Introduction
This report has been compiled using desk-based research, interviews and discussions with people with learning/intellectual disabilities, their parents and staff who work with them.

We would like to thank everyone who participated in research for this report, especially people at CHANGE. CHANGE is a leading UK organisation campaigning for equal rights for people with learning/intellectual disabilities. Some of the material for this report draws on previous research and training which CHANGE has undertaken in this area; for example, the ‘Talking about Sex and Relationships’ project delivered in partnership with the University of Leeds Centre for Disability Studies. In the past CHANGE worked with parents with learning disabilities, campaigning for better support and producing accessible resources about pregnancy and parenting (see www.changepeople.org for more details). Many of these parents spoke about not receiving any sex education when they were younger, and this prompted CHANGE to run this three year research project which looked at the sex education currently available to young people with learning disabilities in the UK and how this could be improved. The research was led by co-workers, one of whom had a learning disability. As well as conducting interviews with parents, and focus groups with teachers CHANGE led a drama group for young people with learning disabilities, who produced a play demonstrating key changes they felt needed to be made to improve sex education. Members of the group then went on to take part in conferences and training of professionals. CHANGE produced five accessible booklets: ‘Sex and Masturbation’; ‘Safe Sex and Contraception’; ‘Friendships and Relationships’; ‘Lesbian, gay, bisexual and trans’; and ‘Sexual Abuse’. The project report, which includes an accessible summary can be accessed here: www.changepeople.org/free-resources/

Part A of this report outlines current living arrangements for adults with learning/intellectual disabilities and how these have changed over time. There is a brief summary of the structure of education and other support for young people and adults with learning/intellectual disabilities. It also discusses laws and attitudes to the relationships and responsibilities of adults with learning/intellectual disabilities. Part B of the report documents what people would like to see happen in relation to sex education for adults with learning/intellectual disabilities in the UK.

Part A – Background

Brief History
Before the Industrial Revolution in the early 1800's people with learning/intellectual disabilities lived within their families and played roles within the community. As industrialisation and mechanisation developed it became more difficult to continue working in this way, and people began to move into hospitals or poorhouses. From the 1870s some women with learning/intellectual disabilities lived in convents with nuns, and often worked in laudenettes within these convents. Within institutions in the early 1900s men and women usually lived in separate areas, as there was often a fear that young women with learning/intellectual disabilities would become promiscuous. Women (and sometimes men) were often sterilised as there was a belief that any children they had were likely to be ‘feeble-minded’. In 1913 the Mental Deficiency Act recommended...
the segregation in colonies or institutions of people deemed to be ‘defective, idiots or imbeciles’, and anyone certified as such by two doctors could be held against their will. Any education taking place in these institutions was around physical tasks that people were required to take part in within the institution.

In 1971, 60,000 people with learning/intellectual disabilities were living in long stay institutions (DH 2007). A new report Better Services for the Mentally Handicapped (DHSS, 1971) introduced the idea of Community Care, rather than segregation in institutions. The report advocated homes within the community. Local Authorities were required to provide small residential homes and hostels in the centre of populations. Between 1971 and 1981 numbers in the longstay hospitals dropped and the number of people living in Local Authority homes doubled.

It was reported in 1979 that staff in homes were still unsure about allowing people to have sexual relationships. The Jay Committee Report Care of the Mentally Handicapped recommended that people ‘should be able to live in a mixed sex environment, and have the right / opportunity to get married’. However they also reported that around 40% of staff in hospitals and homes felt more people should be sterilised. Until the 1980’s, women with learning disabilities were sometimes sterilised against their wishes, despite a Sterilisation Bill having been rejected by parliament in 1931. Sexual relationships did happen within institutions where people lived, but this was seen as a problem and something to be hidden; sexual contact was often ‘exploitative and non-consensual’.

In 2001, Valuing People, a government White Paper (DH 2001) called for an end to longstay hospitals. However the last longstay hospital did not close until 2009 and in some areas, new private sector hospitals have opened. In 2009 another White Paper, Valuing People Now, an update on progress (DH 2009), said that people with learning/intellectual disabilities should be able to choose where they live. The report also stated that like everyone else, people with learning/intellectual disabilities ‘want and need personal and sexual relationships’.

Current Services
A survey of adults with learning difficulties in England in 2004 found that 69% of people with learning/intellectual disabilities were living in private households, either alone or with relatives, and 31% lived in supported accommodation (Emerson et al 2005). Of those living in supported accommodation 62% lived in residential care, 3% in longstay hospitals, and 3% in NHS hospitals. Currently almost 80% of adults with learning disabilities live in independent sector residential care, with smaller numbers living in adult placements, local authority residential care homes or nursing care (Emerson et al 2013). The level of residential care provided varies in different areas. The report Transforming Care published in 2013 investigating abuse in a large residential homes reports that over 3000 people are still living in larger medical units or hospitals known as ‘Assessment and Treatment Units’ (DH 2013). This report states that everyone living in hospitals will be re-assessed by June 2013, and anyone being ‘inappropriately cared for’ will move into community based support by June 2014.

Until recently, the school leaving age for children in the UK was 16 years of age. However, the government has recently changed the law so that all children (including those with learning/intellectual disabilities) have to remain in some form of education or training until they are 18 years of age. Many children with learning/intellectual disabilities attend schools for children with Special Educational Needs. Special schools usually have smaller class sizes, and are attended by young people with a very wide range of disabilities and learning needs. Some pupils with learning/intellectual disabilities attend mainstream schools with some additional support. A survey of 76 special schools in 2009 found that 90% provided some form of sex education, but this was only compulsory in two thirds of these schools – others gave parents the option of withdrawing their child (Garbutt et al, 2009).
The Learning and Skills Act 2000 states that all mainstream schools have to offer Sex and Relationships Education (SRE), and have a school policy written by governors about this education; however parents have the right to withdraw their child from SRE. Sex and relationships education should help pupils understand physical and emotional development, and ‘enable them to make positive decisions in their lives’. Primary school (ages 5 – 11) must cover how babies are conceived and born. In secondary school, education should include sexuality and safe sexual practices, concepts and laws about sexual consent, exploitation and abuse, and information about further support available. The guidance also says teachers must ensure that pupils with Special Educational Needs or Learning Disabilities are properly involved in this. Unfortunately a government review in 2012 stated that SRE needed to be improved in a third of primary schools, and half of all secondary schools (OFSTED 2012). Valuing People (DH 2001) states that people with learning disabilities should have the same rights as everyone else to post-compulsory education. Some mainstream Further Education colleges offer short-term skills-based courses for students with learning/intellectual disabilities. Some people with learning/intellectual disabilities working with CHANGE reported that they had been sent on the same course more than once.

Abuse and safeguarding
In the past, the Sexual Offences Act 1956, made it an offence for a man to have sex with a woman who is ‘known to be a defective’. This made it difficult for anyone to be prosecuted for having sex with a woman who had moderate or mild learning disabilities who gave consent without fully understanding. A new Sexual Offences Act was passed in 2003 which includes sexual activity with someone who does not have the capacity to consent. The Act states that consent must be freely given, and where someone’s disability prevents them from communicating whether they wanted to have sex, courts should assume that they did not consent. It also makes it an offence to obtain sexual activity by inducement, threats or deception and an offence to incite sexual activity or engage in sexual activity in the presence of a person who does not have the capacity to consent to sexual activity.

A report in 2001 found that the number of incidents where people with disabilities have been sexually abused is four times higher than for people without disabilities. People with learning disabilities were reported to be most at risk (Mencap 2001). Another study found that alerts about possible abuse of adults with learning disabilities made up 30% of all possible abuse reported to local authorities (Beadle-Brown et al 2010). In May 2011 a television documentary investigating allegations of abuse at Winterbourne View Hospital was broadcast on national television (Panorama’s Undercover Care: The Abuse Exposed, BBC). This led to a larger investigation and the government report Transforming Care: A National Response to Winterbourne View Hospital (DH 2013). Following the TV programme, the Care Quality Commission (CQC), a government body with responsibility for inspecting health and social care services, inspected nearly 150 learning disability services and found that some services were using physical restraint too often as a way of managing behaviour. The Transforming Care report states that new guidance on the use of restraint will be developed, and more effective procedures need to be used when employing new staff.

The report also highlighted that when people had raised concerns about care, these concerns were not always followed up. From April 2013 staff training now has to include letting people know how they should report any concerns about abuse and mistreatment, including ways to report it without speaking directly to their own manager. There must also be policies to say how anyone making a report will be supported. The CQC will also have a team which investigates and keeps a record of any reports.

Self-advocacy awareness raising
Conferences where people with learning/intellectual disabilities discussed issues including relationships and employment have taken place in the UK from the 1970s. Some self advocacy groups developed in the 1980s, with the first UK People First group established in 1984; People First is an international
movement of people with learning/intellectual disabilities. Central England People First was established in the 1990s. There are now People First groups across the UK, with differing aims and focuses (for example, www.peoplefirst.org and www.leedsadvocacy.org.uk); other self advocacy groups also exist such as ‘Opening Doors’ based in Norwich (www.openingdoors.org.uk), and ‘Skills for People’ in Newcastle (www.skillsforpeople.org.uk). These groups often fulfil a number of roles, including providing skills training, coordinating social groups, supporting people to deal with personal problems. More recently, most self-advocacy groups have been at least partially financed by local government or councils, which had an impact on how much they can campaign or protest against services. Many self advocacy groups have been under pressure in recent times due to widespread cuts in budgets and funding available.

There are also examples of groups where self-advocacy is a part of their work, although the group or company has more specific role. The Lawnmowers Independent Theatre Company, run by and for people with learning/intellectual disabilities, originally formed in 1986, and often produces work focused on particular issues around the rights of people with learning/intellectual disabilities. In 1994 they produced a play called The Big Sex Show which was about the right to have a relationship, and to have sexual health information. They have also done work about independent living and are currently working to improve access to employment (see www.thelawnmowers.co.uk). CHANGE is an organisation led by disabled people that campaigns for the rights of people with learning/intellectual disabilities. People with learning/intellectual disabilities are employed to work on campaigns. The rights of people with learning/intellectual disabilities to be supported to be parents is an area that CHANGE has focused on since 1994 – this led to campaigning for better sex education for people with learning disabilities. CHANGE has often worked in partnership with self advocacy groups, who are also campaigning for the rights of parents with learning/intellectual disabilities.

Leonard Cheshire Disability is a charity that campaigns and works towards equality for all disabled people. From 2007 to 2010 they had a project called In Touch which worked with young people promoting the idea that all disabled people have a right to accurate and accessible information about sex, sexual health, sexuality, and safer sex. Within this project they considered what resources were available to young people with learning disabilities (www.lcdintouch.org). The Outsiders Club was formed in 1979 with the belief that disabled people have the right to have sexual relationships, and went on to campaign for the sexual freedom of disabled people. The Outsiders Trust is now a charity that provides support and education about issues around sexuality and disability. They have now developed the Sexual Health and Disability Alliance (SHADA) which aims ‘to support the sexual health and lives of disabled people and to challenge negative asexualizing stereotypes’. They include learning/intellectual disabilities within their definition of disability (www.outsiders.org.uk). Disability Rights UK (www.DisabilityRightsUK.org) campaign for equal rights for Disabled People, and currently don’t focus on sex education, or sexual relationships. In the past, in the UK, advocacy groups for people with physical disabilities and learning disabilities mainly developed separately, though more recently there has more communication between the two, though we are not aware of collaborative work in the area of sex education.

Adult sex education
There is no national organisation responsible for delivering sex education to adults with learning/intellectual disabilities; this means that the amount of education or support available varies a great deal in different areas. Community Learning Disability Nurses will sometimes support people to gain knowledge, yet in some areas there is no-one in this role. The move towards independent living progressed at different paces in different areas, and the provision of support around relationships may have links to this. Any sex education that does happen takes place in a variety of settings. Life Skills courses in Further Education Colleges may include this. Some sexual health clinics do outreach work aimed at people with learning/intellectual disabilities. There are some organisations that deliver sex education to groups of adults, such as The Josephine Project, which has gained international recognition (see http://rendezvous.blogs.nytimes.com/2013/03/26/a-doll-helps-disabled-women-find-their-voices/?_r=0) and Tina Training (www.tinatraining.co.uk).
However, rather than sex education courses for adults there are now a number of organisations that deliver training for professionals to learn about delivering sex education to people with learning disabilities. The Family Planning Association delivers a three day training course ‘Liberating Life Choices: promoting the positive sexuality of people with learning disabilities’ and a five day course ‘Delivering sex and relationships work with people with learning disabilities: practical approaches’ (see www.fpa.org.uk/professionals/training-courses). People attending these course may then give training, or support within places like advocacy groups or educational centres. In recent years a number of different resource packs for delivering sex education have been produced that are intended to support professionals delivering sex education or sexual health support. Some include activities or session plans, such as ‘Puberty and Sexuality for Children and Young People with a Learning Disability’ which was put together by NHS Leeds or ‘Living your Life’, a resource produced by Brook, a sexual health charity (www.brook.org.uk). Other resources exist that are intended to be used in a flexible way. CHANGE produce a Sexual Health and Relationships Photo Image Bank which contains over 500 drawings and 100 photos linked to sexual health and relationships that people can use to produce their own resources. Bodysense produce anatomically correct cloth models that can be used in workshops, and will provide training to people who purchase them (www.bodysense.org.uk).

There are no laws or guidelines to suggest it is wrong for adults with learning disabilities to receive sex education or sexual health information. In 2008 the Family Planning Association focused their Sexual Health Week campaign ‘It’s my right’ on the right of people with learning/intellectual disabilities to have sexual relationships. However, there are still varied opinions about how necessary this is, and the introduction of sex education can cause a variety of reactions. In one case a learning disability nurse worked with a man with learning disabilities who was having sex with men. He was provided with information and supported to ‘come out’ as a gay man. However, when his family discovered how staff had been involved they were extremely angry about this. Some professionals speak about feeling cautious about how much information or discussion they can have about sexual health or education, due to a lack of policies or guidance about appropriate ways to deal with the issues.

Stars in the Sky is a dating and friendship agency developed by people with learning/intellectual disabilities in London (www.starsinthesky.co.uk) The organisation organise social activities, and arrange dates for adults with learning disabilities, and aims to challenge negative views of people with learning/intellectual disabilities. There are now six other affiliated organisations in other parts of the UK. Some of these have been developed by existing self advocacy groups. Valuing People Now (DH 2009) stressed the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and lead fulfilling lives with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need to provide adequate support to maintain a strong family unit.

Parents with learning/intellectual disabilities are more likely than other parents in the UK to have children taken into care by social services; research suggests that between 40 – 60% children of parents with learning disabilities are taken into care (Booth and Booth, 2005). Abuse is rarely give as the reason, children are often said to be ‘at risk of harm due to neglect’. Social Services are sometimes involved from the point where a woman discovers she is pregnant. This can lead to links to support, but can also mean that the parents feel ‘under the spotlight’ and scrutinised. The Department of Health produced Good Practice Guidance on Working with parents with learning disabilities (DH 2007a). However, this guidance is not always followed. CHANGE produced an accessible version of the ‘Birth to Five’ information book that new parents are provided with, but this accessible version hasn’t always been made available to parents with learning disabilities in all areas (www.changepeople.org/buy-our-resources/shop-books).

A recent survey of use of contraception by women with learning disabilities found that 46% of the women included were using the contraceptive implant, and 24% taking the contraceptive pill. Just under half of the
women were either already, or expected to become, sexually active. (McCarthy 2010) This suggests many women with learning disabilities may be using Long Acting Contraception unnecessarily.

Examples of Sex Education

‘The Josephine Project’ delivers sexual health project to women with learning/intellectual disabilities, and more recently began working with men. The Josephine Project was originally developed by a group of women with learning disabilities, and is still lead by a group of women with Learning Disabilities ‘the Josephine Dream Team’. More recently men with learning/intellectual disabilities were consulted throughout the development of the character ‘Jack’, looking at how Jack should look and what issues should be covered. The workshops use life size cloth figures, which include anatomical features that can be used to educate and encourage discussion. For Josephine these include demonstrating how sperm reaches ovaries, a foetus, a detachable breast with a lump. The heart is used to discuss feelings and her head includes space to place questions and thoughts. Drama and role-play and other creative tools are used in women-only workshops lead by women with learning/intellectual disabilities. The workshops look at sexuality and sexual health, as well as issues like pregnancy, periods, menopause, and cancer. The male character, Jack, includes some similar features such as a head where thoughts and questions can be placed. Other features include a penis that becomes erect, a bag containing sperm, a prostrate, and happy and sad faces to show feelings. Jack is used in drama workshops for men with learning/intellectual disabilities to explore issues.

‘The Josephine Project’ is part of a community arts organisation ‘Them Wifies’. ‘Them Wifies’ is a registered charity and company limited by guarantee which aims to use the arts in social development work, and as tools for change (www.themwifies.org.uk). The organisation receives funding from various trusts and foundations, and also earns money through providing services and co-ordinating consultation work. Over the last year they have worked with around 250 women and 30 men with learning/intellectual disabilities in the North East of England. Work is currently taking place to replicate the models for delivery by a supported living provider in other parts of the UK; this will provide an income through social licensing (www.choicesupport.org.uk).

The Pearl Service is an easy access service provided by a NHS Sexual Health Clinic at Charing Cross hospital in West London (http://www.chelwest.nhs.uk/about-us/learning-disabilities/links/pearl-service-leaflet.pdf). There is no direct funding for this service; it takes place within the mainstream sexual health clinic, delivered by existing staff using clinic resources. Senior sexual health staff developed the service in 2008 in partnership with service users with learning/intellectual disabilities and the NHS Learning Disability team. The adults with learning/intellectual disabilities developed accessible patient information, which includes a picture book ‘A visit to the Pearl Clinic’ and also worked to promote the clinic to other people. However, when the clinic offered to promote the service at a local support service meeting, parents and carers decided they did not want them to do this.

The service offers advice, information and free condoms as well as other contraceptive services and screening for sexual health infections. People can refer themselves, or be referred by other people, but will only be seen if they are happy to consent to the appointment. Another person can accompany someone into the meeting, but the person with learning/intellectual disabilities will always be asked whether they are happy for that person to be there. When the service was first developed there were some doubts from clinic staff due to concerns about whether they would be able to meet the needs of people with learning/intellectual disabilities. Training provided by the local Learning Disability services helped to resolve this issue. Staff now use the five CHANGE sexual health booklets, along with the ‘A visit to the Pearl Clinic’ book in meetings. The service has been used by approximately 20 people a year, though at times numbers have been higher or lower. Staff and key workers from other parts of the country also contact the service.
frequently to enquire about their services. When this happens staff try to direct them to appropriate services in their local area, and sometimes provide advice over the telephone. The Pearl Service has also supported the development of similar services in another part of which follow the same model (see www.camdenproviderservices.nhs.uk/bridge-service)

**Part B – How People would like things to be**

To learn more about the opinions of adults with learning/intellectual disabilities about the sex education they had received, or sexual health services they would like to access to CHANGE employees and volunteers with learning/intellectual disabilities were interviewed for this report. Several adults had received some basic sex education whilst in school, but those who knew more had also been spoken to by their parents. Another young adult who had received no sex education at school, and had no conversations about it at home felt that being given accessible information to read by themselves would be useful. One person said if they wanted to know more about sex and relationships they would look at the CHANGE booklets. They thought the books should be available in surgeries and clinics, but felt that wasn’t possible at the moment due to the lack of money in their budgets to buy the resources. One person remembered having a conversation with their social worker about sexual health, which they found interesting at the time. The social worker gave them an information booklet, which was small and contained a lot of text. As this person doesn’t read they haven’t looked at the booklet since then, and found it difficult to remember the details of what they were taught. They felt it would be good for people with learning disabilities to be told about one person, perhaps someone at a social club, who they should go to with any questions that come up to do with sexual health.

Young people, aged between 16 – 25, told CHANGE that sex education was important so that people know the risk of getting infections ‘like AIDS or crabs’ from having sex. Being taught about how to have ‘safe sex’ and avoid diseases was also seen as an important topic by the adults with learning/intellectual disabilities that were interviewed. Most of the young people taking part had some knowledge and understanding of different sexuality, but none of the adults interviewed mentioned learning about this in lessons.

One person who had a relationship while at college felt that sex education hadn’t been helpful in preparing him for this and that there should be a lot more information and support for people with learning/intellectual disabilities about having relationships. They also made the point that their parents were supportive of the relationship, but the other person’s parents didn’t approve and wanted the relationship to end. All the people with learning disabilities that were interviewed felt people with learning/intellectual disabilities have the right to have relationships, and one found it upsetting to learn that some people don’t agree with this. The idea that parents of people with learning/intellectual disabilities might also benefit from having training about how to give information about sex education was also mentioned by some people with learning/intellectual disabilities, and professional staff.

One way to deliver sex education suggested by two adults with learning/intellectual disabilities was through group work with adults. One person felt sessions lead by parents with learning/intellectual disabilities would be useful as ‘they have been through the experiences themselves’. Another person felt sessions in youth groups would be a good idea, as people would learn about where support was available. Some people with learning/intellectual disabilities and also some parents felt that ongoing support was important, because of potential difficulties in remembering information that was given earlier in life.

Parents of young people with learning / intellectual disabilities were interviewed for the previous CHANGE sex education research. All the parents interviewed felt that sex education was important for their son or daughter. However, it is important to consider these parents had all agreed to be interviewed about
sex education, so were likely to be open to talking about it. Some parents had decided to give their children some sort of sex education as they were unsure whether they would be taught about it at school. Interestingly, in focus groups held in special needs schools looking at the same issues, some school staff describe similar feelings about needing to provide information, as school may be the only place young people may receive education (Garbutt et al, 2009). This shows that there is frequently confusion about how and where sex education can be accessed. Some parents thought their child had received some sex education at school, but were unsure what had been taught, and how much had been understood. None of the parents spoken to had been provided with any sex education resources without having to search them out, or ask several people. One idea that several parents felt would be helpful was having a specific person or helpline to contact if they wanted support with this topic. Most parents didn’t feel it was appropriate to visit a doctor for sex education, unless it was to deal with a specific problem, or to arrange contraception. Several mentioned that they felt Doctors don’t have the time available to do this. Some people felt that support from Community Learning Disability nurses could be helpful, although one mother who had asked for advice from a nurse about how to approach puberty and sex education with her son was told it would be better not to talk about anything like that with him, unless he asked questions.

Several parents talked about how important it was that education included discussing privacy and appropriate behaviour. Some people felt that education about relationships and respect is more important than being taught details of things like how babies are conceived. The large majority of parents interviewed felt that their sons and daughters do have the right to have a relationship and said they would like that to happen. However, some parents went on to say they worried about the potential problems their sons or daughters may experience in developing a relationship. In one case a parent whose son had a girlfriend (also with learning/intellectual disabilities) held different opinions to his girlfriend’s parents about how much freedom to give the couple to spend time alone together. This illustrates how much control parents may have over their adult sons or daughters’ relationships, even when they are trying to encourage them to be independent.

Teachers spoken to in focus groups said when sex education happens it is often on a one-to-one basis, when an incident makes it clear that the topic needs to be raised. The majority of teachers thought it would be more useful to have structured classes. Some teachers felt that when sex education did happen in special schools it was more likely to be at an appropriate level for the pupils and could be delivered in smaller groups. Some teachers in special schools said they didn’t think young people with learning/ intellectual disabilities would receive better sex education in mainstream school. They had concerns that people may be in classes where the level of information was too complex, or that they would get inaccurate information from other young people. This can be an issue for all young people.

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