication attempts. For example, if you discover someone you support masturbating in the dining room, what should your response be? If that individual is already involved in formal sex and relationships education sessions at FE college, including information and videos about masturbation and is able to understand what s/he is being taught, then the reactive strategy would be to ask the person to go to a private place. This would be followed up with a one to one discussion about the importance of privacy later that day and by ensuring that privacy is included in the next formal session at college.

For someone who is not able to understand all of this, then the reactive strategy should be to support the person to go immediately to a private place, help them to remove any clothing hindering masturbation and place their hand next to his penis or her clitoris.

A sex toy may be offered if this has been part of a previously introduced plan for supporting effective masturbation. The aim of this is to give a clear message that s/he is able to continue masturbating as

they are now in private. Where possible, an agreed sign for private should be a focussed piece of communication work.

The difficulty with this approach is that for some people, the process of moving them from where they started masturbating gives them the message that they should stop. This is why the introduction of a sex toy may help re-establish masturbation in private.

Crucial in offering sex education support is to know the preferred communication approach used by any one individual. If you are to know what support is required and how to provide this, it is essential first to know how the person communicates. There are too many systems and approaches to mention here but we do want to outline some aspects of communication that we think underpin our approach throughout this pack.

By recognising communication as a two way process, any attempts at communication by another person must be responded to. In this way, we give a clear message that we are interested in what someone has to say.

A number of key ideas can be highlighted here:

- in order for people to develop communication skills they have to be actively involved in activities. For example, if we are hoping that someone will develop expressive communication centred on mealtimes, then they have to be involved in meal preparation. In the same way we need to determine ways to build up vocabulary and communication skills related to sex and sexuality. Involvement in buying a sex toy or sex educational materials as part of a planned, recorded programme could be a solution for some

- we encourage people to get involved in most day-to-day activities that are important to them. This is not with the intention that they can learn to do these tasks without support, but rather to create opportunities for communication development. Out of shared and joint routines comes a negotiated vocabulary. Our challenge is to consider this in relation to sex education
- as soon as someone has learned a routine based around an activity we would make several tiny incremental changes to that routine. This encourages problem-solving and helps the individual to develop concepts of the world
- when we are developing activities for an individual, if there are ways of linking separate activities, then we should do this. For example, someone may get involved in pouring milk from a jug, next they learn to find the milk in the fridge, then they may get involved in shopping for milk, putting the milk jug in the dishwasher, putting it away in the cupboard etc. In this way, a more developed concept of their immediate environment will be encouraged. Learning to keep a sex toy clean, use lubricants and change the batteries could be built into a routine for masturbation. This might also include a routine of self care, involving bathing and use of sensual-smelling essential oils, that the individual identifies as pleasing

We conclude this section by returning to a key section of Aitken and Millar (2002), where they describe a method for building a communication profile of an individual. This profile highlights in broad terms ways in which a person communicates and describes corresponding ways in which they can be consulted about events in their life. We have considered adaptations to this way of creating a profile, so that it both provides a communication profile for the adults we are supporting, as well as influencing ways in which we can offer

support with various aspects of sex education. Overall we are developing a personal profile that will help describe the learning support the person needs.

In their original profile, Aitken and Millar (2002) suggest gathering information in a number of areas and we have considered how this relates to sex education.

Part 1 – general profile

This asks questions about the language spoken in the home, vision and hearing impairments, physical abilities and any other major areas that would impact upon an individual's communication style. In relation to sex education, we also need to know how a person's vision, hearing, physical and intellectual abilities impact on their ability to access information. The following questions need to be considered:

- what is the person able to express at present about sex and sexuality?
- previous history of sex education?
- how does this person relate to people?
- how does this person generally understand the world around him/her?
- how will vision affect ability to access materials?
- how will hearing affect ability to access materials?
- how will physical abilities affect ability to access materials?
- how do any medications affect level of understanding or expression of sexuality?

To answer these questions we can consider the individual in existing real life settings. Does the person enjoy watching videos? Does the person use their hearing to get information about what is happening?

Part 2 – Receptive communication

This determines an individual's ability to understand information presented to them. Does the person understand more or less everything that other people say or sign? Does language need to be kept simple, or is it routines and situational clues that the person understands? We need to explore a person's ability to understand words, pictures, social signs, symbols. Does the person read more than 100 words, does the person recognise picture clues? Answers in these areas will influence what and how you offer learning support.

It will, for example, influence:

- how sex education is delivered – If the person is not using language, then resources that rely on language will be no use. If the person cannot understand that a cartoon is being used to relate to them, then it is likely that videos and line drawings would also be too abstract
- when sex education is delivered – if person's world is clearly rooted in the here and now and routines, then this suggests a more concrete level of delivery is needed
- where sex education is delivered – similar to above, if person's world is clearly rooted in the here and now and routines, then this suggests moving teaching nearer to the time that it is required
- who does the teaching? – if a person has limited receptive understanding this would mean that it is best to be someone who knows the person well who offers support because this person is likely to have a better communication relationship and understand the specific communication systems used

Part 3 – Expressive communication

This provides a useful summary of how someone gets messages across to others. Does the person speak or sign intelligibly with more than 100 words? Do they communicate fluently in some other way? Do they make their feelings known through other people? Is s/he able to express himself/herself through writing, pictures and symbols?

Within the context of this resource pack, how someone expresses things can help us determine when someone really is asking for information and guidance on sex and/or sexuality issues. It also determines ways in which an individual can contribute to their learning sessions and helps also to determine the level of communication support they require, which in turn will also indicate who should be supporting them.

How someone communicates expressively will influence:

- how sex education is delivered – if a person has good expressive communication, then this might mean that you can relate abstract concepts and ideas to their situation. There will be a continuum that suggests a need to move towards more concrete strategies for people with more limited expressive communication
- when sex education is delivered – partly this links to the ideas of proactive and reactive strategies. If someone has an ability to engage in conversations, then if they are masturbating in the living room, you can have a discussion about why it's not appropriate there and at that time. You can direct them to a private place. However, good expressive communication might also mean that the person is able to ask questions as particular situations arise. More limited expressive communication might meant that questions do not get asked and we need to interpret behaviours as potential questions

- where sex education is delivered – again an individual with good expressive communication is able to ask about links between different places – would this be OK in this place? Would it be OK to ask Brenda (another service user) about this? Conversations like this will mean that learning can move away from the here and now
- who does the teaching? – for anybody with communication support needs we would need to make sure that whoever is supporting them has good communication skills and is able to engage with the individual

So how do we know where to start? How do you go about building up a Profile for Learning Support and what will this tell you about areas to offer support in and ways to go about offering it?

In the section on communication we will present a method for building a communication profile that grows from the principles and questions offered by Aitken and Millar, but first let us consider the important factors that will influence what support you offer and suggest ways that you could go about this.

Six Honest Serving Men

We have developed a series of check lists that will allow you to determine an individual support plan for the people you are working with based on their own individual needs and abilities as well as their expressed wish for specific pieces of knowledge and skill development.

These checklists ask various questions, each of which have a series of background information sheets that you can refer to as you fill it out. This process should not be seen as a comprehensive assessment of an individual's knowledge, skills and abilities but should instead be used as a method for generating ideas and approaches that will support the person. It is also a useful tool to be certain that all key members who are supporting one person are in agreement about the way forward and the reasons why they are taking a particular approach.

We have based the checklists on an extract from a well known poem:

The Elephant's Child by Rudyard Kipling
I keep six honest serving-men
(They taught me all I knew);
Their names are What and Why and When
And How and Where and Who

We want to address each of these questions in relation to sex education:

- What should be learned?
- Why should it be learned?
- How should it be taught?
- When should it be taught?
- Where should it be taught?
- Who should support this?

But we first want to turn each of these into 1st person statements and in this way, it is easier to see the power behind these questions and the consequent need for professionals and carers to tackle each area:

- This is the information that I want
- This is why I want that information
- This is how I should get that information
- This is when I should get that information
- This is where I should get that information
- This is who should give me that information

What should be learned? or "This is the information that I want."

There is a reasonably definitive list of what we need to know about human sexuality, sexual functions and associated behaviours and we include a grid for you to use on page 109. There are also a range of useful resources in the reference list where you can get ideas about the range of information that you need to help people with complex communication needs to access. The real challenge here is not to edit what we think the person should know, or does not "need" to know.

As we have already discussed at length, it is every adults' right to have access to information about sex and sexuality and as support workers the challenge is to act as a conduit for this information. A useful analogy is to consider that we can offer people two things: roots and wings. The roots of social/sexual development lie in the development of self-esteem, communication, choice and decision making skills, control and forming a network of supports and relationships. The wings of social / sexual development are the content areas of social/ sexual skills and knowledge needed to enable one to participate as fully as possible in life (Miller 1994).

In order to determine exactly what you need to address in terms of sex education with any individual, we recommend that you carry out a knowledge assessment prior to any support being given. This will mean your support is designed around information gaps that the person has. If the person is already aware of body parts and their names, then there is little to be gained in covering this topic again. However, if you are uncertain that a person really understands any particular topic area, then we would suggest that you consider covering it. Knowledge assessments are also useful to determine if your support has been successful. Has your support made any difference to the person's knowledge? We include a number of knowledge assessments in the references, although you can check if your organisation already has one in place.

Why should it be learned? or "This is why I want that information."

This is the central part of your support and it is here that we begin to gather a picture of what an individual is asking us in terms of support in developing their learning. Some people have argued as we put this resource pack together, that in mainstream education settings we would not ask "Why does someone want information?" On the surface it can look as if society does provide sex education before children and young people ask questions or get into difficulties. To some extent, this is correct and there will be much incidental learning taking place for young people as they go about their daily lives. However, if sex education is unfolded in schools in an appropriate and skilled manner, then it is our opinion that it does address questions that are already in people's minds.

This means we cover topics such as masturbation with seven year olds quite differently than we do with 13 year olds. This is because age appropriateness is the key with young people and also, due to the impact of physical maturation, different aspects of sexuality will begin to raise questions for them as they mature. We also know that most young people have others they can direct questions to such as teachers, family members and friends (albeit some of the resulting answers may be questionable, such as those discussions 'behind the bike shed'!)

While we must not confuse adults with complex communication needs with young people, there are certain parallels as they are classed in law as vulnerable adults. This means we have to consider why we are offering support and be able to articulate this. Documentation of your observations and your thinking is vitally important here. (Downs and Farrell 1996, Carson 1992). To facilitate your thinking about this here are some scenarios which relate to many of the dilemmas we have raised so far.

People who find themselves in very vulnerable situations, like the young woman who stood at the side of the swimming pool and ran her hands down the front of her body to clear water from her costume. She was 25, deafblind and to some people in the pool her behaviour may have been interpreted as a sexual invitation.

Q. **Why might she want to learn about appropriate and inappropriate behaviours in public places?**

A. (in her imagined words) Because I don't know why people keep looking at me and I have no idea why the group of teenage boys in the pool followed me around.

People who engage in harmful behaviours, like the 17 year old woman who had discovered by accidental exploration that her personal stereo could be placed on top of her genitals with part of it inside her vagina giving her a wonderful feeling.

Q. **Why might she want to learn how to use a vibrator?**

A. (in her imagined words) Because one day I might hurt myself if I place something really dangerous into my vagina.

People who hurt themselves, like the young man who had to go to hospital when he caused abrasions on his penis.

Q. Why might he want to learn how to masturbate properly?

A. (in his imagined words) Because I'm fed up hurting my penis and spending hours every day trying to do something that feels good, but at the same time is really sore.

People who cause offence to others, like the young man who kept touching women's breasts whenever he was in an enclosed space such as a lift.

Q. Why might he want to learn about the physical differences between men and women?

A. (in his imagined words) Because I have no idea why the front of women seems to be different from me. I just want to find out what is underneath their top, but every time I try to find this out people tell me to stop.

People who are scared every month, like the young woman who has no idea what is happening to her body every time she menstruates. She always gets very anxious.

Q. Why might she want to learn that menstruation is something that happens to other people and it is a natural event for her.

A. (in her imagined words) Because every time that thing happens to me, I feel really unwell, I get scared and frightened and embarrassed. I think I am doing something wrong.

People who are not experiencing life to its full, like the woman who prefers that women assist in personal care tasks but she does not know what all the feelings and sensations going on in her head are all about. She tries to touch her own genital area when she is being changed and this is the only time of the day that she is able to do that. The women just take her hand away.

Q. **Why might she want to learn about physical intimacy and masturbation?**

A. (in her imagined words) Because every time women help me to change, I feel a bit excited and I wish I could touch myself like that at other times of the day.

It is clearer when we reframe behaviours in this way that we could ask ourselves a really awkward question: 'How dare we not support this learning?' Because if we are not able to teach the young man about what's beneath a woman's top, then can we really expect him not to ask the question through his behaviour?

If we don't support the young woman to have time and space and skill to masturbate herself, then should we not accept that she touches herself throughout her personal care activities? If we don't support the young man that we know is getting into difficulty with masturbation, do we then accept responsibility for his hospital admissions?

In each of the examples given above there are behavioural clues that we can observe and it is these observations over a long time period that allow us to locate the voice of the individual and listen to the question or questions they might be asking us. It is by doing this that we are able to respond directly to the individual learning objectives that are set in reality by the person themselves. We no longer direct the teaching but simply refine behaviours that are already there for an

individual or offer support to fill gaps that have been identified by the person. Most people we support will not be able to give us direct questions and so we must respond to behaviours that we observe.

Many organisations will already have detailed procedures in place for gathering observations and making sense of it all and so we do not propose to outline an entire process here. The important part for you is to locate the individual's voice as an important part of this whole process. Within the context of the Adults with Incapacity Act, we can use evidence gathered here to determine that we are acting in the person's best interest.

Analysis of all behavioural information will allow you to determine where sex education, or particular aspects of it, fit within appropriate priorities for any one person. So if, for example, someone is hurting themselves on a daily basis through a poor masturbation technique, risk analysis suggests that you should offer support soon. For someone else, you might discover that masturbation only occurs inappropriately, when they at the shopping centre on busy days. At all other times, masturbation seems to occur in their bedroom. Maybe this is not a sexual activity, but simply a great way of getting out of an uncomfortable situation and other activities would interest the individual more.

These observations will be used to generate the evidence you require to understand if consent is or is not being given for participation in sexual relationships. We will explore this more fully in some of the Life Examples, but if you are building a picture over time about how someone lives their life, you will be able to consider that new behaviours, activities or relationships are either within their usual repertoire or could be seen as a natural and reasonable extension of this.

If a man you support always looks excited when other men are around, or looks more closely at the television when certain men are on and he likes looking at magazines with pictures of male pop stars, it will be reasonable to conclude that he likes men. If you know all these things then you should not be surprised if, when a new male resident moves to the house that within weeks they want to spend lots of time together, they like to be near each other and whenever they are together, they both smile and laugh. After a few weeks more, you notice that they are holding each other's hands when they sit watching TV. You will be able to see that a picture emerges that the men like each other and so, when a staff member discovers the two men in a bedroom engaging in oral sex, we might be able to consider that this is a consensual relationship that has been developing for the last few weeks and months.

Without these observational clues, it will be more difficult for staff to determine that any sexual activity between the men is consensual or abusive. What a tragedy if a potentially meaningful relationship was thwarted because staff were unaware of the signs and individuals. But what a tragedy too, if staff simply allowed sexual abuse to take place. This is a difficult area and we will return to it, both in the Life Examples and also in the Dilemmas section.

Consent is the crucial key that opens the door to sexual relationships. If there is anything that we can do to help support people to make clear that they are consenting, then it needs to be done.

How should it be taught? or "This is how I should get that information."

The how questions relate to materials that can be used to support the learning: real-life, videos, dolls and other sex education materials.

There are a wide range of abstract support materials, such as videos, drawings, photographs and books and also a growing range of more concrete materials, such as anatomical dolls and models. The logical progression of this abstract-concrete continuum is to consider real-life situations where learning can take place. For example, if we were trying to support someone to learn about their own body, we could use personal care routines, such as bathing and dressing. However, this is much more complex at a concrete level if we are supporting learning about bodies of the opposite gender. The earlier in someone's life that this type of information is given, then the easier it is to deliver in real-life situations. However, as we know many adults with complex communication needs are often not helped to understand these issues so we need to address how concrete learning opportunities can be addressed before they cross legal, ethical and cultural boundaries.

By answering the relevant questions in The Profile for Learning Support you will create a clear picture of why you have chosen particular support methods. This profile may also indicate that more abstract methods have been used unsuccessfully or would not work for a particular individual eg someone has no useful vision and cannot access video materials.

The dilemma here is that the law prevents certain interventions such as observing a service user masturbating or physically assisting him or her to achieve sexual pleasure or orgasm. This is possible in other parts of Europe but not currently in the cultural and legal climate in Scotland. (Valios 2001)

The principal factors that can influence how you support learning to take place will include the level of an individual's vision, hearing, physical impairment, conceptual understanding and other individual traits.

A few useful tips to link some of these observations to real questions about the person:

- do you think that this particular route to giving information will be helpful?
- does the person ever watch TV? Videos? Do they find these meaningful?
- if you know a person learns recipes at college and then makes meals back at home, what does this tell you about the methods you might need to employ to support them?
- the how questions will also be limited by what others in your planning group consider to be reasonable resources. Your organisation, for example, may not support the use of sex aids.

When should it be taught? or "This is when I should get that information."

In reality, there are two factors to consider in relation to when something needs to be understood. There is the question of when is the most appropriate time in someone's life for the specific learning to take place. We have already seen that masturbation will be explored in very different ways for 7 year olds and 13 year olds and if we consider menstruation, generally it is accepted that information about this ought to be given to girls before it occurs for the first time. In relation to people with complex communication needs, the process of explanation will depend on the girl/young woman's ability to relate information given today to an event that might happen sometime in the future.

There is then the question of when learning should take place in relation to routine activities. If a young woman has started menstruating, should we support her to learn more about this as it actually happening, or should this be planned time as close to menarche as possible? Similarly, if someone is masturbating in the living room of their house, do we support learning right there and then, or do we wait for another suitable time? Again, knowing how to answer this will depend on a person's ability to remember or to transfer learning from one situation to another.

We can also identify that there are particular challenges for staff in schools and resource centres, since by their very nature, these are places that find it difficult to encourage concrete, real-life learning opportunities.

For example, if someone is masturbating in their own living room, it is reasonably straightforward to direct them to their bedroom and pick up on learning opportunities there. This is not so easy in a typical school or resource centre setting.

The factors that will influence when you support learning will include conceptual understanding, memory, abstraction/transfer of skills and these will all be explored in the Profile.

Where should it be taught? or "This is where I should get that information."

Many of the factors that influence when you support learning, will also be applicable in determining where learning should take place. If we continue our exploration of menstruation, is it best for a girl to learn about this in a classroom setting, or in the bathroom where she will manage her menstrual hygiene? Similarly, can the person understand about masturbation if this is supported in a classroom and not their own bedroom? Again, the Profile will help you to determine where is the most appropriate place for learning support to be offered to any individual.

We must be conscious also of the wide variety of real-life situations that we can draw people's attention to. If we are working on body awareness, for example, we can use laundry baskets as a way of discovering differences in clothing, we can use magazines, TV programmes, trips to the swimming pool etc to explore body awareness of self and others. Longhorn (1997) is particularly useful in these areas. Similarly with more explicit sex education if we are finding out about condoms then places where these are available are increasing and can be used to consider the availability and about making the link to future planning for masturbation or sexual intercourse.

Factors that will influence where you support learning will include conceptual understanding and transfer of skills.

Who should teach this? or "This is who should give me that information."

There will be considerations here that relate to the policy and practice framework of your particular setting, as well as considerations that relate to the individual person. For example, some settings will encourage gender specific support, unless there is a clear, alternative view from the person. We would also advocate that it should only be people involved in the delivery of sex education who are comfortable in doing so, and who are appropriately trained and supported. These factors will necessarily limit who supports specific pieces of learning.

Factors that will influence who supports the learning from the perspective of the individual, will include the communication skills required for learner and supporter to understand one another, the level of trust the person places in others, the likelihood of embarrassment and so on.

The central question that arises here is around the possibility of physical support to learn sexual knowledge or skill. Should this be offered by someone who knows the individual well, because this maximises the communication potential, or by someone who does not know the person at all, because this minimises the potential for confusion about sexual relationships? We do not have one clear answer here, because again decisions will have to be made by a group of people who know an individual very well. Some consideration is given in other countries to buying the services of a sex therapist or worker (Valios, 2001) and while this is not possible in today's Scotland, we will consider the implications of this in the Dilemmas section.

We offer here a process that allows you to develop an individual learning support plan for any person. We would remind you again that a policy framework is essential for you to operate within, which should lead to the development of a detailed list of the sex and relationships areas your agency is able to support. Next we turn our attention to the profile for learning support that outlines how you are going to access this for each individual person and finally, agree the support that can be offered to the individuals you work with.

Profile for Learning Support

Sex and Relationships Education

Part 1 – general

Personal and Social Development

1a) Describe what the person is able to express at present about sex and sexuality.

1b) What type and level of sex and relationships education has this person already had?

1c) How does this person generally relate to other people?

Sensory abilities

2. Does this person:

	Yes	No	Comments
a) have sufficient vision to access learning materials? (eg videos, pictures etc)			
b) have sufficient hearing to access learning materials? (tapes, video soundtracks etc)			

Understanding

How, when and where to support learning

3. Could this person:

	Yes	No	Comments
a) relate to and learn from videos of cartoons/puppets?			
b) relate to and learn from videos of real people?			

	Yes	No	Comments
c) relate to and learn from cartoons?			
d) relate to and learn from line drawings?			
e) relate to and learn from pictures of real people?			
f) relate to and learn from representational models and dolls?			
g) relate to and learn from anatomically correct models and dolls?			

4. Is this person able to:

	Yes	No	Comments
a) learn new skills in situations removed from daily routines? (eg learn cooking in a college class)			
b) transfer new skills/knowledge to different situations? (learn to cook in one kitchen and follow the same recipe in other kitchens)			

5. Who should support this learning?

	Yes	No	Comments
a) Does your organisation have any gender-specific policies that will determine who supports learning in SRE?			
b) Does this person express any preference for support in SRE from a male or a female?			

Receptive communication

	Yes	No	Comments
6a) Understands more or less everything that people say or sign to him/her – all the time, in day to day conversation			
6b) Understands much of what people say (or sign) to him/her – if the language used is kept simple			

	Yes	No	Comments
6c) Understands roughly what people are meaning, through tone of voice, familiarity with routines and other situational clues – at a very simple level			
6d) Reads with understanding around 100 familiar words			
6e) Reads with understanding – a few single key words			
6f) Recognises and understands picture clues, logos, timetables, social signs, symbols in the community but cannot read/understand written words			

Expressive communication

	Yes	No	Comments
7a) Speaks, signs or communicates fluently in some other way (eg picture exchange, gestures, symbols, communication aid), so that most people can understand what s/he means most of the time.			

	Yes	No	Comments
7b) Speaks, signs or communicates fluently in some other way so that most people could understand some of what s/he means.			
7c) Signals meaning in ways other than speech (eg gestures, pointing, face, eyes, general behaviour, sounds, movements) that can usually be understood by one or two familiar people.			
7d) Makes feelings understood through other people – ie who know the background and daily routines well, and who can interpret his/her meaning from knowledge of his or her usual behaviour and responses etc.			
7e) Writes and spells intelligibly or types at level that roughly matches reading ability			
7f) Writes or types one or two words (eg own name), copy written text			
7g) Draws pictures to explain what s/he wants.			

Life story examples

We have developed a number of life story examples to illustrate the processes and tools that are explored in this resource pack. These examples are based on the types of situations that have arisen in the experience of the authors, but the examples given here do not represent real people. We have considerably altered the details so that no person could ever be identified. They are examples that were briefly introduced on p63 (Six honest serving men – building a personal profile).

Example 1 – Mary

Mary is 25 years old and congenitally deafblind. She is the young woman who stands at the side of the swimming pool and runs her hands down the front of her body to clear water from her costume. Given that she is 25 and able to get around by herself, perhaps to some people in the pool her behaviour could be interpreted as a sexual invitation.

Personal and Social Development

Mary does not appear interested sex as such. She has never been known to masturbate and when she goes about her house, she often leaves her housecoat undone. Staff think this means she is not that aware of her sexuality. However, she is aware that she is woman and most key people in her life think that she considers herself to be a young girl. She shows no real preference in the company of men or women, both amongst the staff teams and the other people who live with her. The only exception to this is shopping for clothes which she prefers to do with a woman.

No one knows much about any sex and relationships education that Mary has had in the past. She did go to a specialist school but there are no records of sex education classes. A few years ago, she did a class at college where she spent some of the time sorting out pictures of men/women; boys/girls. She appeared to know what this all meant.

In general Mary likes her own space. She has a single room and spends a lot of time in it. She shows no real preference for different people, although she is very aware of who her parents are and always recognises her sister when she comes to visit. Occasionally, Mary will be aggressive towards other people if they appear not to be understanding her communication. She uses a lot of signs and

gestures to communicate and also draws pictures of things that she wants.

Sensory abilities

Mary has good residual vision. She uses this to get about places, watches TV, recognises signs and gestures from a distance of about 6 feet. She reads magazines and catalogues and appears to recognise details in pictures. She is profoundly deaf with no functional hearing at all.

Understanding

Mary likes watching TV and could probably relate videos to her situation. She likes looking at catalogues to choose outfits, although she is drawn to things that are often too small for her. She has learned lots of recipes at college and cooks back in her house. She follows recipes using combinations of line drawings and photographs of the ingredients and processes. She remembers events from before and often keeps photographs of holidays etc. She uses brochures to plan holidays and she has pictures that she can use to plan out her day/ week.

Communication

Only the staff team who support her and her family are fully able to understand what she is trying to communicate. She understands much of what people say to her (6b) and she recognises and understands pictures and words (6f).

She is really only able to be fully understood by people who know her really well (7c) and although she does not write, she does use lots of drawings to explain what is in her mind (7g).

Why do we want to support learning?

By observing her behaviours over many weeks, staff interpreted that she did not understand issues around public and private. This is where they wanted to offer support. [3] They discovered that not only was she

displaying inappropriate behaviours at the swimming pool, she was also leaving the toilet door open, wandering around the house with her housecoat open, and opening her bedroom curtains, sometimes in a state of undress.

What learning needs to be supported?

Staff decided to support her to appreciate that she was a grown woman and what behaviours might be appropriate/inappropriate both in the house and at the swimming pool. At other places outside the house, there were no particular issues arising.

How, where and when to support this learning? Who should support it?

A number of videos and line drawings were available to support this learning and since they knew that she could learn in one situation and remember it in another, they opted to do teaching once a week at a set time.

A number of role play situations and discussions with Mary were followed through using picture sequences of how to get about the house, what to do when you get up, what do after a bath, what to do at the pool once you have your shower etc. However, they also reinforced all this learning at specific times (at the pool, after she had had a bath, when she was getting up in the morning etc).

There was no complicated support needed so two staff were chosen to develop the sessions and the whole staff team and her family reinforced this at appropriate times.

After a few months of this support, the staff saw a reduction in going around the house with open housecoat, more appropriate behaviours in the pool and waiting until she was dressed before opening the curtains.

[3] There would be many other areas of support that could be offered to Mary but for the purposes of this example we will concentrate on this area

Example 2 – Caroline

Caroline is a 17 year old woman who had been observed by staff placing her personal stereo on top of her genital area. She did this most nights when she was in her bed. On one occasion, staff noticed that she had placed the edge of the personal stereo inside her vagina. She appeared to be enjoying the sensation that was resulting from this.

Personal and Social Development
Caroline is obviously interested in masturbation. This has been known to key people in her life since she was about 13, although it is only in the last few months that people have noticed that she has been using the personal stereo to help her. Previously, she simply used her hands, although people have noticed that she sometimes used to rub herself against furniture.

Caroline has never been offered any support to learn masturbation techniques. She appears to have discovered masturbation by herself. When she was going through puberty, her Mum had offered her some explanations about the changes that were happening to her and had attempted to draw Caroline's attention to the physical changes that were taking place.

Sensory abilities
Caroline is deafblind, with only the slightest residual vision, which she appears to use to determine whether it is night or day. She has some hearing which with good quality headphones, enables her to listen to her personal stereo.

Understanding
Videos and pictures could not be used to support learning with Caroline. She does have around 20 objects of reference that she understands (cup for drink, costume for swimming, coat for going out

etc), although she also understands and uses finger-spelling and some adapted signs. However, it is thought unlikely that she would relate a model vagina to her own situation. Most of her learning takes place in real situations. For example, she learned to make a drink in her own kitchen. She needed lots of physical assistance to do this. She also learned to bath independently by getting physical support to do this when she was a young girl. When she moved to her new house at 17 years old, she did not need additional support to re-learn this, other than being shown where the taps were, cupboards etc, so this indicates an ability to transfer skills.

Communication

Caroline seems to understand lots of what key people in her life are trying to communicate (6b) but we can certainly say that she understands events from routines and situational clues (6c). She understands around 20 objects of reference and also hundreds of signs/finger-spelling. Similarly, she uses these objects and signs to get messages across, but many of the signs are idiosyncratic so you need to know her well to fully understand (7c, 7d).

Why do we want to support learning?

Mainly because there is a worry that Caroline will hurt herself if she continues to use her personal stereo to stimulate herself. This has become an almost nightly occurrence and while she could be encouraged to put the stereo away at night time, there are occasions when she wants to listen to music.

What learning needs to be supported?

There is a belief that she is enjoying the stimulation that she is getting at present and we should introduce vibrators that can offer her increased enjoyment with significantly reduced risks.

How, where and when to support this learning? Who should support it?

A plan was agreed as follows. It was thought best to introduce the vibrator to Caroline for the first time once she was in her bedroom and ready to go to bed. When she had her pyjamas on, the staff member would assist Caroline to open her top drawer and together they would find the vibrator. The staff member would help Caroline to switch it on and encourage her to explore it. It would be placed on Caroline's arm and gently rubbed up and down by the staff member. The staff member would then place it on Caroline's stomach and help her to hold it there for a few seconds. The staff member would help Caroline switch it off and switch it on again. They would repeat this action a few times.

Once the staff member was sure that Caroline understood how to switch the vibrator on and off, she would leave the room. She would look in to Caroline's room, over the next 30 minutes a few times to observe if Caroline was effectively using the vibrator. If even on one occasion she was observed to be using it appropriately, staff would immediately leave the room and cease observations for the next hour.

It was thought that Caroline would learn how to use it after this type and level of support. However, if after 5 nights of this level of support Caroline appeared not to understand what she could do with the vibrator, it was agreed staff could help Caroline to remove her pyjama bottoms and they would assist her to place the vibrator next to her vagina. This level of support would also be offered for 5 nights and only if this was unsuccessful, could the staff assist Caroline to insert the vibrator into her vagina.

It was agreed by the Personal Planning Group that only 2 members of the staff team would be able to assist Caroline with this learning. Strict guidelines were drawn up about the length of time that each support stage could take, and in what manner the observations should be

carried out. Although the whole Planning Group were involved in planning all stages, only the two staff members and the senior manager would have access to the reports that would be written after each support session.

Example 3 – Colin

Colin is 23 years old. Frequently over the last few months, it has been noticed that he goes through to his room and attempts to masturbate. He can do this for up to two hours. He does not always seem to have an erection, although he keeps rubbing his penis during this time. On a few occasions he has come out of his room with his underwear down and approached other people, whilst still attempting to masturbate.

Personal and Social Development

Colin is obviously interested in masturbation because he attempts to masturbate on average 4–5 times per week. He does not seem to show any sexual interest in other people, although he does enjoy the company of other people, particularly some of the male staff who he likes to go for a pint with. He comes from a large family and appears to know his brothers and sisters. He enjoys their regular visits and likes going with them to the local café.

At his Day Centre, Colin has participated in some SRE classes. He has learned about gender differences, life cycle processes, public and private, appropriate behaviours, and one lesson on relationships. He is also aware from the world around him and from TV which he enjoys, about relationships and some sexual activity, although it is difficult to be sure what he really understands of all this.

Sensory abilities

Colin has good vision but a significant hearing impairment. He has a hearing aid, but he prefers not to use this.

Understanding

Colin really enjoys the TV and videos and these are used in other situations to support his learning. He likes some DIY tasks and in the past he has been able to follow simple instruction leaflets to construct cupboards, although he did need some assistance to complete this. In the SRE classes that he took part in, he seemed to relate the pictures

and line drawings that were being used to his own situation. Alongside the line drawings he gathered photographs of himself at different ages and was able to match himself as a baby, toddler, young boy, teenager etc to the appropriate line drawings.

Communication

Colin has a reasonable grasp of BSL and uses this to give and receive information (6b, 7b, 7c). He supports his signs with a number of gestures and if he gets really stuck, he sometimes draws pictures, although these are often difficult to interpret unless you have some idea of the context which Colin is talking about (7g).

Why do we want to support learning?

Over the last few months, it has become increasingly obvious to staff the Colin is attempting to masturbate more often that before. It was known that advice was sought 5 years ago from a specialist in the local hospital's genito-urinary department. No physical causes were discovered for difficulties with masturbation. This has been an issue going back for many years, but it has only recently been observed again by staff. Some people think that it is beginning to interfere with other activities that Colin enjoys. Staff have been interpreting his recent behaviour (coming out of his room whilst attempting to masturbate) as a plea for assistance and information. He does not attempt to masturbate in any other inappropriate places or situations.

What learning needs to be supported?

Staff have interpreted all of these behaviours in two ways: he needs to be given some sort of stimulation to encourage satisfactory masturbation and he needs to develop a better technique for achieving orgasm.

How, where and when to support this learning? Who should support it?

A combination of line drawings, photographs, models and videos will be used to support this learning. It has been agreed that 2 staff will support this learning and they have set aside one hour slots twice in the week. These sessions will be run over a number of weeks.

In the first instance, Colin will be shown a series of line drawings that illustrate the steps that should be taken before someone masturbates. (Colin appears to understand all these steps just now since he does go to this bedroom). Once this sequence is established and Colin knows what is being referred to, he will be shown a model of a penis. The staff member will demonstrate an effective technique for masturbation on this model. We will also use an fpa video which demonstrates, using puppets, how to masturbate. Finally a video sequence will be shown that shows a man masturbating.

In addition to this learning support, Colin will have access to pornographic magazines in the classes, featuring both men and women, heterosexual and homosexual sex. He will be able to read through these as he wishes. These magazines will be kept after the class by the 2 staff who are supporting him with this.

In order to make the link for Colin between these sessions, on any occasion in his house when Colin attempts to masturbate, either of these 2 staff will offer him access to the pornographic magazines. Over a number of weeks, we should be able to determine if Colin is showing a preference for any particular magazines. It may be that the magazines do not work for Colin and we may show videos with explicit images instead.

If neither of these suggestions work, staff will support Colin to purchase a latex vibrating vagina that he can use over his penis to assist masturbation. As Colin can see well, he can be helped to understand the instructions and to relate these to himself.

Example 4 – John

John is deafblind as a result of maternal rubella and lived in a hospital for 20 years from the age of 16. During that time he was not supported to communicate effectively with anyone. In 1990 he was discharged to live in supported accommodation with Sense. At the age of 36 staff had to begin supporting John to learn everything about his new home and about living in a town with neighbours who were not other hospital patients or staff. They also established a communication system based on some sign language and symbols so John can communicate some of his thoughts and wishes.

In terms of sexual health and information it is clear that John has had anal intercourse but what is not clear is if he consented to this and there is nothing in his hospital records about sexual relationships that he has had in the past. In his new home John shows a preference for male staff and regularly tries to touch male workers' and his two male flat mates' genitals. This leads him to masturbate often in public areas of the house.

There is a mixed reaction from the staff team, some of whom are concerned that he has previously been abused and needs some help to reconcile this and cannot get their head round his sexual interest in other men. Others think he is gay as he is clearly sexually aroused by other men and shows no interest sexually at all in women. He has some vision and his interest in men extends to pictures and men on television.

The team are working hard to develop John's understanding of inappropriate touching of others, particularly for the other service users to whom they have a duty of care. This is proving a challenge as one of the other men lies on the settee a lot in the evenings and John seems really attracted to him. This other man seems neither to encourage his attention nor does he reject it. However, it is always

initiated by John and as consent is not clear, staff intervene and are now vigilant to try and avoid the situation arising. They are also trying to help him realise that the only appropriate places to masturbate are in his room or in the toilet. To help him with the latter, his room has recently been decorated with his favourite pictures of male stars that he helped choose out of magazines.

This is discussed at John's review meeting and everyone agreed that he should be supported to visit the local sexual health clinic for men who have sex with men for a sexual health screening and advice. They also discuss the possibility of supporting John to visit gay venues but these are mainly pubs and clubs. John has never shown an interest when he has visited pubs before. The concern is if John did meet another gay man who was interested in having sex with him would he be able to give consent and understand his right to insist on safer sex? This idea is not supported by the review group. What the group ask staff to look at with John is what he enjoys doing socially, by trying out more conventional social arenas rather than gay venues. They are also going to explore other ways for John to meet other gay men such as a hill walking group as this is an activity he really enjoys.

Key Dilemmas

We have debated and discussed sex and sexuality issues in varying degrees of depth throughout this pack. As initially highlighted from the start, we have not been able to provide definitive answers to all the questions that we know are out there. In this short section, we pull together the most important of these unanswered questions for you to consider and continue to debate, with the aim of, we hope, leading us towards conclusions that, with careful legal and policy change, would mean comprehensive support for the sexual health, education and sexuality issues faced by people with complex communication needs.

Dilemma 1

Questions with no answers?

The reason we called this pack 'Batteries not Included' is because we cannot always give definitive answers as the questions are not simply being set by us, but by wider society and the various cultures that society represents. This is a key dilemma. However, it should not stop everyone from continuing to ask questions about sex and sexuality issues for people with complex communication needs and attempting to reach solutions. Traditionally it has proved difficult to give specific practical guidance to staff teams about what to do in every situation with every individual with complex communication needs. The commissioners and authors of this report believe that only through discussion and effective communication about the difficulties faced, will change be effected.

Dilemma 2

Is morality constructed in a way that is relevant?

There are deep philosophical questions about ethics and morality that place the sexuality needs of people with complex communication needs at risk, as it is easy to use such arguments to avoid doing anything at all. We would argue that the law and associated policy offers necessary protection and that morality has little meaning for people with complex communication needs. This is because of the way the moral debate over sex and sexuality has developed over the years and how it varies across cultures. It is also, in the domain of non-disabled people, based on the ways in which the dominant majority are expected to behave.

The moral debate is such a difficult issue generally and one which it seems that opposing views will never compromise. In relation to disabled people who communicate differently and relate to others in unique ways, then to impose a set of sexual values which may or may not be their choice and which the person is unlikely to be able to defend or debate seems judgemental and risks moulding them into something they are not. Again the law imposes a structure for us all in terms of public behaviours. Surely then we all should have creative space to develop our private sexual self? This is an area of support for people with complex communication needs.

Dilemma 3

A step too far – or is it?

People with no residual vision need help to access materials; there are also issues around the use of 'hands-on support'. Without access to materials and hand-over-hand assistance some sexual activities such as masturbation will be extremely difficult if not impossible to achieve. What we can do in law in the UK is assist people to access materials such as vibrators or latex vaginas. To support this work, there needs to be effective policies to empower staff and protect service users. What we cannot do today in the UK is show service users how to use sex aids because this will involve witnessing or perhaps touching the person when they are sexually aroused.

There are two future solutions to this. One, change the law to allow staff, within clear guidelines, to demonstrate and facilitate masturbation with sex aids. This is done in other countries (eg Denmark) and can be managed in a matter of fact manner that does not involve the staff member in the sex act itself but can allow appropriate contact such as hand-over-hand guidance to masturbation. The other option is to bring in the skills of a massage professional or sex worker to assist. Again this is possible outside the UK, and changes to the law are needed but if this is debated and agreed as the best way forward, then organisations who support people with complex communication needs will need to champion such change.

Dilemma 4

Proactive versus reactive

Do we wait for someone to show some interest? For example, if a deafblind person has shown no interest in sex, including masturbation, is this because they are genuinely not interested or because they have no idea that such a thing is possible? For many people with complex communication needs, self-exploration will lead them successfully to masturbation. However, for others it will not. How can we replicate the kind of information and learning that is around for other adolescents for deafblind youths? How did we all learn about masturbation? Is that same route available to a deafblind person?

We support the proactive route as masturbation and recognition of one's sexuality is an important part of life that should not be denied to disabled people. The inclusion of masturbation and sex education needs to be an explicit part of support extended to all service users. Staff and managers of services need to use their professional judgement to assess whether on accessing sexuality information, the person is coping and modify approaches accordingly as they would with any other activity of daily living. However, we need to consider that for many people, finding out about sensual feeling and orgasm can be an earth shattering life event, that can be, for a time, all consuming. This is "normal" behaviour and should not then mean that sex education becomes a closed book.

Dilemma 5

Are we sure consent has been given?

How do staff know if the person they are supporting has consented to an intimate or sexual relationship? If we assess behaviours and believe that these confirm that consent is being given by letting the relationship develop, does this leave the possibility that either party is being abused? If we do not let the relationship develop, then we will never be able to confirm if consent is being given and this raises another question – is stopping the relationship abusive in terms of human rights?

As professionals, we have a duty of care to service users and part of this includes protection from abuse. If we are not clear at the outset that consent is being given, are we duty bound to discourage potential intimate or sexual relationships? Given that there will be many disabled people who will have difficulty in communicating clear consent prior to a sexual act taking place, in a way that others can understand, are we in the uncomfortable position of saying that relationships involving people with complex communication needs are generally to be discouraged?

In relation to dilemmas and services, where do we think services have got to so far?

- many are offering reasonable learning support on sex and relationships to people with residual vision

- generally for people with complex communication needs, services take a reactive approach to personal and social development after specific issues have arisen

- the need for hands on support has been clearly identified but no real progress has been made in the UK with how to apply this to sex and relationships education for people with complex communication needs

- the majority of sex and relationships education is based on the assumption that disabled people are heterosexual and does not take a diverse approach to supporting service users to explore the sexuality of their nature

Overall there are many questions left unresolved. But if we continue to push the boundaries, challenge for necessary institutional change and approach sex and relationships education with this group of people in a creative and diverse way that recognises the needs of all involved, then there is hope for real progress in this area.

Training and staff development issues

Why do we need to address training and staff development? Three key reasons emerge:

1. In the UK many adults are not comfortable discussing sex and relationships issues with sexual partners, their closest family, friends or colleagues. How then can we expect support staff to feel comfortable discussing such issues with service users? Many took up post because they want to help disabled people live independently in the community and had an understanding that this meant assisting/developing skills in a range of domestic and social areas.
2. Sex and relationships are not generally associated with the needs of any disabled people, particularly people with complex communication needs. That this should be a part of the job as support worker has not been universally recognised and appreciated. Intimate care will have been considered but sexuality support generally does not appear on job descriptions.
3. The sex and sexual health information gap. Most people who offer support services will have been out of the education system for a while and will be relying on a combination of sex education classes a long time ago and personal experience. Due to this suspect partnership in terms of accuracy, it is necessary to ensure that support staff have opportunities to get up to date, relevant information if they are to extend SRE support that is meaningful.

Training on sex and sexuality for service providers should enable the following:to empower managers to develop realistic policies and practices on inclusion with regards to sex, sexuality and relationships

- to focus on the ideas, skills and systems at all levels: policy, service, team, support worker
- to work positively and effectively with parents and carers on the issue of sexual rights for people with complex communication needs
- to develop the possibilities and potential of alternative ways of learning and be creative about how to address sexuality support to people with complex communication needs

The most effective training package to progress cross-organisation change in sexual health support will need to explore values and attitudes alongside policy and practice review and the development of effective communication skills around sex and sexuality.

Team building is important, as people with complex communication needs are usually supported by a number of people across 24 hour care. A consistent approach is needed to increase confidence in planning, developing and delivering appropriate sex and relationships education to people with complex communication needs.

Staff and managers who have not had the opportunity to address sexual health needs may not have had the chance to talk about the effect that both SRE and intimate personal care has on them at a personal level. When we explicitly understand that people with complex communication needs are sexual beings like everyone else, then our relationships with them as workers has to change. It is important to acknowledge the way we react to this knowledge and establish effective ways of communicating with service users. Training in sexual health, if based on values and attitudes and using the experiential learning model advocated and used by fpa across the UK,

will encourage participants to look at their own sexual health and well-being by asking basic questions about the very nature of our sexuality. In relation to such training, fpa's experience is that the first subject raised is masturbation. This tends to happen sooner than in any of the other sexual health course offered by fpa. This is because it is often the presenting problem for staff – inappropriate masturbation – so it is key to staffs' anxieties about sex and sexuality. Training should be developed in such a way to help staff understand the messages behind masturbation, what it means for both the individual and themselves.

Because of the range of the work experienced as a support worker, staff are at risk of becoming desensitised to intimate care and the likelihood of seeing someone masturbate. It is swallowed into the workers psyche, almost akin to the disassociation defence mechanism described by sex workers and people who have been sexually abused. Training in this area helps break through this barrier and allow the development of ways of dealing with sexuality issues in a person centred way.

By engaging with supporting another person to develop sexual awareness and fulfilment, staff lay themselves open to risk and training should help develop skills to protect themselves and have clear boundaries. It should enable people to recognise, acknowledge and feel comfortable about their feelings about this aspect of their work. Training should also give staff and managers the tools to support, and where necessary challenge, parents who may have concerns about acknowledging their sons and daughters as sexual beings. Where possible training in sexual health should be extended to parents and other family members so that they can increase their skills, knowledge and confidence in supporting the person with complex communication needs in this area of their life.

Appendix 1

The things we all need to learn about sex

Topic	Activities for someone with complex communication needs
Age and stage development	Family photos Life stories Conversation about growing and changing bodies
Age appropriate behaviour	Life stories Meeting people of various ages and talking about this
Names of general body parts	Develop names/signs/symbols for body parts Pictures/slides Anatomically correct dolls Videos Touching own and others bodies
Names of genital body parts	As above except for touching other bodies, unless involved in consensual sexual relationship
Differences between male and female bodies	Pictures/videos People Smells Touch (non genital) Anatomically correct dolls

Topic	Activities for someone with complex communication needs
How the body changes over time	Photos of individual as baby, child, adolescent, adult Back up with same picture series of others s/he knows
How the body works	What are body fluids? When supporting male service users to wash after masturbation, if semen is evident use smell, texture to establish communication. Same for women with menstruation and where possible with vaginal secretions. If she uses a vibrator for masturbation when supporting her to keep it clean then smell, texture can be used here. Include function of clitoris here as this is often ignored and usually requires stimulation to achieve female orgasm
Difference between public and private places	Wide ranging community based and programme of activities. Developing signs and symbols to represent masturbation/sex and private (yes) and public (no)
Learning to say no to inappropriate touch/abuse	'No that's private' Discussion about abuse – good touch, bad touch

Topic	Activities for someone with complex communication needs
Making choices	Part of general communication strategy – extending this to sex and relationships choices
Learning to negotiate	Step on from above and again needs to fit into general communication work
Rejecting unwanted sexual approaches from others	As above
Recognising and naming feelings	As above
Periods and sanitary protection	For adult women who are already menstruating then use the opportunity her period gives to explore the best way of sharing information about process and protection. Use smell, touch, tactile calendars
Wet dreams	Use the semen to explain and explore understanding. Touch texture, smell, connection with the fact that it happens at night

Topic	Activities for someone with complex communication needs
Masturbation and privacy	Create individual environmental stimulation in persons room – what seems to encourage them to masturbate eg Buy a sex toy and develop understanding that this is for the bedroom only. If the person has physical impairments, ensure that they have private time alone positioned where they can stimulate their genitals, free from incontinence equipment and other restraints.
Relationships	Part of general development of understanding about relationships, extended to loving touch, loyalty and affection. Explore the differences in sexual/ sexually attracted relationships and others such as love for parents, affection for support worker etc Help individual develop communication for associated emotions.
Sexuality	Heterosexuality and same sex relationships. Discussing who love who and why. Use real life examples where possible – Film/TV/Pop star role models.

Topic	Activities for someone with complex communication needs
Sexual acts between two people	Vaginal, anal and oral sex. Use pictures, videos, cartoons where possible. Use vibrator as a symbol to discuss sex with another person if the individual enjoys using the vibrator.
Conception, Pregnancy and birth	Discuss conception using words/signs/symbols/picture as appropriate Invite pregnant women to explain about the growing baby and use touch – feel when it kicks. Meet the baby soon after it is born if possible. Discuss childbirth – again can use examples in age and stage development (first point in this table) and compare to previously pregnant woman and her new baby. May need to advertise locally for pregnant volunteers if no one on the staff team can oblige!
Sexual health services	Visit and arrange an appointment – may mean briefing GUM/FP staff on individuals communication system and needs. May involve a series of brief visits to build confidence/understanding.

Topic	Activities for someone with complex communication needs
Sexually transmitted infections	Symptoms and risks discussions. Link to visits to GUM and if possible use some of their leaflets. Follow on discussion to sexual intercourse and use drawings, pictures, slides, videos where possible.
Well woman/man checks	Breast examination – encourage these as part of health routine. Cervical smears – it is recommended that all women have these carried out routinely. Women who have not had sex are still at risk of cervical cancer and remember it is difficult to be entirely sure of any woman with complex communication needs sexual history as she will not be able to discuss this with you easily. Build up confidence by discussing as part of sexual intercourse. If she uses a vibrator vaginally she will be used to the sensation of penetration. Discuss in this context of smears. Clearly if these tests are going to create high anxiety for the woman and it proves impossible for her to develop an understanding then they may need to be avoided. However, best practice suggests every effort should be made to support women to learn about them and accept them as part of routine health care. Testicular checks – encourage these as part of health routine.

For ideas on how to take any of the above forward refer to the references and resources list on pages. In particular, Sexual Health Resources for Young People who are Blind or Partially Sighted published by RNIB.

Appendix 2

Sensuality toolkit

The following is a range of suggestions to make up a sensuality toolkit for use with people with complex communication needs. The idea is that these items can be used directly with individuals being supported to express their sexuality. Staff can build up a general toolkit including the following suggestions and when working with an individual establish an individual one for the person's own use:

*

1. External use vibrator	For stimulating sensual areas such as nipples and genitals. Can be used over clothing as a demonstration.
2. Ribbed internal use vibrator	For vaginal or anal stimulation – does not look like a penis anatomically
3. Realistic penis vibrator	As above but anatomically similar to a penis
4. Soft latex vagina	To insert penis into to help men achieve orgasm
5. Liquid silk lubricant	To help with easy insertion of vibrators, dildos or penis into vagina. Can also be used to ease clitoral stimulation.
6. Extra pleasure condoms	These increase feelings of pleasure to the penis during masturbation or intercourse.
7. Massage oil	Can be used for general or sensual massage either by the person themselves or by a third party.
8. Aromatic oils/ bubble bath	Scents that individual likes that are known to be relaxing
9. Batteries	Essential to make vibrators vibrate!
10. Samples of sensual materials eg leather, silk, feathers	To be used for sensual stimulation depending on preference of individual.

* Items 1–7 can all be purchased on line at fp Sales (www.fpsales.co.uk). This is not an exhaustive list and imagination combined with awareness of the tactile preferences of the person being supported are crucial.

Appendix 3

Exemplar Policy: Personal Relationships and Sexuality

Introduction

1. Company X is committed to working practice that encourages people to develop lifestyles which are meaningful to the individual. This includes their personal and sexual development and the development of the whole spectrum of relationships.
2. This policy covers practice in all of Company X's adult services, including, residential, day, respite and holidays.

Company X's position is:

- that we have a responsibility to assist clients to learn about choice in all areas of life
- that adult clients have a reasonable expectation to have relationships, including sexual relationships, with people of their own choice
- that these matters are private and personal for the client but must also be open to scrutiny to afford the highest level of protection and meet the demands of the law
- that the organisation will support staff in providing appropriate support to clients

Additionally, we want clients, their families and staff to feel confident that all working arrangements that aim to support personal development are:

- reasonable responses to expressed need
- individually based
- take account of safety and dignity for all concerned
- within good practice guidelines and within the law
- acceptable to the client and his or her representative and staff

Suggested Contents for Policy

Policy Statement

Good Practice – Areas to consider
Communication and sensory impairment
The law
Issues of consent
Vulnerable adults

Making good decisions
Individual needs
Decision making framework
Roles and responsibilities
Documentation
Monitoring and review
Risk taking and management

Staff support and Training
Support and supervision
Training

Common Issues
Personal health and sex education.
Relationships
Personal health and hygiene
Masturbation
Sexual relationships
Pornography
Sex Aids

(Other areas can be added as necessary)

Policy Statement

Personal and sexual development must be an integrated part of any person centred planning process. Staff should adopt a proactive approach which aims to inform and educate individuals rather than adopting a 'responsive' approach where action is only triggered as a result of a 'problem'.

Company X recognises that service users have the same personal and sexual needs and rights as other people. Sexuality is viewed as a natural and expected part of individual's life experiences.

Company X recognises its responsibility to ensure that personal and sexual expression is, within the law and does not devalue stigmatise or exploit individuals.

Company X staff will be appropriately selected, supported, trained and supervised, to enable them to work with users to express their personal and sexual preferences and meet their needs.

Company X recognises that the sensory impairment and communication ability of users will have a significant impact on access

to information about personal and sexual development. Work will therefore take into account such issues and will focus on giving information to promote understanding, choice and independence.

Company X will work in collaboration with the individual, family, carers and advocates, purchasing authorities and other relevant professionals to ensure maximum support and protection of the user.

Company X recognises that the impact of sensory impairments and limited social access will possibly result in access to a reduced range of relationships, or difficulty in maintaining relationships. Company X will work to support a wide range of acquaintances, enabling, friendships, family and close relationships.

Good Practice – Areas to consider

Communication and sensory impairment

Information for the individual is likely to have been limited or incomplete because of the sensory impairment. It is reasonable to consider that for the person who is congenitally deafblind, understanding of personal and sexual issues might be fragmented and will almost certainly be significantly delayed.

Any attempts to provide information and support for an individual must consider the form of communication most likely to enhance understanding and in a manner which maximises any residual hearing and vision.

It is acknowledged that because of significant sensory and communication difficulties a practical contextual approach to teaching might be required. Exactly how this might be achieved given the nature of some of the required learning is dealt with under point 36.

A person who acquires a sensory loss may loose the methods by which their friends, family and partner communicate with them. Services should work to enable the relationships to continue by developing alternative methods of communication and by supporting the maintenance of the contact.

The Law

Issues of Consent

A person may be defined in law as being unable to give consent (see appendix – The Law). If the person does not fall clearly under that definition then Company X and other parties involved in supporting the individual in a relationship or activity will need to consider whether both partners are freely consenting.

The personal planning group or any member of staff who accidentally 'disturbs' a sexual activity will need to decide whether an act or relationship is non-consenting. They can ask three questions:

- Can the person/s consent?
- Does the person/s give consent freely?
- If so, is there anything, which might make consent invalid?

In determining whether the person can consent, factors, which might enable judgement of this, are:

Can the person make Company X aware of what has happened?

Does the person have enough knowledge and understanding to know of some potential consequences?

Do they have a clear understanding of sexual relationships and rules?

It is important to acknowledge that the capacity to consent can shift depending on the persons understanding. A person who is deemed unable to consent at one moment in time might undertake a learning programme that then enables them to make an informed decision. Equally a person who was able to consent might (as a result of ageing and sensory loss) loose their capacity to give valid consent.

In determining whether the person gives consent freely it is important to distinguish between informed consent and saying 'yes'. Many people with learning difficulties might have been 'taught' to do as they are told and remain compliant. Giving informed and valid consent is quite different.

In determining whether there is anything which might make consent invalid it is relevant to consider whether the person is 'complying' because they feel under pressure. This might occur in an unequal relationship where there is a fear of displeasing or angering the dominant partner.

Vulnerable Adults
People who receive services in 'institutions' and who are dependent on others for their personal care are less likely to disclose and therefore particularly at risk. This includes many Company X residential clients.

Company X staff and managers should adopt practices in relation to personal care, that reduce risk of abuse and should work to inform the client about their own protection (see Company X Policies on Personal Care and Protection).

Making good decisions

Individual needs

Assessment to determine the needs and wishes that the individual is expressing should be structured and part of an holistic approach. Consideration must be given to the person's cultural and religious background and staff must not assume all cultures have the same attitudes and values. If a person wishes to behave in a manner which is contrary to their families or communities' belief and norms, they should be advised of the consequences of this, if they are able to understand. Ultimately, Company X has a responsibility to support the individual clients in their own choices. It is also important to gain information on past history so that any future action is informed by relevant past events (this is especially important if the person has experienced abuse).

Decision Making Framework

Any information or learning opportunity which is related to personal health and hygiene or is about non-sexual relationships will be planned and provided in a manner which can be described as the services 'usual' practice.

Any information or learning opportunity which is related to sexuality or sexual relationships, will require a planning strategy that is recorded in more detail than usual. The person themselves should be involved to the maximum of their capabilities. If they areunable to do this then preferences and views should be carefully considered, objectively, by others who know the person well.

Once a 'need' has been identified then a 'Personal Planning Group' should be convened. This should always involve:

- the person themselves whenever possible
- a ‘designated’ representative of Company X from outwith the individuals direct service
- a member of the management team from the service
- someone who knows the individual well

This group might also involve:

- family/carer/advocate
- purchaser representative
- outside advisor/specialist

When this group considers the unmet need and designs an intervention to address this they must consult all other members of the optional group above for comment. It is acknowledged that there might be some disagreement between carers/family and the perceived or expressed need of the user.

This must be discussed and attempts made to resolve any differences of opinion. However the most important person is the individual and judgements must be based on meeting the needs of the person.

The exception to this is the purchaser who must give written consent to any intervention of an intimate or sexual nature before it goes ahead. It is conceivable that the purchaser might restrict action and that this might not be judged to be in the person’s interest. Staff must seek to present information to enable the purchaser to make swift and informed judgements about how to proceed.

(THIS POLICY POINT WILL HAVE TO BE CONSIDERED IN THE LIGHT OF HOW A PERSON IS SUPPORTED).

Roles and Responsibilities

Company X will always have at least two individuals who are particularly experienced in the development of responses to personal and sexual development. There must be at least one male and one female staff member in this position. These 'designated staff' will take a lead in advising, training and enabling the planning and support of work in this area. One of them will always be a member of a 'Personal Planning Group'

Staff must aim to ensure all needs of an individual are assessed and addressed. Staff must maintain a professional and respectful approach at all times and should discuss in supervision any situations which might compromise this (eg clients who sexually approach staff, unease dealing with certain situations etc). No staff member will be asked to carry out 'teaching' which makes them feel uncomfortable or that is in conflict with their values or beliefs.

Any teaching with a client should be agreed following an open discussion and be part of the person's service. This is particularly important if the programme involves private sexual counselling.

Any teaching of an intimate or sexual nature will be undertaken in a sensitive and respectful manner. It will be done by a member of the planning group who has agreed to undertake this. It is recognised that teaching sessions will:

Be as short and unobtrusive as is necessary.

Be designed to promote independent behaviour as soon as possible

Only be undertaken with clients who the service knows well and with whom a 'trusting' relationship exists.

May involve named staff member touching the persons sexual organs where this is considered to be necessary in order to effectively achieve the objectives of the training.

In such instances, the following safeguards should be adhered to:

- The decision to do this training is made at the Personal Planning Group ie, this decision should not be made informally by one person
- The most appropriate person should be selected to do this – it may be more suitable that this is undertaken by an appropriate outside agency – the needs of the service user should be considered when making this decision
- The consent of the person should be sought
- The training should be carried out in private
- A careful and accurate record should be kept
- The should be no skin to skin contact – gloves or other barrier cloths should be used

The service user involved should be provided with as much information as possible to enable them take a more informed role in decisions about themselves.

Documentation

Any 'personal planning meeting' must be minuted and records kept confidentially. Any written programme which has been agreed must also be maintained in a discreet manner and made available on a 'need to know' basis.

Any teaching of an intimate or sexual nature must be observed (as discreetly as possible) and documented with both the 'teacher' and observer signing the account as an accurate description of what took place. This information must be then filed confidentially.

The 'designated person' from Company X should oversee each programme and ensure that practice is according to policy guidelines and that recording and monitoring is appropriate.

Monitoring and review

Monitoring will be determined by the Planning Group dependant upon the intervention. Individuals who cannot be directly involved in the planning group eg family or purchaser, will receive information to enable them to play an active part at a distance in the monitoring and review process.

Practice will be monitored at a national level to enable practice development.

Risk Taking and Management

Services are not expected to achieve the impossible and achieve a risk free life for Company X clients. However, they are expected to protect users from risks, which could be anticipated, and this includes the risks associated with sexual activity.

It is important to record such risks and assess the situation to enable action to be identified which will reduce any risk. Where it is deemed useful or where a group are undecided over a course of action they may refer to Company X Practice Development Department (or whatever other groups or committees are in place) for advice and support.

Staff Support and Training

Support and supervision

Staff should make themselves familiar with this policy during induction as part of the Core Module support. They should discuss any issues that they are not comfortable with during supervision with their line manager, or another senior member of staff. Staff may have difficulties because of their own personal values and attitudes – while these will be respected and support given, staff should not obstruct any planned work that is being done with individuals to meet their needs.

Training

Staff will have access to workshops and post-induction materials on Personal Relationships and Sexuality. (This would need to be more detailed according to what is available within any organisation). This training will be available for all staff at a time agreed between the member of staff and their line manager.

This training is mandatory – staff cannot choose not to take part. The sexual development of service users is an important part of their overall development and therefore is not something that staff can choose to be uninvolved in. If a member of staff has any personal issues relating to the training they should discuss these with their line manager or other senior manager who will support them as far as possible. If there are current issues for the member of staff then they may be able to postpone the training while they receive appropriate support – this will be decided in discussions with their line manager. The training will be sensitive to people's feelings and recognises that we have varying values and attitudes that can impact on the way we view these issues.

Common Issues

Personal health and sex education
Although Personal health and sex education should be considered for all clients, this does not mean all clients will engage in a formal programme as this will be dependant as identified needs. It should not be the case, however, that this happens only as a result of a 'problem'.

Relationships
It is important that opportunities and information are provided to clients to enable them to develop a wide range of relationships.

Friendships and relationships are as important to the individuals we support as they are to others. Staff should actively support access to these by extending networks and creating opportunities to be with other people. It is also important that staff acknowledge that 'hurt' and disappointment are as likely a part of making and breaking relationships as the positive valued aspects and that individuals need to be supported in all expressions of those relationships.

It should also be recognised that people might come to the organisation with existing relationships, which they should be supported in maintaining.

Personal Health and Hygiene
Staff should consider information and learning in relation to enabling the person to manage their own body and bodily functions.

Masturbation
Masturbation is an acceptable and natural part of an individual's sexual behaviour. Individuals who are unaware of their surroundings because of sensory impairments might not easily identify an appropriate place to masturbate. Staff, in helping clients to locate appropriate venues

should adopt a manner that conveys 'its ok to engage in this behaviour – but not here'.

Sexual Relationships

Individuals who are able to freely consent to a sexual relationship should receive information about contraception, pregnancy and parenting and sexual health, as well as a balanced range of information about emotional and sexual responsibilities to self and partner. This should cover both heterosexual and homosexual behaviour.

Pornography

The use of legal pornographic material might be requested by individuals for sexual arousal or entertainment – it is part of sexual activity for many adults. It can be used to aid the development of sexual awareness or sexual stimulation. While staff should not encourage the use of these materials, neither should they deny access to an individual able to make the choice. Staff should not impose their own attitudes to pornography on service users.

Access to materials that are believed to be illegal should be stopped and advice sought. An individual planning group may advise the person of suitable materials to use as part of a planned, fully documented education program – these materials should not portray exploitative situations. No person should act without consultation and guidance from the planning group. This planning group should also consider how materials could be made more accessible (eg tapes, Braille etc.)

Sex Aids

Planning Groups responsible for putting together a learning programme might consider that an appropriate way of meeting the persons needs is to access sex aids. Judgements about what and how this might be achieved should be considered carefully and be part of the planning process.

Other areas that might be considered in this policy statement:

- Pregnancy
- Abortion
- Sterilisation
- Marriage
- Parenthood
- Co-Habitation
- Petting
- Same sex relationships