

# Broadsheet for UKDHM 2021



**UK DISABILITY HISTORY MONTH 2021**

**RELATIONSHIPS + SEX**

LONG STAY HOSPITAL

**WOMEN**

**MEN**

**YOU DON'T HAVE SEX**

**YOU ARE NOT A FIT PARENT**

**DOCTORS' EUGENICS**

**YOU WILL ALWAYS BE A CHILD**

**STERILISATION  
↑ THIS WAY ↑**

**HIDDEN IMPAIRMENTS**

What's wrong with you?

There's nothing wrong with you!

ADHD  
Asthma  
Autism  
Auto-Immune  
Cancer  
Cardiac  
COPD  
Deafened  
Dementia  
Depression  
Diabetes

Dyslexia  
Dyspraxia  
Epilepsy  
Fibromyalgia  
HIV  
Lupus  
ME  
Post-Covid  
PTSD

*And many more long term conditions...*

**18 November – 18 December**

**[www.ukdhm.org](http://www.ukdhm.org)**

## Disability and Hidden Impairment; Disability Relationships and Sex

This year's UKDHM focuses on two enduring stereotypes that make disabled people's lives more difficult and act as a barrier to our inclusion.

People with Hidden Impairments are often not thought to be disabled people. In the media and popular culture one has to 'see' our impairment. 'What's wrong' with the person who identifies as disabled? Yet the majority of disabled people

have hidden impairments and so it is often assumed we are liars when we try to exercise our rights.

Disabled people are not seen as 'sexy'. We are often viewed as perpetual children, as a threat to the gene-pool and asexual. Based on these falsehoods the shocking history of our treatment has denied our right to family life, children, relationships and sexuality. Yet disabled people are as varied as everyone else, with no less capacity and need for expressing emotions, our sexuality & having relationships.



Disability  
Discrimination Act  
1995

### UK Definition of Disability and who

is covered People defined as disabled under the Equality Act (2010) have protection from discrimination and harassment and



Equality Act 2010

have a right to reasonable adjustments. (First introduced by 1995 Disability Discrimination Act).

**'You are disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities'.**

These [Impairments](#) are a large number, including:

- sensory, such as those **affecting sight or hearing;**
- impairments with **fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy;**
- progressive, **as in motor neurone disease, muscular dystrophy and forms of dementia (in early stages);**
- **auto-immune** conditions such as **Systemic Lupus Erythematosus (SLE);**

- organ specific, including respiratory conditions, such as asthma, and cardiovascular diseases, including thrombosis, stroke and heart disease;
- developmental, such as autistic spectrum disorders (ASD), dyslexia and dyspraxia;
- learning disabilities;
- mental health conditions with symptoms such as anxiety, low mood, panic attacks, phobias or unshared perceptions; eating disorders; bipolar affective disorders; obsessive compulsive disorders; personality disorders; post-traumatic stress disorder and some self-harming behaviour;
- mental illnesses, such as depression and schizophrenia;
- produced by injury to the body, including to the brain.

The Act states that a person who has cancer, HIV infection or multiple sclerosis (MS) is a disabled person and protected by the Act effectively from the point of diagnosis. **Many of the above (in red) could count as hidden impairments, as the effects on day to day life are not visible.** Where a person is receiving treatment or correction measures for an impairment, the effect of the impairment on day-to-day activities is to be taken as that which the person would experience without the medicine, treatment or measures/aids.

It has been a slow process for employers and service providers, despite being covered by the Disability Discrimination Act (1995) and then the Equality Act (2010), to recognise their responsibilities to disabled people with hidden or non-visible impairments. [Hull City Council](#), partly as a result of successful litigation at the Courts and Employment Tribunals, issued clear advice :

**“Types of Hidden Disability** Whilst there is now a better understanding of some of the conditions that constitute hidden disabilities, it is vital that all interactions with adults, including advice, information and assessments, are conducted with hidden disabilities in mind. This is to ensure all relevant care and support issues that the adult has are identified, to ensure they receive the appropriate support services relevant to their individual needs. This process is vital to ensure they are not discriminated against, as a result of a hidden disability being missed or reasonable adjustments not being made. The lists below are not exhaustive; there will be other physical *conditions*.



**Hull**  
City Council

Adult Policies, Procedures  
& Practice Resource

**Mental health** For many adults who suffer with mental health problems, their issues may not be immediately obvious and can be misunderstood. Without good working relationships and without a member of staff undertaking a comprehensive assessment with the adult, key aspects of the care and support that they require may be missed and their problems, therefore, could be compounded. Such issues may include depression, stress, bipolar disorder, psychotic and neurotic thought processes and suicidal thoughts.

**Developmental disabilities** Other conditions which can be hidden include:

- Dyslexia (development of literacy and language related skills affected);
- Dyspraxia (perception, language and thought processes affected);
- Attention Deficit Hyperactivity Disorder – ADHD (inattentiveness and hyperactivity-impulsivity);

- Autistic spectrum disorder (communication, relationships with others affected);
- Asperger's syndrome (an autistic spectrum disorder).

Adults with such conditions have often developed ways of coping which may make it more difficult for staff to identify them as disabled. Even when someone can function well in many situations, this does not mean they are not disabled.

Issues to be aware of include:

- communication issues (verbal and non-verbal);
- understanding instructions;
- the speed at which they process things; and
- interpretation of social situations.

Some of these conditions may also co-exist with other hidden disabilities.

See Autism UK: [What is Autism](#) and [Related Conditions](#) for more information.

Adults with a learning disability or autism may have needs for care and support (within section 9 of the Care Act 2014 – the duty to assess – see [Assessment and Self-Assessment chapter](#)).

**Physical health conditions** Not all physical health problems are clearly visible. There are many conditions which can be hidden to include hearing and sight impairments, chronic fatigue syndrome / Myalgic Encephalomyelitis (ME), chronic pain and chronic illnesses such as fibromyalgia, epilepsy, diabetes, kidney failure and sleep disorders. Such conditions should also be taken into consideration as a “hidden disability.



**Social Model** The definition of disability quoted above is very much based on the individual or Medical Model approach. UKDHM comes from a Social Model Perspective, although impairment

The Medical Model of Disability



This is a diagram of the traditional Medical Model of Disability, which the Social Model was developed to challenge.

The Social Model of Disability



The Social Model of Disability states that the oppression and exclusion people with impairments face is caused by the way society is run and organised.

and chronic illness

exist and they sometimes pose real difficulties for us. The Disability Movement comprises those disabled people and their supporters who understand that

they are, regardless of their particular impairment, subjected to a common oppression by the non-disabled world. We are of the view that the position of disabled people and the discrimination against us are socially created. This has little to do with our impairments. As a disabled person you are often made to feel it's your own fault that you are different. The difference is that some part or parts of your body or mind are limited in their functioning. This is an impairment. THIS DOES NOT MAKE YOU ANY LESS OF A HUMAN BEING. But most people have not been brought up to accept us as we are. Through fear, ignorance and prejudice, barriers and discriminatory practices develop which disable us. The understanding of this process of disablement allows disabled people to feel good about themselves and empowers us to fight for our human rights. The Disabled People's Movement believes the 'cure' to the problem of disability lies in the restructuring of society. Unlike medically based 'cures', which focus on the individual and their

impairment, this is an achievable goal and to the benefit of everyone. This 'social model' approach suggests those disabled people's individual and collective disadvantage is due to a complex form of institutional discrimination, as fundamental to our society as sexism, racism or heterosexism.

[The Wales Trade Union Congress](#) carried out a survey of disabled workers in 2018 and found most respondents with hidden impairments had had to prove they were disabled and were often not believed by workplace colleagues. With the majority of disabled people (up to 80%) having hidden impairment, stereotypes play a major role in this harassment and discrimination.

### **Government and media created**

**Stereotypes** The widespread stereotyping of disabled people has helped to create negative attitudes and barriers to disabled people's participation in society, including in the workplace. Some sections of the media have given increasingly distorted coverage to the issue of benefit fraud (often using individuals in receipt of disability benefit as the subjects). This is despite the fact that according to research by Scope, "disability benefits have the lowest levels of fraud" at less than 0.5 per cent. This type of distorted coverage has been prominent in some sections of the press and on television (with programmes such as the BBC's Saints and Scroungers). Often 'scroungers' are depicted as 'undeserving' claimants who are feigning disability in order to defraud 'decent hard-working tax payers', taking benefits away from the 'really disabled' (who are



often depicted as helpless ‘sufferers’ in need of charity rather than support to live independently).

The UK Government encourages members of the public to report people they suspect of benefit fraud to the Department for Work and Pensions through the benefit fraud hotline and website. Many do so, despite the fact they may have little or no knowledge of the disabled person’s circumstances or understanding of the fact that not all impairments are visible. It is perhaps not surprising that a freedom of information request revealed that of a million alleged cases of benefit fraud put forward by the public between 2010-2015, [85 per cent were completely](#) unsubstantiated. This has resulted in many thousands of disabled people being put through unnecessary and stressful benefit fraud investigations.

In the workplace, the effect of this type of stereotyping can be seen when people assume that a disabled person who is for example, on disability related sick leave is, **‘swinging the lead’**, **‘putting it on’** or using a condition as **‘an excuse’** (even when they know nothing or very little about the person’s circumstances). Such accusations are more likely to be made towards anyone who is disabled but does not show visible evidence of it. These attitudes can leave disabled people exposed to the risk of hostility, harassment and discrimination. There is an unhelpful trend to characterise disabled people’s lives as polarised extremes where there is either a **‘superhuman’** and heroic **‘triumph over the odds’** by an individual (e.g. as in much coverage of Paralympian athletes) or at the other extreme, as a **‘tragedy’**. Often the disabled person



is then portrayed as a **helpless ‘sufferer’** to be treated as an **object of pity or charity**.

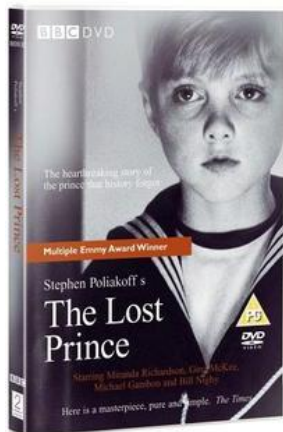
Such extreme stereotypes are damaging and unhelpful because they can lead others to make assumptions that a disabled person will not be capable of having a job or living independently, or to assume that it is up to a disabled person to single-handedly overcome the barriers they face by supreme effort, without consideration or adjustments from others. These stereotypes distract focus from the reality of most disabled people’s lives and from society’s responsibility to address the real barriers that many disabled people face when trying to live their everyday lives, with the right to the same independence, equality of opportunity and quality of life as others enjoy.”

**Epilepsy** and related fitting is one of the oldest known hidden impairments. The word *epilepsy* is from Ancient Greek ἐπιλαμβάνειν, 'to seize, possess, or afflict' and they called it the ‘sacred disease’ as it was sometimes associated with visions. In many parts of the world it is still associated with stigma and possession by evil forces. Many famous figures from history such as Pythagoras, Aristotle, Napoleon, Joan of Arc and Alfred the Great have been attributed the condition, though modern research by neurologists have cast doubt on this.



However, Roman Emperors Julia Caesar and Caligula are thought to have had epileptic seizures. **Michael IV the Paphlagonian** (left, 1010–1041), a Byzantine emperor, had frequent tonic-clonic seizures since adolescence. The seizures were interpreted at the time to be demonic possession as

punishment for his sins. His royal entourage were alert to signs of an impending seizure and tried to hide the emperor when he was ill. More recently the Queen's Uncle, **Prince John** (below right, 1905-1919) had epilepsy. His story was told in the acclaimed TV drama *The Lost Prince*. Though much

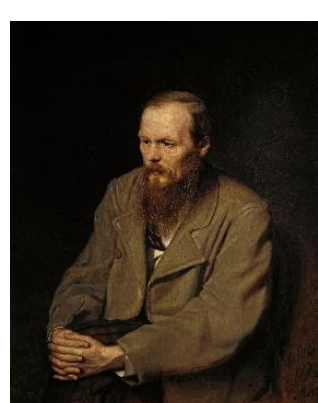


loved, particularly by brother George and his mother Queen Mary, he was secreted away with his nanny Bill on Sandringham Estate as his fits became more frequent. At this time most people



with pronounced epilepsy were locked away in asylums as it was considered a form of madness. The Royal family kept it a secret until after his death and were worried about their blood line which already carried deafness, porphyria and haemophilia from Queen Victoria and her descendants caused by in-breeding, marrying with relatives.

Writers responded differently to their condition. **Edward Lear** (right, 1812–1888) an artist, illustrator and writer known for his nonsensical poetry and limericks. His epilepsy, which he developed as a child, may have been inherited (his elder sister Jane had frequent seizures and died young). Lear was ashamed



of his epilepsy and kept it a secret. He did, however, record each seizure in his diary. **Fyodor Dostoyevsky** (below left, 1821–1881) a Russian writer whose epilepsy was probably inherited (both his father and his son had seizures), incorporated his experiences into his

novels – creating four different characters with epilepsy. Dostoyevsky's epilepsy was unusual in that he claimed to experience an ecstatic aura prior to a seizure, whereas most people experience unpleasant feelings. Popular musicians include **Prince** (1958–2016) American singer, who had epilepsy as a child and sang about his condition in the song "The Sacrifice of Victor". **Ian Curtis** (1956–1980), the vocalist and lyricist of the band Joy Division, was diagnosed with epilepsy aged 22. The cover of their album Unknown Pleasures resembles an EEG tracing, but is actually the tracings of the radio emissions of a pulsar. He would often suffer *grandmal* seizures while performing and his dancing would mimic the seizures he suffered. In 1980, the condition was a primary cause of his suicide aged 23. Epilepsy is a neurological condition characterized by recurrent seizures. These can vary from brief and nearly undetectable periods to long periods of vigorous shaking due to unusual electrical activity in the cortex of the brain. Seizures can be brought on by factors such as stress, excessive alcohol use, flickering light, or a lack of sleep. The cause is not known in 65% of cases though genetic and environmental factors are involved. There are six main types of generalized seizures: tonic-clonic (*grandmal*) tonic, clonic, myoclonic, absence and atonic seizures. They all involve loss of consciousness and typically happen without warning. Seizures can lead to injury and death and more commonly temporary or permanent memory loss. There are over 40 types of seizure and they are different for each individual. There are more than 600,000 people with epilepsy in the UK with 87 diagnosed every week. There are also 21 epilepsy related deaths per week. Around the world there are 39 million people affected. In 69% of cases

seizures are controlled by inexpensive medicines. This allows many people with epilepsy to pass as non-disabled. **Allan**



**Sutherland (left)** has epilepsy and 40 years ago was a leading light in the growing Disability Rights and Disability Arts Movement. He initially was worried whether he would be accepted because his epilepsy

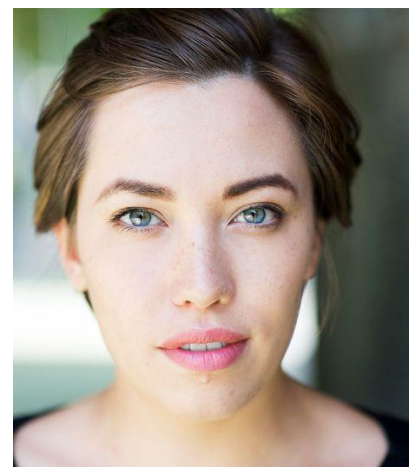
was controlled, so he presented as someone with a hidden impairment. In a speech he gave in 1982, **Coming Out Disabled** he developed this theme. “Approximately one person in fifty has some kind of epilepsy. I myself was diagnosed epileptic at the age of four. Yet it was not until I was in my early twenties that I met anybody else whom I knew to have epilepsy.... All my attitudes to my disability, all my feelings about how to respond to other people’s reactions to my disability had to be worked out from scratch. My epilepsy was a part of my identity, but a purely personal part. Unlike my colour, my class, my sex, it was not something that I had in common with anybody else I knew. This is one of the things that has in the past kept disabled people from starting to develop a shared radical consciousness: unlike most other oppressed groups, we, with certain notable exceptions such as the signing deaf, do not have a cultural identity of our own. We are exiles in an able-bodied world.”

“I cannot honestly say that I took any particular pride in my identity as an epileptic - I use that term ‘epileptic’ deliberately, because I am not just a ‘person with epilepsy’; my disability is an integral part of my identity, and those who wish to know me these days must accept that fact, not disregard it as if it were somehow separate from the ‘real me’.... And I certainly did not then have the anger that I now have at how other people with epilepsy are treated in this society: I hadn’t yet learnt about the



discrimination in employment and education, the ignorance and incompetence of much of the medical profession, the pressures that build up on some people in their own isolation, the nervous breakdowns, the unnecessary deaths... People who have epilepsy are therefore faced with a choice as to whether or not they reveal their condition to other people. Epilepsy is one of the most stigmatised of disabilities, associated in many people's minds with mental illness, mental deficiency, irrational violence, sexual perversion or possession by demons... As a result, the vast majority of people with epilepsy do not make their condition known to any but a small group of relatives and friends. I don't agree with this. Though it's an understandable response, it's a poor way of bringing about change. Ignorance and fear breed hostile reactions, which lead people who have epilepsy to keep the fact secret, which leaves the ignorance and fear unchallenged. We have to break this vicious circle, and the only way we can do that is to come out into the open. **The more visible we are, the more difficult it is for others to hold false beliefs about us."**

In the 2020s fighting to make it as an actor can be tough. "It's a cut-throat profession," says **Isabella McGough (right)**. "You need to look physically strong, and show that you've got the strength of mind, body and soul." The 23-year-old Londoner is up for the challenge though, juggling rehearsals with a job at a pub to pay the bills and teaching work on the side. "I've always tried to live my life to the fullest and not miss out on anything," she says. This is why she hesitates to tell people that she has epilepsy. It's not the type that's sensitive to flashing lights, but she's at risk of





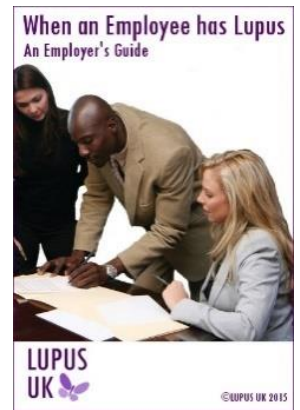
seizures if she overexerts herself or doesn't get enough sleep. "I'm fortunate," she says. "I've never had a seizure at work, but there are times when I've had to call in sick because I have to stay in bed and sleep." She doesn't feel she can always be upfront about the reasons why she might need to take a break. "There have been times when I've said I had flu symptoms because, as an employee, I don't feel that [needing to rest] is a good enough excuse to have a sick day. That's when you feel almost guilty for it." It's a dilemma that will be familiar to hundreds of millions of people worldwide who have physical or mental health conditions that affect their day-to-day life, but which are not apparent to the outside world.

The above analysis equally applies to the many 1000s of people with other long-term 'hidden' conditions: to liberate them from 'medical model' thinking and get them to come out and identify as disabled people and join the struggle for equality and against the oppression of disabilism. **Some of these impact on particular parts of the population i.e. women or Black people.**

**Endometriosis** is a condition impacting on 1 in 10 **women** where tissue similar to that in the lining of the womb grows elsewhere in the body, such as on the ovaries and in the fallopian tubes. Symptoms can include lower abdomen or back pain, severe pain during periods, pain during sex, bowel and bladder symptoms, and fertility problems. The symptoms can vary for different women, with some more severely affected. It is often recurrent, linked to menstrual cycle and would in many cases count as a disability with employers, where they have been told by the person affected and would be required to provide reasonable adjustments such as flexible hours, home working and allowing more time-off work. There is currently no

cure for endometriosis, but there are treatments that can help with symptoms. These include painkillers, hormone treatment, such as hormonal contraception, and surgery. **Rachel, 26**, her job was to oversee and manage the smooth distribution of cosmetics and medical beauty products for the fulfilment of online customer orders. The foreign-owned distribution warehouse had state-of-the-art mechanisation and processes were highly automated. Rachel loved her job and she was known as the 'queen bee' at the warehouse, everyone liked her and listened to her. Rachel, over the past 36 months, has developed an acute form of Endometriosis, which has also led to IBS, infertility and mental health problems. Some mornings she cannot get out of bed. Rachel explained her health condition to the HR Manager at work who seemed sympathetic. Over the following months, Rachel was in a poor way and it was affecting her job. Rachel's factory operated 24 hours a day, with many different shift patterns available. Others had been allowed to change. There was an unspoken inference that Rachel was probably exaggerating her symptoms. Eventually the company made the decision to take Rachel off the line and gave her job to one of her colleagues, a male who had been chosen as her replacement and considered less likely to have gynaecological problems due to his sex, therefore would fit their needs. The case progressed to court and was heard by an Employment Tribunal in January 2020. Rachel was successful in her claim and was awarded compensation. Rachel went to lawyers covered by her home insurance. She won the case. Rachel kept her original job. Her employer was forced to make the necessary preparations to ensure that there was adequate cover in her department for when she was taken poorly.

**Lupus**, also known as **systemic lupus erythematosus (SLE)**, is an impairment that happens when your immune system attacks your own organs and tissues. Molecules called antibodies within your immune system normally detect and destroy foreign invaders such as bacteria and viruses. However, in lupus and other autoimmune diseases, the immune system turns on your body and attacks your own tissues. Lupus acts differently in different people, and it can affect multiple systems in your body- skin, kidneys, bones. Depending on which systems of the body are affected, the symptoms of lupus vary from person to person. 90% of people who get Lupus are **women** and it is 2 to 3 times more common amongst **Black people**.



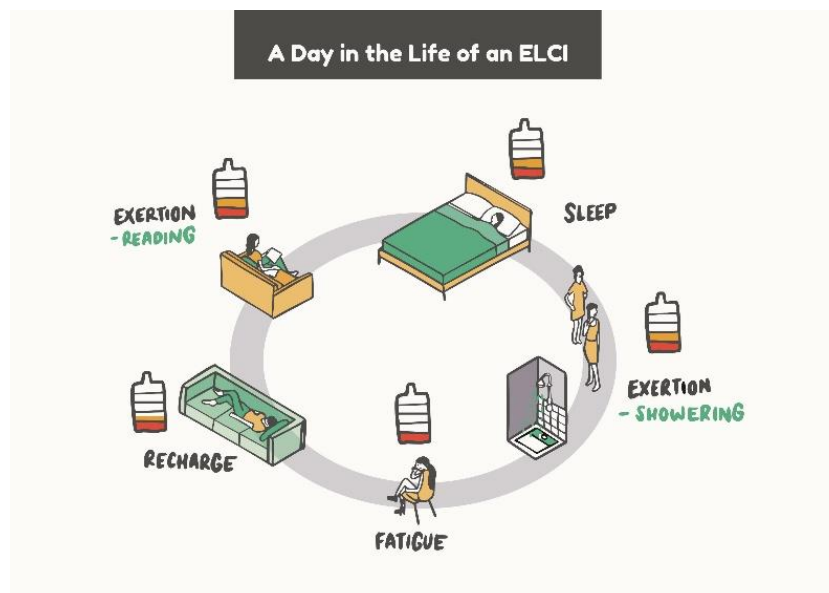
**Sickle Cell Anaemia** Haemoglobin is the substance in red blood cells that is responsible for the colour of the cell and for carrying oxygen around the body. People with sickle cell are born with the condition, it is not contagious. It can only be inherited from both parents each having passed on the gene for sickle cell. Sickle cell trait is found in 1 in 4 **West Africans** and 1 in 10 **Afro-Caribbeans** and is also found in people who originate from the Mediterranean, Asia and the Middle East . It is less common in white Europeans. The main symptoms of sickle cell disorder are anaemia and episodes of severe pain. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then stick together, causing blockages in the small blood vessels. These painful episodes are referred to as sickle cell crisis. They are treated with strong painkillers such as morphine. People with sickle cell are at risk of complications- stroke, acute chest syndrome, blindness, bone damage and priapism (a persistent, painful erection of the penis). Over time

people with sickle cell can experience damage to organs such as the liver, kidney, lungs, heart and spleen. Death can also result from complications of the disorder. Treatment of sickle cell mostly focuses on preventing and treating complications. In 1950s with mass migration from the Caribbean, health professionals did not understand sickle cell and so recipients were often treated as 'guinea pigs' and subject to racism. The Black Community had to set up the [Sickle Cell Association](#) (1971) to get the condition taken seriously.

[Pamela Roberts](#) had sickle cell anaemia. "At the time of growing up sickle cell was not classified as a disability, but social leprosy due to ignorance and lack of information... In 1983 having left school I co-founded an educational resource for girls in Walthamstow. I was hospitalised with a series of crises for a long time after which my invisible disability became visible. In 1988 the Girls Project folded and I had made one professional video '**Is it a bed of Roses?**' looking at prejudice faced by young unmarried mothers. I got a chance with a BFI New Directors Award. This led to me coordinating a video production training for Black disabled women in 1990. It soon became apparent that what I was doing was totally unheard of. The industry was being confronted by a Black, disabled woman. Producers would gasp in astonishment, mop their foreheads fervently and adjust their glasses to make sure they saw right".



**Energy Limiting Chronic Impairments** “There's just no flicker of understanding of how much work, for many of us, goes into maintaining the health we have and that this work needs to be done before anything else is asked of us” Charlotte. “The stiff joints, the blurred vision, the headaches, nausea and vertigo, all of that I can tolerate but it's the fatigue that keeps me housebound and out of work. No matter how much rest I get or how hard I will myself to try, I simply have no energy. When even the simplest tasks are monumental challenges that leave you drained, how are you supposed to live?” Michael.



Participants in a ground breaking study [“I already have a job... getting through the day”](#) often contrasted the common perception of ‘fatigue’ (heavy or extreme tiredness) with the lived experience of ELCI (Energy Limiting

Chronic Illness), in which ‘fatigue’ is a debilitating, all-encompassing level of physical and cognitive fatigue that is disproportionate to the level of activity. Participants in our first focus group described this ‘fatigue’ as “wading in cement”, “a heavy aching feeling that makes it hard to move your body at all”; “severe, constant, body/mind consuming”; “brutal”; “life-destroying”; “a bone deep, spaced-out exhaustion” and “so tired you feel drunk”. The authors of the report identify up to 5 million people in the UK living with a multitude of long term, largely hidden impairments, who would be classed as ELCI. They

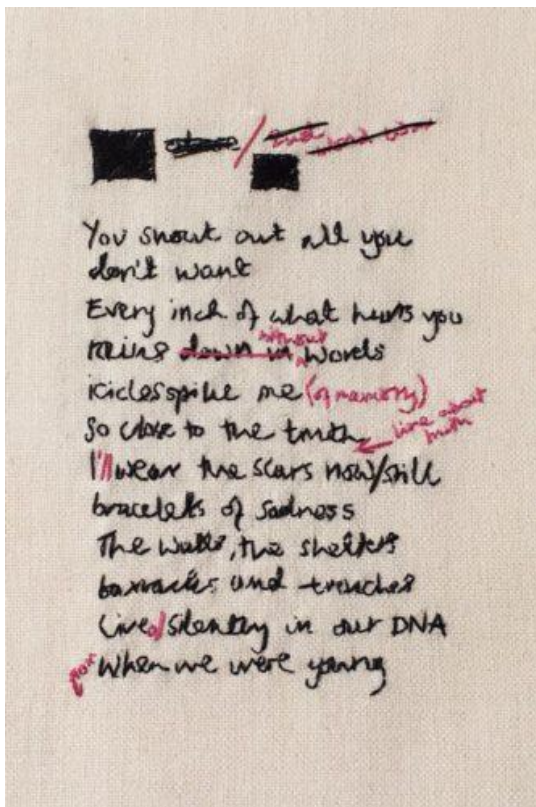


argue that many job training, assessment and work opportunities do not make reasonable adjustments for this group who need time and rest to recharge in-between activities.

**Examples of ELCI include:** ME/CFS (myalgic encephalomyelitis/ chronic fatigue syndrome), fibromyalgia, lupus, chronic pain, hypermobile Ehlers Danlos syndrome, long Covid, as well as conditions causing: respiratory failure, asthma, endometriosis, kidney failure, inflammatory bowel conditions, sickle cell disease, autoimmune conditions, neurological conditions, migraine, endocrinological conditions, and rheumatological conditions. [Chronic Illness Inclusion](#) is a Disabled People's Organisation. They 'champion social, structural and systemic solutions to the problems caused by chronic illness, rather than individual therapeutic solutions. This includes addressing healthcare inequalities and inequities in the allocation of medical research funding, as well overcoming social and cultural barriers to equal participation in society and oppose the disbelief that often denies our reality. Members have a wide range of hidden impairments.

[Clover Peake](#) 'I have never known a way of life unaccompanied by these conditions. Difficulty with how my body functions has always been the case. I am 44. I had a hysterectomy at 40 because of endometriosis. Since the surgery, which was meant to improve my pain, I have been diagnosed with many of the other conditions. To the naked eye it's not possible to see the difficulties I have unless I use my walking stick. All my symptoms could be passed off as anxiety or a low mood state. It was as though mind and body are incapable of meeting. Frustratingly, many of my conditions do not show up in regular clinical tests.

Armed now with more understanding of my health, I am forging a new identity. It is possible in certain social situations to conceal my impairments, though very often it is easier to stay at home because my unpredictable symptoms can sometimes cause me embarrassment. It is ironical that if I want to take part in a social or professional event, the effect on my health will be felt several days later. The poetry and tapestries produced for *Archetype*, which was published last year were a body of work predominantly created through the limitations of my health and domesticity of single motherhood. The tapestries were a half cross stitch in ox blood wool. It's a ruminative and



meditative medium. The poems were written often a word at a time on my phone while pushing my son in a swing with my other hand. I used the creative work as a lament, a catharsis of aspects of loss within mine and my son's life. Clover is a poet, clothes designer and artist often working in fabric.

["TUC Member has ME](#) Management and HR did not believe she was disabled, but this was confirmed by an

OH report. Member is a lawyer... ME made it difficult to appear in court and travel. Extensive, regular rest breaks and working from home were recommended. The employer failed to apply these reasonable adjustments. Member went off sick, employer sought to proceed under absence management policy. The union representative suggested a transfer to a role which involved working from home. This was declined and a grievance

was lodged. With ET hearing looming, employer allowed member to transfer to an office and home-based role. Attendance record has improved dramatically”.

**Neuro diversity** ‘[Neurodiversity](#)’ is the idea that cognitive conditions, such as autism, ADHD, dyslexia and dyspraxia, are natural variations in the way people think and process information. The term recognises both the difficulties that people who have these conditions may encounter in the workplace and also the unique strengths that can derive from thinking differently. The ‘social model’ of disability says that neurodivergent people are disabled because society and workplaces are organised for the benefit of neurotypical people. Under this model, employers should change their environments, policies and cultures to remove barriers faced by neurodivergent workers. Many of whom will have developed strategies that can outwardly ‘mask’ the effects of the condition (or conditions). This may be on the basis of formal advice, or such strategies may have been developed by the individual. The existence of coping strategies is not a reason to deny a person support (including for obtaining a diagnostic assessment.) Coping strategies can in some cases involve making undue sacrifices on the worker’s part (such as working very long hours to catch-up). Successful coping strategies can also lose their effectiveness if an individual’s circumstances change.’



Stephen's early life as a disabled person was spent in a state of denial. He spent a long time masking his neurodiversity, playing the clown, doing his best to please people. At school he found ways of excusing himself from 'remedial' lessons. Not having any involvement with other disabled people during these early days, Stephen didn't have anyone

to share insights with or to recognise that what he was experiencing was a form of discrimination. It was only when he came across the Social Model of disability that things began to change for him.

"I first came across the Social Model in my twenties. Through this I got involved in self advocacy. Sharing this understanding with other disabled people in a group setting also proved to be invaluable in terms of my own growth. This understanding altered my life as a disabled person. It helped me to comprehend social injustice and the idea of how inclusion can be facilitated if we are minded to give it a go. I felt a mixture of relief, and negotiation with a lot of preconceptions I realised I had about 'bodies and minds' and 'human nature' the way things should or shouldn't be. It was easier at the time to think about how barriers apply to physical impairments, but I struggled with how this fits with '[dyslexia](#), [ADHD](#), [dyspraxia](#)', pain etc. I think the Social Model is an incredibly easy and accessible way of understanding how discrimination and oppression impacts on disabled people. I recognise that it can be more complicated to apply it to some impairment experiences, such as with pain. I understand that some people

search for absolute truths and explanations, and the social model gets caught up in this. I feel its value is in the way it reveals social ‘barriers’ and ‘enablers’, and questions the exclusive ways of the world, and presents inclusive possibilities.” [Stephen Lee Hodgkins](#)

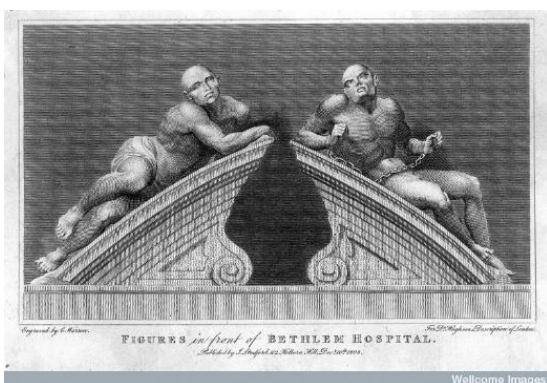
[Union member with autism](#) “I’ve worked for a railway company for 17 years... recently I was diagnosed as being on the autistic spectrum... I told my employer and asked for a discussion on reasonable adjustments. I know I can do the job but there are few measures that would help me organise myself and fit in better and/or protect me from punitive action if I make (non-safety critical) mistakes that others might not, e.g. losing stuff! It took them over six months for Occupational Health (OH) even to reply. The reply was that because I can do my job there is no point having the appointment! Funnily enough when someone goes off sick they are sent to OH within days... eventually, after I kept pursuing the issue, I got the appointment and have had some adjustments recommended.”

**Hidden Physical Impairment Saeeda Bugtti** is a teacher with long term back problems and writes “We often get support with physical aids etc, but there is a real lack of understanding around the emotional trauma suffered by those with hidden impairments. In my experience and that of many other colleagues who have spoken to me about this. Things have got worse during Covid. When you have a hidden impairment it is invisible, but you also become invisible when you experience the non-verbal discriminations on a daily basis. You feel alone. This has a huge impact on our mental and emotional well-being



which directly compounds the trauma you already experience. This is an important issue that needs addressing”.

**TUC Member** “The comment “you don’t look disabled”, the snide remark and the disgusted looks happen all too often. I have a blue badge which allows me to access my place of business and I park outside the building – normal access arrangements require all staff to park in the staff car park and then walk onto site, which is quite a long walk. My mobility problem is due to having been diagnosed with osteoarthritis in both knees. (Following weight loss and cortisone injections) I now walk a little faster, I get the snide remark “don’t you think you should be walking onto site now.” I find these comments really rude and put them down to certain individuals being jealous that I am allowed access with my vehicle to the site”.



## **History of the Mental Health System**

Though the Bethlem Hospital was set up in C14th most ‘mad people’ were treated in their homes or poor law house after 1600. A distinction was made between ‘Melancholia’- acting in

- depression and many other hidden mental impairments and ‘Raving’-acting out. Increasingly as the C19th wore on ‘Mad’ people were incarcerated, motivated by eugenicist ideas and public order scares. The treatments were often barbaric- incarceration, lobotomy, restraint or Electro Cathode Treatment. Psychiatry in 1960s to 1980s came to rely more on therapy but this was replaced by an increasing dependence on drugs. Today drugs dominate overwhelmingly. Care in Community became the political watchword after 1980 as Asylums and Mental Hospitals were emptied. [A Survivor or](#)

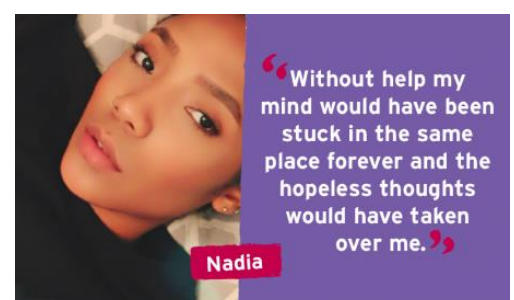
[Users of Mental Health System Movement](#) developed. They made demands against involuntary treatment and to have control over what was done to them. Much of what was argued by them became incorporated in the NHS and shaped particularly Article 12 of the UN CRPD. The stigma of those many years remains not least in the underfunding of mental health services. [Recovery in the Bin](#) a group of mental health survivors argue for a social model approach, “a meaningful ‘recovery’ is impossible for many of us because of the intolerable social and economic conditions, such as poor housing, poverty, stigma, racism, sexism, unreasonable work



expectations, and countless other barriers”. The underfunding and under resourcing of mental health services means that service users are under pressure to conform to a narrow idea of recovery. The changes to the social

security system promote the ideal of work being good for everyone’s health while undermining any real hope of a good life, which is what recovery is supposed to be about”. They wish to be known as ‘Unrecovered’. Such analysis points all of us with different impairments to realise that the answer to the oppression we experience which is deeply rooted in our and other neo-liberal capitalist societies is not individual, but is social and collective. [Shaping Our Lives](#) advocate survivor struggle for equality .

[Mental Health Issues](#) Mind describe a wide range of mental health issues which impact on people and most of these are invisible. People’s generally

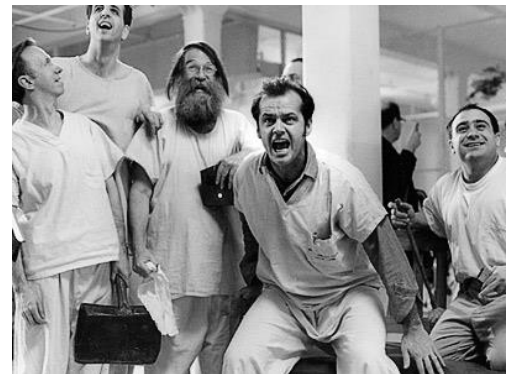


negative reactions to anyone disclosing their condition often draws on stigma and prejudice from more oppressive times, fuelled by fear and ignorance, encouraged by sensationalist media. [Time for Change](#) ran from 2007 to March 2021 as a campaign to change attitudes to mental health to the 1 in 4 in the workplace, schools, colleges and the community. They had a big impact in changing attitudes and produced useful resources to keep the process going.

**[Nadia](#)** “I was told that my reason for being depressed was “pathetic”, and that I “had plenty of things going” for myself, but depression doesn’t work like that. It doesn’t look at what you have going on in life ...I wanted the people I care for and confided in to open their hearts and minds to understand that depression isn’t a choice. I didn’t want to be depressed - nobody wants to be depressed. Being told I was wrong for being depressed, made me feel even more hopeless and incapable of overcoming it with the “weak mind” that I was being told I had. I felt like a burden to those I cared about and as if I had let my family and friends down, for letting what was considered “a bad mood” get the better of me. I was told that I had a history of being depressed for so long, that I’d probably be depressed forever - and that it was only a matter of time till there would be another thing that happened to trigger it all over again... I think it’s easy for someone who has no experience with it personally, to assume that people who are depressed or experiencing thoughts of suicide are weak - but that’s wrong. They aren’t weak, they are alone in their thoughts and tired of battling it till they’ve lost their ability to think... Even if you don’t understand or can’t relate to people in these positions, it can help just to listen..”

**TUC Member** A has diabetes and is susceptible to work-related stress. He was bullied by a manager (leading to) lengthy periods of absence. Member was in breach of a disciplinary warning regarding his attendance. The union rep advised an OH appointment which found that A was disabled both with diabetes and work-related stress and that the absences should be regarded as “injury at work”. This was accepted. A grievance against the bullying manager was upheld. Mr A was therefore moved to a new role as a reasonable adjustment and was permitted to work from home.”

**Jason** has Bipolar. “The misconceptions are that you are reckless all the time; that are hyper all the time. This image of life in films such as ‘One Flew Over the Cuckoo’s Nest’ that you’ve lost control, that’s also everybody’s



misconception of what Bipolar is. You can have mood dips. You can have mood highs, but it can be controlled. The stigma leaves you feeling isolated. It leaves you feeling though you have no friends. I am very fortunate to have the support of my wife and she’s stood up for me when other people wouldn’t. I have a 13 year old daughter who on New Year’s Eve was asking me questions about Bipolar and what she could do to help. You have family. You have friends and you can live a very constructive life.”

## **Conclusion Hidden Impairment and Disability**

**UKDHM** is committed to a ‘social model’ of disablement approach but this does not mean we do not think impairment is important. Mike Oliver and Colin Barnes, two veteran campaigners and academic defenders of the ‘social model’,

identified how “the negative assumptions and ideologies surrounding impairment are so deeply embedded within social consciousness that they become naturalised as ‘facts’”.

Understanding of disability as a socially created category is thus obscured, blocking development of political consciousness among disabled people themselves. The Equality Act and Disability Discrimination Act enhance this process of obscuring, but as has been shown in a number of situations in the workplace and life, it is the culture of solidarity, faced with a common oppression that can bring about change and provide empowerment to those who feel marginalised, reinforced by their low self-esteem. Whoever is oppressed by the negative social response to their impairment is being disabled and together this can be changed.

## **Disability Relationships and Sex**

The American disabled feminist Anne Finger argues that the disability rights movement has not put sexual rights at the forefront of its agenda: 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (1992: p.9)

**The common ground between the disbelief about people with hidden impairments (as those with visible impairments do likewise) and the widespread, though reducing, belief that disabled people are non-sexual, incapable of being parents is disabilism.**



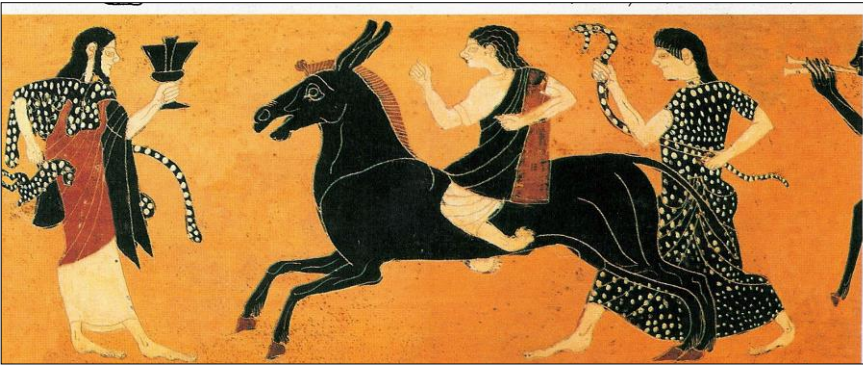
**Disabilism** can be described as a network of beliefs and structures in society and through which 'non-impairment' is privileged as the normal, natural, and desired bodily/mental state. In a disabilist society, impairment is cast as inferior, defective and less than human creating barriers that disable in attitudes, self-esteem, organisation and environment. Therefore, disabled people must strive to become 'normal' or challenge with their own counter-culture through Disabled People's Organisations.

The oppressions experienced by disabled people in their sexual and intimate lives have long been overshadowed by wider fights for their rightful place within civil and public life. The consequences of this are the omission of the 'personal and individual dimensions of oppression. [‘The oppression disabled people](#) can experience operates on the 'inside' as well as on the 'outside' and operates at both the public and personal levels, affecting what people can do, as well as what they can *be*'. The oppression has been built up through cultural and historical experiences which operate through stereotypes, but also internalised oppression where disabled people absorb how they have been treated as an expression of their self-worth. As the biggest sex organ in the body is the brain, knowing our history how we have been oppressed and how to develop self-worth and self-esteem is crucial to our confidence and empowerment to form relationships and have joyous sexual experiences.

**Examining the long history of human relations and sexuality we can pick some cameos to illustrate the force of myth,**

superstition and culture that build the oppression disabled people experience.

**Greek and Roman Mythology** use many of the same Gods with



different names. Their stories either explained why things were or gave a strong moral lesson to human beings. These

Gods were created by human beings to give explanation to life.

**Hephaestus** was a Greek God who lived on Mount Olympus. Son of Zeus and Hera (below left). They attempted drowning of Hephaestus drawing on contemporary ancient Greek thinking (Plato's Republic and Aristotle that disabled babies should be exposed to the elements to kill).



There is irony in the Hephaestus stories. Hephaestus either has a club foot or is injured by Zeus (right) hurling him out of Olympus by his leg. In whichever variant he is disabled. He has to work, unlike other Gods, as a blacksmith and a fine



craftsman. The Gods laugh at him because of how he walks and try and have adultery with his wife Aphrodite.

Hephaestus is cunning and chains his mother to a throne he specially designed to find out his parentage and /or force a marriage with Athena or Aphrodite (right). When he finds Aphrodite in bed with his brother, Ares, he chains them and to the mirth of other Gods.



[This trope is repeated](#) much later in D H Lawrence's Lady



Chatterley's Lover (left), where Lady Chatterley satisfies herself with the virile gamekeeper because her husband is a 'cripple'. This scenario, where a disabled man is judged to have lost sexual power because of his impairment and his sexual partner has carte blanche to seek solace elsewhere, has become known as the '[Chatterley Syndrome](#)'. However, today many spinally injured people have found sexually fulfilling lives through different techniques. The syndrome reflects life before our liberation which is still an on-going process and seems to be necessary for each individual in each generation, though an active movement and social media helps.



[Old Testament](#) creates the idea of the normal body as good and impaired person as bad. First, in order to take a leading role in the performance of rituals and ceremonies, a member of the community had to pass the test of bodily normality. Therefore, it was

unthinkable that a person with a disability could ever serve as a high priest and take a leading role in the highest rituals of the cult; thus disability became a clear marker for an institutional exclusion barrier. This kind of exclusion procedure was clearly established through a direct order from God: **“For any man who has a defect shall not approach: a man blind or lame, who has a marred face or any limb too long ..a man who has a broken foot or broken hand, ..or is a hunchback or a dwarf, or a man who has a defect in his eye, or eczema or scab, or is a eunuch.**



No man of the descendants of Aaron the priest, who has a defect, shall come near to offerings made by fire to the LORD. He has a defect.. he shall not come near to offer the bread of his God. .He may eat the bread of his God, both the most holy and the holy; ‘only he shall not go near the veil or approach the altar, because he has a defect, lest he profane My sanctuaries; for I the LORD sanctify them.” (Leviticus . 21:16–23) The passage illustrates not only the idea that a person with disability was considered to be impure, but the very idea that God found most pleasure in a perfect and normal body. Many Christians have argued that the **New Testament** gives a different view, but disabled people are still penitent sinners. This set a cultural tone for European culture as disabled people as unclean and sinners as other.

The Founder of Protestantism in Germany, **Martin Luther**, sincerely believed that Satan was responsible for the malformed children known as changelings, and that such satanic child exchanges occurred frequently. In Luther's theological view, a changeling was a child of the devil without a human soul, "only a piece of flesh.“ “Take the changeling child to the river and drown them” he preached. This was an explanation for disabled children for example hydro-cephalous, Down’s syndrome, cerebral palsy and other conditions. Disabled people are therefore ‘evil’.



This theme continued during European witch hunts, aimed largely at women. Disabled women have always faced this stigma. Many women with mental health conditions – along with older

people showing signs of dementia, and people with benign and cancerous growths – were caught up in the European witch-hunts of the 17th century. One observer at the time, [Reginald Scot](#) (a Justice of the Peace in Kent), noted that they were “commonly old, lame, blear-eyed, pale, foul, full of wrinkles...lean and deformed showing melancholy in their faces to the horror of all that see them.” But the combination of impairment and patriarchal sexism meant witches and later other women, especially with learning difficulties, were accused of hyper-sexuality and licentiousness; having intercourse with the Devil. This has led to persistent abuse of disabled women, particularly in institutions, where they have been raped and abused for centuries. Early 19th-century whistle-blowers gave evidence of such maltreatment. The noted [French psychiatrist](#)



[Charcot](#) characterised ‘attitudes passionnelles’ as stages of hysteria amongst his female patients’(left). Many of the stages were described in sexual terms such as ‘extase’ (ecstasy)’.

Women as the bearers of the next generation were particularly vulnerable to cultural fads, theories and moral panic and disabled women more than any others. Early on some charities created safe places for those with learning difficulty to live and learn such as Earlswood Asylum for Idiots (below, 1847).



“[Attitude surrounding](#) reproductive fitness that suggests having a disabled partner is potentially contaminating as it could pass the ‘problem’ on to the next



generation. Disabled people have challenged this on many levels: for example, sexual relations are not all about procreation, not all impairments are inheritable, and many disabled people accept their impairment and the possibility that it might be passed on. Deaf (with a capital D) people, for example, consider deafness to be a culture, rather than an impairment, and believe it should be embraced and celebrated. With eugenics – a now-discredited social philosophy – **Francis Galton** pursued the theory of contamination to its logical end. He argued, along with others who took up his ideas, that people with disabilities (along with the poor and the generally ‘unfit’) should be prevented from breeding. The **eugenics movement**, which started in the UK, was taken up with enthusiasm in the USA. By 1914 nearly two-thirds of US states had made it illegal for “feeble-minded” and “insane” people to marry. The so-called ‘Ugly Laws’, first passed in the 1880s, prohibited the “unsightly” from being seen on the street at all. Between 1907 and 1928 thousands of Americans were compulsorily sterilised. The legitimisation of eugenic views throughout Europe and America ended in a logical, if horrifying, outcome: the systematic murder of thousands of disabled people in Germany after the Nazis came to power in 1933. Compulsory sterilization of disabled people started immediately. By the end of World War II, it is estimated that some 350,000 disabled people had been murdered”. Katherine Quarmby

In the UK the Mental Deficiency Act was ushered in by its hand maidens such as Bernard Shaw, H.G.Wells, Beatrice Webb, Marie Stopes and Churchill and many other influential people. In 1910 [Winston Churchill wrote to the Prime Minister Asquith](#) **“The unnatural and increasingly rapid growth of the Feeble Minded and Insane classes, coupled as it is with a steady**

**restriction among all the thrifty, energetic and superior stock, constitutes a national and race danger which it is impossible to exaggerate”.**

Churchill had wanted compulsory Sterilisation but due to opposition had to settle for incarceration for life in sex segregated institutions. The phrase **“feeble-minded”** was to be defined as part of the Mental Deficiency Act 1913, of which Churchill had been one of the early drafters. [“The Act defined four grades of “Mental Defective”](#) **“Idiots”[Severe Learning Difficulty today]** who could be confined for life, whose symptoms had to be present “from birth or from defective in mind as to be unable to guard against common physical dangers.” **“Imbeciles”[Moderate Learning Difficulty today]** were not idiots, but were “incapable of managing themselves or their affairs, or, in the case of children, of being taught to do so.” The **“feeble- minded”[Mild Learning Difficulty today]** were neither idiots nor imbeciles, but, if adults, their condition was “so pronounced that they require care, supervision, and control for their own protection or the protection of others.” If they were children of school age, their condition was “so pronounced that they by reason of such defectiveness appear to be personally incapable of receiving proper benefit from instruction in ordinary schools.” **“Moral defectives”** were people who, from an early age, displayed “some permanent mental defect coupled with strong vicious or criminal propensities on which punishment had little or no effect”.

After the Great War the Mental Deficiency Act was implemented by Local Authorities from 1919. By 1939, 34,290 were in Institutions, 9,455 in workhouses, 4,841 in Guardianship arrangements. The majority were women, not least because

unmarried mothers were often deemed '**morally defective**'.

Overall using pseudo-scientific methods such as IQ tests,



125,859 had been ascertained as [Mental deficient](#). (Left: Meanwood

Park, Leeds. At its height over 840 inmates in male and female villas).

The sex segregation, which was rigidly enforced did not always work, illicit relationships found a way, but female

inmates who got pregnant were usually sterilised after giving birth. The whole endeavour apart from its barbarity was based on a false assumption that these groups if they had children would produce off-spring more defective than themselves. Scientifically this was just not true.

McCarthy offers a profound insight into the sexuality of learning disabled women from England. Her book **Sexuality and Women with Learning Disabilities** (1999) quotes from exceptionally rich in-depth interviews from the 17 women who were taking part in a sex education group with McCarthy. The women described themselves as having very little choice or control over their sexuality and experiencing little or no enjoyment in intimacy. This was the case with women living in the community as well as in residential services. A large proportion of the group had experienced sexual abuse and gender-based violence.

**Abuse** Many other disabled people were segregated in C19th and C20th as institutions of all types grew. Asylums, long stay mental hospitals, orphanages, children's homes, care homes and segregated residential special schools. Abuse including sexual was widespread usually carried out by staff as they were often not supervised and had the power to do what they

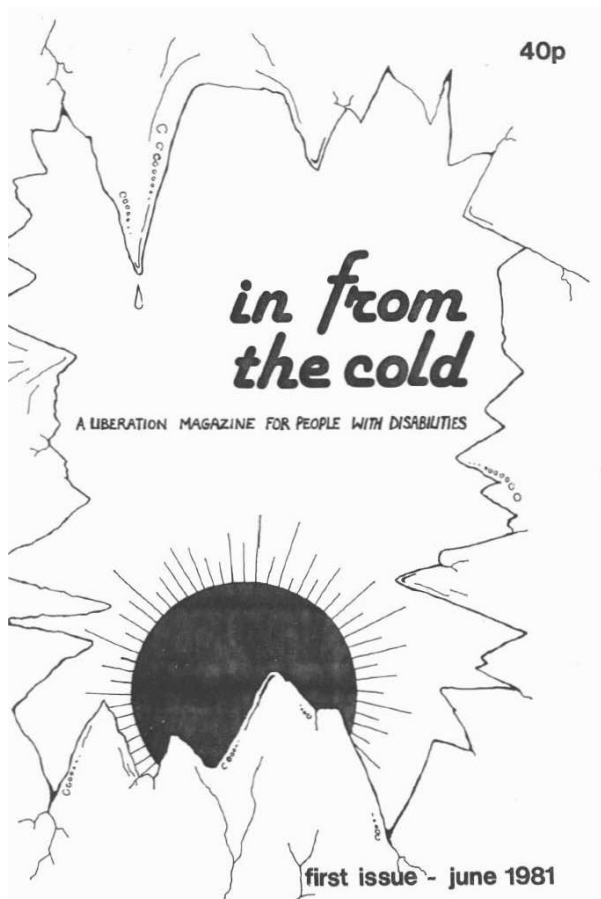
wanted. This was one of the main motivations for developing Care in the Community with widespread long stay hospital closures in 1960s, 1970s and 1980s. Only a few well publicised cases scratched the surface of what would have been for many a living hell and despite much tougher regulation today, still continues e.g. Winterbourne View, Whipps Cross, Wharltton Hall and Eldertree Lodge. Remembering that disabled children are 2 to 3 times as likely to be subject to abuse, our family homes are also not safe. It is estimated that child sexual abuse in the family environment comprises up to two-thirds of all child sexual abuse reported to the police (Children's Commissioner for England, 2015). Studies suggest that 15–20% of girls and 7–8% of boys experience some form of sexual abuse before the age of 16 ([Kelly and Karsna 2017](#))

**Abuse of disabled women doubles in 7 years.** In 2014, the ONS figures were relatively similar for all females; 2.6% of disabled women experienced sexual assault, compared with 2.2% of non-disabled women. The latest data, published in March 2021, showed rates for disabled women had more than doubled to 5.7%, while rates for non-disabled increased to 3%. Rape and sexual abuse is not about sex but power and disabled women are seen by overwhelmingly male perpetrators as weaker and less likely to resist. [Tackling Violence Against Disabled Women & Girls 2019](#). This research, DPO led, established that there are severe barriers to equality of outcome for disabled or Deaf women who are survivors of violence, particularly at the intersection of gender, disability, ethnicity, poverty and multiple disadvantage. Under-resourced public services and over-resourced segregated, privatised provision contributes to barriers to safety and longer-term independent living after

physical or sexual violence, psychological or psychological abuse, institutional, domestic violence and hate crime in England today. Equality of outcome and the return of life chances can be achieved, by coproduction of solutions with disabled survivors who have a lived experience of violence. This could assist to remove and prevent violence that is correlated with poverty and segregation and tackle barriers in the complex and expensive national and local webs. A great deal of regulation in safeguarding, inspection, commissioning and for-profit or charity provision is not fit for purpose and is failing the disabled people it purports to serve.

**Towards Liberation** In 1981 the **In from the Cold Collective** started the Disabled People's Liberation Network (DPLN). One of their demands coming from the Women's Movement went further than other parts of the burgeoning UK Disability

Movement such as UPIAS ([Union of Physically Impaired Against Segregation](#)) or BCODP ([British Council Of Disabled People](#)) whose thinking was based on more structural and economic factors. "To learn to recognise the effects of society's conditioning on people with disabilities, and to create ways in which people's awareness can be heightened to a point where their self-image changes from a negative to a positive one, from weak to strong".





**Micheline Mason** (Foreword Issue 1 in from the cold). “The feeling most of us seemed to share was a relief at no longer being isolated; we had been ‘out there’, each fighting the whole world on our own, and were suddenly ‘inside’ a group of people with similar ideas. The ‘battle’ became an exciting and enjoyable challenge. Also, one of the hallmarks of the oppression of people with disabilities is being excluded from ‘Life’. So ‘In From the Cold’ seems like a good direction forward for us.” There is also an article by [Jonathan Griffiths on Relationships](#). “Somewhere in everyone are deep physical and emotional needs for love and satisfaction. They must be admitted to the wider world, but sometimes this can be much worse than being a teenager if everyone your age got there years ago. How do disabled people cope with this? How dare they learn and blunder in such an intimate and personal area with no-one else in a similar state? Yet they must try. If you are asked for help, be loving and very honest”

[The sexual politics of disability - Untold desires, 1996](#) was the first attempt by disability studies in the UK to examine disabled people and their sexuality with a qualitative in depth study of 44 mainly disability activists. “Homosexual people were more likely to respond to advertisements than heterosexual people. We had some difficulty reaching heterosexual people, particularly heterosexual men. Heterosexual people, especially men, were more reticent and less forthcoming than gay, lesbian and bisexual people... Too often disabled people, because of their impairments, are viewed as incapable of sex and love, as incapable of independent living, as incapable of parenting and enjoying family life. The testimony of this book is that disabled people can enjoy sexual citizenship, can participate in these experiences, because so many of our respondents, regardless of

their impairments, clearly do. We are aware that the experience of many disabled people is different. But this book argues that because some disabled people have positive sexual and emotional lives, then all disabled people can potentially enjoy sexual freedom and emotional expression. The obstacles are not biological, they are social, political, and economic. If this book has a conclusion, it is that disabled people are entitled to their sexual rights, and the time is long overdue for society to meet them". Ch. 8.

In 2008 to 2011 [Kirsty Liddiard](#), a disabled researcher, interviewed in depth 26 disabled respondents (15 men and 10 women) about their sexual stories, told by disabled people on their own terms and in their own ways. Stories that shed light on areas of disability, love and life that are typically overlooked and ignored. A sociological analysis of these stories reveals the creative ways in which disabled people manage and negotiate their sexual and intimate lives in contexts where these are habitually denied. In its calls for disabled people's sexual and intimate citizenship, stories are drawn upon as the means to create social change and build more radically inclusive sexual cultures. As a woman researcher, she had to deal with many oppressive attitudes from the disabled men-objectifying women, using prostitutes and pornography. More generally disabled women can be exposed to fetishist and 'devotees', people attracted to them by their impairment rather than their personality.

**CHANGE** ran a ground breaking project 2007 to 2010 [Talking about sex and relationships: the views of young people with learning disabilities](#)



The project aimed to find out about the views and experiences of young people, parents and teachers around sex and relationships, with a long term aim of improving the future of sex and relationships education for young people with learning disabilities. The methods involved extensive drama workshops with young people with learning disabilities, a national survey of special schools, interviews with parents and focus groups with teachers/ governors. The project was innovative and user-led, tackling a subject on which there had been little previous large-scale research.

The **Sex and Relationships** project embodied an emancipatory, user-led paradigm. People with learning disabilities led the planning of the project. Young people gave their views and ideas about sexuality and relationships using drama, coming out of 2 drama groups of 16-25 year olds with learning difficulties. The following findings emerged. They understood about friendships and were happy to talk about friendships. Most of the young people were good at talking about feelings. They were good at thinking about why someone might feel sad, happy, tired, upset etc. They demonstrated a good knowledge about going out with someone. Most young people in the drama group knew that gay and lesbian meant people of the same sex in a relationship together though some had picked up some prejudice. Lack of places to meet came up. The young people talked about the practical difficulties of getting condoms e.g. catching a bus, counting the money, it being hard to tell your mum, not being allowed to go out on their own because they might get lost, difficult to ask people where the condoms

are etc. They were not sure who to tell when abused e.g. police. There were big differences in knowledge about sex and masturbation among the young people. We found that some knew a lot and some knew very little. Some young people lacked basic knowledge especially those from ethnic minorities. None of the young people could say how a period was connected to having a baby.

### **Sex and Relationships Recommendations from project:**



“There needs to be more accessible information about sexual health.



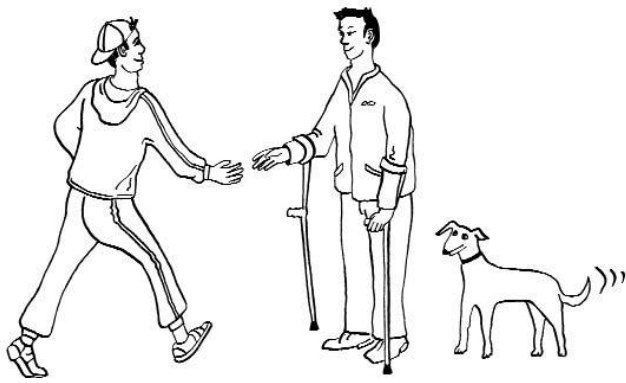
There should be more support for young people with learning disabilities about sex and relationships.



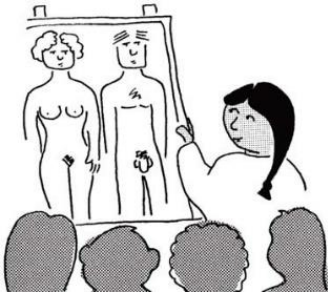
Parents of young people with learning disabilities should get more support around sex and relationships.



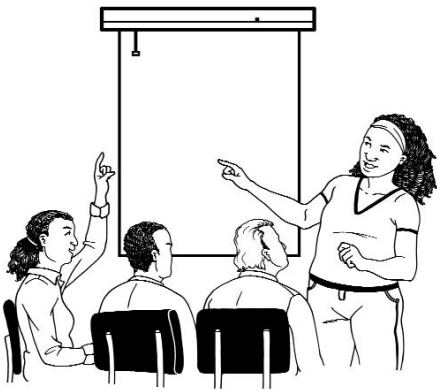
Families from BME communities should get the right support.



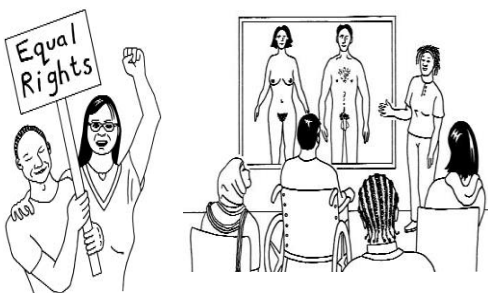
Young people with learning disabilities need more chances to meet with friends and be independent.



People should see sex education for people with learning disabilities as important.



There needs to be better training for professionals about sex education especially in special schools and colleges.



Young people with learning disabilities have a right to sex education including to know about Lesbian, Gay sex and relationships.”

The project produced accessible resources and showed the need for sex and relationship education for all. Ten years later that has become a reality in schools with mandatory [Sex and](#)



[Relationship Education](#). Teachers are told to • Use accessible words • Do not use jargon words or difficult phrases • Do not use slang words • Speak slowly and clearly • Break information down • Go at a slow pace • Give breaks • Keeping checking child's understanding • Give examples • Give extra time • Do not patronise.



Pioneers like [Mik Scarlet The Channel 4 Doc for Sex Talk, Willing and Able, from 1989](#) and Penny Pepper [Doing It](#) have promoted being open about their sex lives as disabled people on TV. More recently a number of younger bloggers have used the internet to good effect. In 'Doing it' 2013 written and directed by Penny, a couple have to make a choice

about contraception. What choices are there? Seems simple, but not for Jackie - who is disabled - and when the doctor you see is young, nervous and more confused than you are. **Mik Scarlet** "One of the most important things about coming to terms with your sexuality as a disabled person is learning to understand the way that your body is different from all the able bodied people out there, and exactly what your body can, and more importantly, can't do. Once you've admitted this to yourself and accepted it, you can start to rebuild your sexuality... So once I had realised that sexuality could be so many different things I set about making sure that I was going to be the best shag ever. I read loads of books and gained a wide knowledge of able-bodied sexual technique. I adapted some of their techniques to fit with my body and this is what I am going to impart to you all. The first tip is great for both

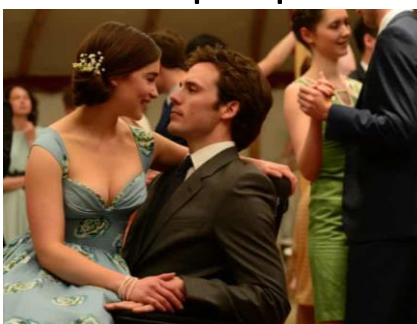
sexes, no matter what your disability. I call it... Hands Free Masturbation. The whole technique is actually quite simple. Just lie on your bed (or sit in your chair – which can be fun if you're bored when out shopping!) and imagine yourself having sex. Not just sex, but the best sex imaginable, with your favourite fantasy partner (or partners) and just don't stop. Keep building on the fantasy and make it as intricate as you want, as kinky as you want and as long as you need. Go wild and be as filthy as you like. Eventually, and it may take a good few goes, you will get there".

In 2006 following a hit show 'Bravetarts' with Liz Carr at Edinburgh Fringe Penny Pepper did an interview with the [Guardian](#). "Pepper, slightly older than her friend at 42, is a writer and performer who describes herself as "very sexually orientated", readier than ever to discuss her own needs and desires having just split up with her second husband. When Pepper was growing up in the 70s, the idea of sex education for disabled people was simply not an issue, because no one believe they needed it. It has been a long journey for Pepper, especially because she spent much of her childhood in and out of hospital for prolonged periods. There was never a hint that someone like her could expect to enjoy any sort of sex life. "When I was 16 a close friend told me about masturbation and that changed my life," she says. "I couldn't wait to try it and it was simply wonderful. But I couldn't believe that no one had talked to me about my sexuality. It's so much part of who you are but when you are disabled it's almost as if you should be totally asexual."

That tentative beginning eventually lead to sexual exploration with various partners, but Pepper was well into her 20s before she felt confident enough to recognise that other people might find her attractive. "I was very nervous and didn't have the usual teenage experience of growing up and being aware of myself as a sexual person," she says. "All the emphasis on 'the perfect body' doesn't help, especially since there's no way I could ever aspire to what is seen as ideal. Being in a wheelchair limits my ability to move in what you would consider the standard sexual ways. It can be hard enough discussing sex with an established partner, never mind having to be upfront from the start and really spell out the realities - for example, telling someone it hurts when he does that, I have no feeling there or I physically cannot manage to do that. That takes a lot of confidence, especially when you compare it to the popular media images where couples just melt into each others' arms and the sex is instantly wonderful." People tend to make assumptions about people with disabilities that have no bearing on reality - or their humanity. Pepper is clearly tired of trying to change these. "Part of the problem is that we're seen as ill, which isn't attractive at all," she says". [First in the World Somewhere](#) briefly tells Penny's life to date (2016).



**Impact of mainstream Films and Media** One of the problems disabled people have wanting relationships and a decent sex life, is to put up with films like **'Me Before You'** which peddle the old message "our life isn't worth living". Jojo Moyes screenplay based on her romantic novel



has a back story of euthanasia. It features Will Traynor (Sam Claflin), the handsome, embittered wheelchair using millionaire living in a castle, who falls in love with Lou (Emilia Clarke), his working class recently hired assistant. She doesn't do the messy bits. He has a private male nurse for that. There are several flashbacks to his sporting life before paraplegia. We are treated to his staunch belief even that as a millionaire with a great woman in love with him his life isn't worth living, as he goes to a Dignatus like clinic to end his life.

(Right Liz Carr, actor/disability activist, protesting outside the Premier in Leicester Square, June 2016 from campaign group Not Dead Yet). The pathetic script that ignores the real issues of adjustment to life in a disabled body and has no protagonist with the disability experience, reinforces the public's view to support assisted dying. How convenient at a time when neo-liberal states around the world wish to cut back on their Human Rights commitments to give their disabled citizens a family life and decent standard of living. (UN Convention on the Rights of Persons with Disabilities). Will clearly thinks he is not a proper man even though up to 95% of men with spinal cord injury experience ejaculatory problems, 80% regain some erectile function by 2 years after spinal cord injury. The ability to achieve erections does not parallel a man's ability to become sexually aroused. Therefore, the ability to obtain and maintain erections should not be used to gauge a man's sexual potential. Even though orgasm is less common than in women, approximately half of men with spinal cord injury can experience [orgasms after spinal cord injury](#).







**The Sessions** is a 2012 American film written and directed by Ben Lewin, based on the 1990 article "On Seeing a Sex Surrogate" by Mark O'Brien, a poet paralyzed from the neck down due to polio, who hired a sex surrogate to lose his virginity. The surrogate

and Mark develop a good rapport and they achieve fulfilling sexual intercourse after a number of false starts. Again it is the brain not the plumbing that has to be aligned. However, it raises the vexed question of sex surrogacy and paying for sex partners-prostitution. For some disabled women and men it is the only sex they are likely to get in our prejudiced society. It could be viewed as sexist and exploitative of women and many feminists are rightly against this. Should disabled people be held to a higher standard than non-disabled people who in their millions pay for sex? If disabled people are included, not isolated and segregated, they have a much better chance of meaningful relationships and sex.

**Have there been inclusive portrayals of disabled people in sexual relationships?** There have been a few but for the most part they have been absent because of prevailing negative attitudes and stereotypes.

**The Body Beautiful (1991 d. Ngozi Onwurah)** This film is an autobiographical piece featuring Ngozi and Ngozi's white mother, Madge Onwurah. They narrate certain portions of the film and appear in the film as themselves. 'The Body Beautiful' discusses both women, and their lives and fears. Madge Onwurah speaks of marrying a Nigerian man, bearing mixed race children, and having breast cancer followed by a mastectomy. The film explores Ngozi's feelings of being raised



by a white British mother, a model in a predominantly white industry, her relationship with her mother and her mother's sexuality. In the film, she envisions her making love to a young Black man, with the scar of Madge's mastectomy exposed. This is a very positive view of a disabled woman making love.



**Sixth Happiness (1997 d. Waris Hussein)**

is the fictionalised autobiographical account of Firdaus Kanga's coming of age within the Parsee community of Mumbai (Bombay) during the 1960s and 70s.

Writer/ lead Kanga (Brit) has been a prominent figure on the London fringe theatre circuit, and this film is based on his novel *Trying to Grow*. Set in Mumbai, India, not only brings to the fore issues surrounding the difficulties faced by those with physical impairment (brittle bones), but also raises our awareness of the Parsee community in India. The depiction of Brit's parents as ardent Anglophiles with fond memories of the Raj presents a glimpse of a non-stereotypical Indian family, one that favours a western lifestyle, preferring western food to traditional Indian fare, wearing dresses and suits, and speaking mostly in English. The story is told in the first person, as Brit takes us through the joys, disappointments, rejections and sexual awakening of his formative years and experimenting with opposite and a same sex relationship. Unlike many films centred around physically impaired people, here we are aware of the actor's real-life understanding of the issues involved. Moreover, the film's grounding in historical events, such as the East-West Pakistani conflict, highlights shared experiences, while emphasising the diversity of individuals worldwide.

## Every Time You Look at Me (disabled producer Ewan



Marshall). It took until 2004 for the BBC to show two disabled leads in a drama! The two disabled actors, Mat Fraser (Chris) and Lisa Hammond (Nicky) “Chris and Nicky are two

people who fall in love although Chris already has a girlfriend and he's 16 years older than Nicky. But the most significant obstacle is their impairments. Nicky is a small person, four feet tall and Chris is a thalidomide impaired person with short arms and no thumbs. He has a beautiful non-disabled girlfriend Michelle and with the support of his parents, he has achieved so much despite his impairment. He thinks he's got it all and life's great. Nicky is a hairdresser in her early twenties who likes nothing more than going clubbing. When Chris and Nicky meet across a crowded nightclub there's an undeniable spark but falling in love with another disabled person is the last thing that either of them would want. Individually neither of them see their impairment as a barrier to succeeding with their lives but when they consider a future together that changes. They must face not just the prejudice of the outside world but also of their own families and of each other. Chris and Nicky are drawn into a relationship that is both liberating and painful”.

**Sexual orientation and disability.** In 1976 Gemma (1976) a network of disabled lesbians was set up in 1980 [REGARD](#) was a social model disabled people's organisation for Lesbians, Gays, Bisexuals and later Trans.

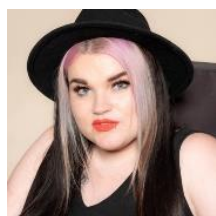


Regard believes that, like everyone else, disabled people are entitled to explore and express their sexuality, to form relationships, to leave these when they wish to do so, and to make mistakes along the way. Disabled people have traditionally been regarded as being asexual. Since to be homosexual, bisexual or transgendered is regarded as being a primary sexual identity, the disabled LGBT community has been largely invisible. For older disabled people this situation is compounded by the way in which all older people's sexuality is generally ignored or considered inappropriate to mention (except as a symptom of 'pathology', for instance in dementia). The needs of the LGBT community are therefore unrecognised within social care provision. Social care providers need to recognise that all disabled people have the right to express their sexuality and to form relationships, and providers need to cater for the needs of LGBT disabled people, rather than assuming that all disabled people are heterosexual and have uniform needs.

In 2005 Norah Fry Research and Regard collaborated on research [Secret Loves, Hidden Lives](#)? Examining the lives of 20 LGB people with learning difficulties. They found that the mental, emotional and sexual health of people with learning difficulties who are lesbian, gay and bisexual is being jeopardised by the failure of many services to meet their duty of care in this area. Despite these barriers the desire to meet and get to know other people was one of the strongest messages from the research. Most people wanted to fall in love and have

more gay and lesbian friends. Despite the very many messages telling men and women with learning difficulties that it is a problem for them to be sexual at all – never mind gay, lesbian, or bisexual – people were forging their identities and striving to lead full sexual and emotional lives. Nonetheless much work needs to be done to ensure that the human rights of people with learning difficulties who are gay, lesbian or bisexual are upheld and supported.

Younger disabled people are using social media to promote



disabled people's sexuality. Kelly Gordon at Pleasure Rebels (Hot Octopus) left

<https://twitter.com/mskelgee> promoting sex aids and

The Love Abilities Festival which is a global virtual disability and sexuality festival, featuring sex ed/knowledge, relationships and more! Lucy Dawson (right) has brain injury and is a model and advocate <https://twitter.com/ludawinthesky>.

Lucy has recovered from [Autoimmune Encephalitis](#) leaving her with impairments but is determined to get on with her life relationships and her blog is a good read.



**Sexual Liberation** has been a slow process for disabled people, but at least because of the struggles of activists who have gone before it is no longer a taboo subject. Some of us are parents and grandparents and even more of us have full and sexual lives.

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