

# Our Bodies, Our Rights: Research Report

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# 'Our Bodies, Our Rights': Survey and Focus Group Findings

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## Introduction

Disabled women's lives and lived experiences have received limited policy attention in the UK, limited visibility, and limited inclusion in mainstream feminisms and feminist projects. Despite increasing movement towards intersectionality and intersectional agendas, disabled people have remained hidden in myriad ways.

As the accompanying policy report 'Our Bodies, Our Rights: Identifying and removing barriers to disabled women's reproductive rights in Scotland' details, there is a lack of robust research examining the lived experiences of reproduction and reproductive rights of disabled women in Scotland. Women with Learning Disabilities' reproductive rights have been recognised and pointed to in the Scottish Government's Keys to Life<sup>1</sup> strategy in implicit ways. The 52 recommendations encapsulate a need to ensure the wellbeing, health and equal citizenship of people with learning disabilities in Scotland, which includes their rights to family life, support, inclusion and reproductive health. Similarly, the 'A Fairer Scotland For Disabled People'<sup>2</sup> delivery plan also points to improving the lives of disabled people in Scotland and specifically references the 'Equally Safe'<sup>3</sup> strategy in recognising the need to support disabled women and girls who are subject to gender based violence.

This delivery plan and the Keys to Life recognise the need to meet international obligations to disabled people under the United Nations Conventions for the Rights of Persons with Disabilities<sup>4</sup> (2006/2008) signed by the United Kingdom in 2009. The UNCRPD explicitly recognises the rights of disabled women throughout. Article 3, the general principles of the convention emphasise respect, dignity, autonomy, participation and independence and explicitly references the equality of men and women. The convention recognises that disabled girls and women are disproportionately at risk of violence (in all its forms) and exploitation.

Article 6 of the convention is dedicated to disabled women and lays out states' obligations to fulfil the rights of disabled women, to take all measures to ensure the advancement of disabled women's rights and 'fundamental freedoms'. Articles 7 and 8 outline the rights of disabled children and states' obligation to provide equal education to disabled people and to '*promote awareness of the capabilities and contributions of persons with disabilities*'. Articles 10, 12, and 13 articulate the right to life and dignity, to equality under the law and access to justice and crucially articles 22 and 23 outline respect for privacy and respect for home and family life. Articles 22 and 23 emphasise the rights of disabled people to not be subject to '*arbitrary interference*' by the state and to '*eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood*

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<sup>1</sup> The Keys to Life: Scotland's Learning Disability Strategy [www.keystolife.info/](http://www.keystolife.info/)

<sup>2</sup> A Fairer Scotland [www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/](http://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/)

<sup>3</sup> Equally Safe: National Strategy [www.gov.scot/publications/equally-safe/](http://www.gov.scot/publications/equally-safe/)

<sup>4</sup> United Nations Convention on the Rights of Persons with Disabilities <http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

*and relationships...*' as such disabled women have the right to found families and to have access to meaningful and equal information on sexual and reproductive health, parenting and family planning. It recognises the right of disabled women and to '*retain their fertility on an equal basis with others*' and that disabled parents are able to parent their children. While this is a brief indication of the rights and freedoms laid out in the UNCRPD they undoubtedly speak to the gendered nature of human rights.

Similarly, the United Kingdom Equality Act<sup>5</sup> (2010) protects and articulates the rights of disabled people to be treated equally, to not be subject to discrimination or unequal treatment. There is further recognition of a risk of discrimination outlined by the protected characteristic (PC), pregnancy and maternity, and potential for intersection with PCs sex, sexual orientation and gender reassignment. However, academic research and grey literature has identified that disabled women face ongoing inequality and discrimination, and that though significant intersectional disadvantage exists in the space between PCs, the legislation is unable to challenge this.

Scotland's disability policy reflects and has aimed to challenge the wider social invisibility of the gendered realities of disability including the reproductive equality, experiences and health of disabled women in Scotland. Engender Scotland, the Scottish Learning Disabilities Observatory and the University of Glasgow have responded to this epistemic gap through the 'Our Bodies, Our Rights' project and aim to make the unequal lives of disabled women more visible in social and health data.

### Disabled women in disability scholarship

*'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain'* (Finger, 1990)

There is a longstanding scholarship examining disablement and the marginalisation, stigma and oppression that disabled people face but this scholarship has had a simultaneous history of neglecting the intimate and reproductive lives of disabled people, and disabled women in particular (Kulick & Rydström 2015). As Sheldon (1999, 6743) argued, '*Disability and gender are inextricably linked and it is important that these links are examined*'. In early disability feminist studies Fine & Ash (1988) emphasised the need for '*societal transformation*' in addition to levelling pre-existing playing fields. What is apparent is that these social transformations have taken place in limited ways and many of the inequalities disabled women face in the following review of research are still relevant now.

Feminist disability scholarship has highlighted the lack of engagement with disabled women by mainstream feminist scholarship as Jenny Morris argues '*even feminist challenges to the dominant concept of citizenship, have, in inserting the private world of the family and women's caring role, still treated disabled people as absent*' (Morris 2005, 5 see also Finger 1990, Morris 1992). Feminist disability scholarship and scholarship examining the lives of disabled women have identified the absence of disabled women in mainstream scholarship and also contributed to an ongoing body of literature and research concerning the lives of disabled women and their interests.

*Having sexual relationships (whether they are heterosexual or lesbian relationships), family relationships, bearing and rearing children, making a home - all these are important human and civil rights which, if denied to nondisabled women, would be the subject of outrage* (Morris, 1995, p. 76.).

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<sup>5</sup> Equality Act (2010) [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents)

As Carol Thomas identifies (1997) childbearing and motherhood is an '*inevitability*' for the majority of women in contemporary societies (whilst recognising the complexities of infertility, adoption and diverse parenting contexts) but underlines that disabled women are not included in these discourses of '*inevitability*'. While disabled women have the same reproductive interests as nondisabled women they are beginning from the point of being denied recognition as potential mothers and carers rather and not from the basis of fighting for the right to have freedom of choice over terminating a pregnancy (Kallianes & Rubenfeld 1997, 204). Sheldon (1999) reiterates this point when she referenced the history of forced sterilization enacted upon disabled women globally, and particularly women with learning disabilities. The sterilization and denial of reproductive freedoms of women with learning disabilities has been an ongoing and destructive force in their lives.

Disabled women's role as mothers and carers of others is often obfuscated by social narratives of dependency that locate disabled women as incapable of caring and mothering (Sheldon 1999, see also Malacrida 2012). As will be evidenced below, disabled women themselves feel that they are discriminated against and marginalised based on their support needs and that this produces a fear and anxiety around children being removed by social and child protective services.

There is very limited social research focusing on the menstrual or menopausal experiences of disabled women and girls (McCarthy 2009 see also McCarthy & Millard 2003), the barriers they face to receiving comprehensive sexual and relationship education on a par with others (Sheldon 1999 see also Hollomotz 2011) and commensurate reproductive health information. Women with learning disabilities are, in particular, persistently excluded from sexual citizenship including information and education about sex, sexual health, consent and relationships which Hollomotz (2011) argues disadvantages women with learning disabilities in recognising and reporting sexual violence (See also McCarthy 2009 and Dotson et al. 2003).

As Kallianes and Rubenfeld (1997) argue, disabled women's reproductive rights are constrained by several factors firstly the assumption that disabled women are not sexual citizens, that there is a lack of societal support for disabled women's role as mothers and reproductive individuals and a lack of health care services that support disabled women. The health implications and inequalities experienced as a result of the exclusion of disabled women from reproductive rights narratives and policy are far-reaching and profound. Tilley et al. (2012) extend this final point regarding a lack of access to health care services, in particular, to women with learning disabilities who are disadvantaged and face multiple and intersecting health inequalities such as poor access to reproductive health and cancer screenings (see also Nightingale 2003) and Pap Smear tests (Dotson et al. 2003). Dotson et al. (2003) evidence, albeit in an American context, that women with learning disabilities are not given the time, sensitivity or accessible information by medical health and public health professionals to make decisions over reproductive and gender based health and that medical and public health professionals often direct information and questions to supporters, carers and family members of women with learning disabilities rather than directing their attention to the person themselves – as Dotson et al. (2003, 197) note:

*'Women with developmental disabilities [learning disabilities] do not receive adequate information about breast self-exams due to the same barriers that limit access to routine Pap smears. This procedure can be explained in language they do not understand or it might be overlooked with the assumption that they will not understand or lack the skills to learn to perform the monthly procedure'*

As indicated in the following data, women with learning disabilities in Scotland told similar stories and discussed a lack of inclusion in routine reproductive health screenings or information. Choice and agency are shown, too, to be constrained in making reproductive health decisions around contraception and as the focus group data shows in detail, disabled women are often encouraged to use in-situ birth control devices and given little or no information as to alternatives, side-effects or what the health implications of those devices are (Dotson et al. 2003 see also McCarthy 1998). This, has the potential, to put disabled women at higher risk of sexually transmitted infections as information about prevention of STIs and condom use is rarely given as contraception is almost always, for women with learning disabilities, targeted at limiting the potential for pregnancy (Dotson et al. 2003).

As Dotson et al. (2003 see also Hollomotz 2011) argue, sex can be a difficult topic to raise with women with learning disabilities (who are disproportionately subject to sexual violence) for a number of intersecting reasons. Often information regarding sex, oral sex and intercourse are not given to disabled women and are instead targeted at parents of disabled girls and women, with masturbation being understood as a 'challenging behaviour' (Kulick & Rydström 2015). The infantilization of disabled women and women with learning disabilities compounds the marginalisation and low status they are afforded and the constraining of their agency and decision making with regards to their sexual lives and reproductive health, as Kulick & Rydström (2015, 6) write *'the idea that people with disabilities somehow aren't interested in sex, or shouldn't be interested in it, both derives from and reinforces the patronizing stereotype that disabled adults are like children'*.

While this is a brief overview of the academic research into the reproductive health, rights and choices of disabled women it does evidence that many of the issues that were highlighted in early disability research remain issues for disabled women today. There is very limited research, indeed, on the sexual and reproductive rights of disabled women and this research seeks to contribute to that knowledge to implement policy change and attitudinal change within the integrated social and health care services that intertwine in the lives of disabled women in Scotland.

## **Research Methods and Methodology**

This research undertaken by a team from the Scottish Learning Disabilities Observatory and the University of Glasgow, explored the reproductive rights and experiences of disabled women in Scotland as part of a project with Engender Scotland. As detailed above and in the accompanying Engender Scotland policy report, disabled women are not well represented in social research examining their corporeal and reproductive rights. As such participatory qualitative research was undertaken with a feminist ontology and an emancipatory research process. There is no singular approach to feminist research or singular feminist methodology. Feminist research has emerged in response to positivist and neo-positivist research that understands there to be objective knowledge or truths about the world (Ramazanoglu & Holland 2002). Similarly, the historical articulation of this positivism has produced a male gaze or '*masculine view of social reality*' that obfuscates the lives of women (Roberts 1981, 2). Feminist research, then, seeks to examine gendered lives and gendered inequalities to provide knowledge that challenges dominant epistemologies and to make visible the unequal power relations apparent in knowledge production and in gendered lived experiences (Stanley & Wise 1983, see also Skeggs 1997).

Sociological scholarship on intersectionality, emerging out of a need to examine and make visible the intersecting inequalities and lives of women of colour, argues the need to research the lives of

women intersectionally (Davis 2008). While mainstream intersectional feminist research rarely includes disability in its focus, Clarke & McCall argue for the need to look at '*different interpretations of the same facts*' by '*putting multiple social dynamics in conversation with one another*' (Clarke & McCall 2013,350). This research sought to explore disabled women's reproductive lives intersectionally by examining multiple social dynamics such as gender, impairment, poverty, employment, ethnicity and sexuality. In order to do this we began from the point of women's experiences through an appreciation of emancipatory disability research (Stone and Priestley, 1996) and feminist standpoints where women '*are the authoritative speakers of our experience*' (Smith 1990, 28). Utilising the work of Dorothy Smith (1990, 1997) we aimed to focus on lived experience and their knowledge and expertise of their own bodily and social realities. This also challenges previous dominant medical narratives around the reproductive lives of women more generally and disabled women in particular (Sheldon, 1999). Through using a feminist approach with a focus on emancipatory principles and lifeworlds we can bring together the relational realities of disabled women's lives by putting the political, social, corporeal and reproduction in conversation with one another (Smith 2005).

It was crucial that the voices and experiences of disabled women with diverse impairments were captured in this research to recognise and represent the heterogenous reality of disablement and the inequalities that disabled women face. As such an accessible online survey and easy read survey were developed by Jo Ferrie and Phillippa Wiseman with Engender Scotland and the research advisory group. This advisory group was made up of members of Engender Scotland, People First Scotland, Inclusion Scotland and the Scottish Learning Disabilities Observatory/University of Glasgow and had disabled women as representatives and contributors. This ensured that disabled women who were not able to attend the focus groups or discussion groups were able to participate in the research. It also sought to overcome any physical or gender-based barriers to participation in recognising that disabled women are also mothers and carers and are in employment.

A qualitative survey was developed to reach as many women as possible and was publicised to advocacy organisations for disabled people and online forums. The survey focused on reproductive health and rights trajectories over the life course and focused on reproductive rights and health from childhood, puberty and menstruation through to sexual health education and relationship education, intimate relationships, family planning, pregnancy and parenting to contraceptives, reproductive health screenings and menopause. This allowed women to present their reproductive experiences over the life course and allowed us to capture a breadth of reproductive experiences across diverse ages. Similarly, the easy read version of this survey was produced in collaboration with women with learning disabilities to ensure that the information was meaningful and accessible. Various advocacy organisations across Scotland supported women with learning disabilities to fill in the easy read survey which allowed us to include women from the Scottish Highlands and rural communities as well as cities and urban areas.

A total of 95 women took part in the online qualitative survey of which 64 women self-identified as having physical impairments, 22 women self-identified as experiencing mental distress 10 women identified as having autism, Asperger's or ADHD and 21 women self-identified as having a learning disability. Women were counted more than once, if they had a combination of impairments, for example, a learning disability and a physical impairment. Thus, the *total* number is lower than the sum of the disaggregated groups. The ranges in age of women who took part in the survey was from 18 to 78 where age was reported. Women with learning disabilities were often supported by advocacy or disabled people's organisations to complete the surveys and sometimes did so as

groups rather than as individuals. Where this is the case we have stated that they are group responses to survey questions by indicating the number of women represented in a particular response.

### **Focus groups**

While the survey aimed to capture and represent the experiences of the diversity of disabled women, surveys must be recognised as being exclusive in character. An easy read survey was developed to best include women with learning disabilities and who required accessibly formatted information, and this was done using easy read guidelines and photosymbols. However, focus groups with women with learning disabilities were undertaken to ensure that the voices of women with learning disabilities were included in a way that was accessible, to give women with learning disabilities the time and space to tell their stories in a safe and private environment with support (where needed and wanted). People with learning disabilities have faced a history of exclusion from social research due to the perception of people with learning disabilities being unable to articulate their thoughts, or to have reliable views (Stalker 1998). Inclusive research seeks to challenge these stigmatising histories by constructing accessible and participatory research methodologies that results in '*enabling greater involvement for people with learning difficulties in the research process*' (Chappell et al. 2001, 47 see also Walmsley & Johnson 2003). Inclusive participatory research is research that is undertaken in collaboration with people with learning disabilities rather than research undertaken on their behalf (Chappell 2000). We ensured that members of the advisory group with learning disabilities took part in formulating the research parameters and making sure all the information and research materials were inclusive and accessible.

For the focus groups we created topic cards that centred around the key themes of the research so that women in the focus groups could decide and prioritise which topics they wanted to talk about. These topics covered all aspect of reproductive experiences across the life course. Three focus groups took place across central Scotland, with 12 women with learning disabilities. Both researchers were present at the focus groups and facilitated group discussions, all participant groups had been contacted prior to the focus groups, we discussed the purpose of the research together and potential focus group participants had an opportunity to ask any questions that they had in relation to the research. Each focus group was comprised of four women, we deliberately kept the focus groups smaller so that women had the space to talk about personal and intimate topics. Each focus group lasted around an hour and were recorded using a digital recording device and then transcribed and coded. The focus groups proved a space in which women with learning disabilities were able to share and discuss their experiences in familiar spaces and participants fed back the empowering nature of discussing topics that they were so frequently excluded from throughout their lives.

### **Sensitive Research and Research Ethics**

Sensitive research forms an increasing part of social research (Liamputtong 2007) and while what can be defined as 'sensitive' research is contested, it can be understood as research that might have a focus on intimacies, private spaces and personal activities (De Laine 2000). Sensitive research can include 'sensitive' topics but can also denote the emotional impact that it has on the researcher as well as the research topic (Dickson-Swift et al. 2007). Liamputtong (2007) discusses sensitive research in relation to those who face inequalities and marginalisation and physical and social risk. While this research is sensitive in nature and required a reflexive (England 2004) approach to data collection and analysis, it does not presuppose or assume that disabled women



are in themselves inherently vulnerable. Rather the data shows that disabled women and women with learning disabilities have agency, autonomy, are aware of their rights and engage in social and political activities to ensure the realisation of these rights.

A sensitivity to the intimate aspects of this research underpinned all aspects of the ethical process. This project sought and achieved ethical approval from the University of Glasgow ethics committee. All participants have been given a pseudonym and have been anonymised fully in the presentation of the survey responses. We have not identified where a person has a physical disability, experiences mental distress or a learning disability. We acknowledge that disabled women are not a homogenous group and that disabled women experience particular barriers or inequality in relation to the impairments that they have or the social attitudes constructed around those impairments. Yet, many of our women identified themselves as having multiple impairments and too refined a descriptor here could have affected our pledge to anonymity.

All efforts were taken to ensure informed consent in the focus groups. Participants were given easy read accessible participant information sheets and consent forms and the beginning of every focus group was spent explaining the purpose of the research, the voluntary nature of participation, the protection of participants' identities and locations and answering any questions that participants had. Participants were reminded throughout each focus group that they were under no obligation to answer any questions that they were not comfortable or happy with or that we could take breaks or move on from any topics that they didn't want to speak about. Consent was discussed at the beginning, throughout and after the focus groups and participants were asked if they were happy for their narratives to be used throughout.

Where advocacy affiliations have been mentioned in the research reports they have been done with the consent and permission of the organisations and their members.

## **Data Analysis**

The survey data and focus group data has been analysed using a thematic analysis. The data were continuously read and reread in order to allow for the emergence of categories that could be grouped into themes (Charmaz 2006). Coding was not entirely emergent as some themes were already present due to the nature of the research and the research topic. Thematic analysis identifies patterns of data and allows for rich and flexible analysis which complements a feminist epistemology (Braun and Clarke 2006, 73 see also Ramazanoglu & Holland 2002). The themes were complex, and themes emerged from participants with learning disabilities that did not, or not in as much detail, from participants who did not have a learning disability. Similarly, the themes presented in the focus group section were structured differently due to the nature of the methodology and the intersubjective quality of focus groups.

## **Findings**

### **Survey Findings from disabled women**

While some of the survey findings are presented in the Engender Scotland policy document they may be repeated here to form the body of findings and rigorous expert analysis from the data collection and research with disabled women and. Survey responses were sent in anonymously and so have been presented anonymously in the following sections. However, it is crucial to emphasise



here the scope and breadth of survey responses; 95 women responded to the online or easy read survey.

## Parental Rights

### A Hidden Population

From the survey responses, it was evident that services supporting children, did not expect parents to have an impairment. Examples given included inaccessible classrooms at parents' night; inaccessible seating at parent's night (for example, the small chairs used by primary schools) and inaccessible assembly venues. Similarly, there were calls for accessibly baby changing facilities in public spaces.

This is compounded by a lack of narrative around help available for parents who face barriers. Many women said there was no information available and this translated into no support. While the following quote makes the point in the context of hidden impairments, the argument was made by women facing physical impairments, mental health barriers and learning disabilities:

*'Tell us three problems you have had.'*

1. *Little advice on pregnancy risks for me and a child.*
2. *No information on whether I'd receive support as a parent.*
3. *Gaining any help with support is made incredibly difficult because I have invisible illnesses, so all they see is a young fat girl complaining'* (Survey respondent)

This quote communicates the lack of dignity and respect felt by many of the women who responded to our survey. There are two possible causes for the issues outlined and both may be at play: firstly, information known that could help disabled women is not passed on to them in a timely and accessible manner; and secondly, service providers do not have this information available. If there are gaps in the knowledge base of our health and social care providers, then as these are having a substantial impact on disabled women, they should be addressed. Further service providers should be facilitated to exchange the knowledge available as many parents who responded were not aware of support available to manage parenting activities such as changing nappies and bathing their children which could be difficult due to chronic pain issues.

## Training and Education

### Health and Social Care

Impairment and ill-health are not synonymous. Some impairments are associated with health issues however, and these can be exacerbated by menstruation and contraceptive choices. Further the women who responded to our survey, did not feel they were given any guidance about the risks here, and how to mitigate against them:

*'Inform women how their impairment can be affected by periods, contraception and pregnancy'* (Survey respondent)

Many women felt that medical professionals had no idea about the relationship between their impairment, and the reproductive body. Yet, half (in most cases) of any population with a given impairment will be affected. This intersection is given little attention by medical practitioners and

women experienced having their real symptoms and concerns de-legitimised and dismissed. This was so systematic that it left many women feeling unable to access advice and support.

Q: *'What would make life better for disabled women?'*

*'Not being told constantly by, what are almost always, male professionals to just live with it or that I'm not worth treating further or don't need help and support'* (Survey respondent)

## Menstruation

*'Periods stopped right after accident, not taken seriously by docs, told 'one less thing to worry about'* (Survey respondent)

The dismissal of periods was universal over the interviews and focus groups. Menstruation appeared to be a taboo for care services, including, worryingly, medical services. Menstruation is important on several fundamental levels: it can be understood, by some, as an embodiment of womanhood and can be linked so socio-cultural identities of maturity and femininity; it is a process within reproductive experiences that should be understood in order to have 'control' over reproductive decisions; and equally, menstruation is a health barometer. Fluctuations in flow (heaviness and consistency), bleeding outside of menstruation, length of cycle, clotting cramping and mood could be indicators of poor health. Unless a woman is aware of this, and supported to relate menstruation to overall physical health, then they are unable to fully control, understand or respond to the health of their bodies. Other experiences moved to other extreme with women's bodies being 'explained' by their impairment and medical professionals missing other potential causes of pain.

*'GPs [should] offer info[rmation] and also not to assume that any medical problems (e.g. with period pains) are always linked to my impairment'* (Survey respondent)

In turn, women should be fully informed about the impact of therapies on their impairment, and their bodies more generally. Some women talked about how medication reduced their sex drive and called for more agency in deciding for themselves, whether this compromise was 'worth it'. Equally women didn't feel informed about the potential side-effects of contraception, particularly weight gain and migraines, or were not taken seriously when they asked GPs for a solution or alternative product.

Q: *'What would make life better for disabled women?'*

*'Professional arrogance when I know how contraception is affecting me, but professionals think they know best based on able bodies studies'* (Survey respondent)

Many women talked about education around periods being limited and while educational for some, missed some practical elements. For example, women would have liked more education about the types of sanitary product available including more non-invasive strategies such as period panties and apps that can track cycles. In turn, women asked for help purchasing sanitary products as the good ones tended to be expensive (including, more recently, menstrual underwear).

## Sex and Relationships Education

Sex education is traditionally delivered early in puberty at school, with some sessions being given to women only, contributing to the myth that menstruation should be hidden, and experiences of menstruation are only of concern to women.

*'Sex education is still woeful, with no attention paid to the needs of women who aren't straight, women with specific physical needs etc. We are taught from very early on to hate our bodies unless they happen to adhere to a very specific definition of perfection, and this has a knock-on effect on our sexual confidence. Education around all of these topics needs to move away from socially constructed defaults around age, sexuality, ability etc, etc'. (Survey respondent)*

Even if high quality sex education is delivered to all women (and men) at school, this will still allow some educational gaps to persist. For example, women with physical impairments may appreciate guidance on alternative sexual positions that those 'mainstreamed'. Further, their needs may change as they age. This may be true too for women who acquire an impairment, for example:

*'Sex painful after injury. Asked for advice. Told to google positions' (Survey respondent)*

The lack of accessible sex advice during the life course isolated many of the survey respondents. It also encouraged them to think that their barriers were personal and individual, seeking support from a general practitioner. In turn this perpetuates the idea that the body is at fault, rather than society not being inclusive. Solutions to this certainly include inclusive sex education. While given during puberty, sex education ought to cover the life course more than it currently does, and could normalise then sex and all bodies, rather than just sex and cis bodies. This would be inclusive as all women age, and many become more physically limited. It would give women who acquire an impairment some idea that there are resources 'out there' for advice and guidance. And more adequately meet the needs of women experiencing impairment during puberty, normalising their sexual bodies.

*'We should be listened to. We should be believed when we suggest how hormones are affecting us. A blanket one service fits all attitude is damaging to our mental wellbeing. More education on maintaining a healthy sex life with chronic pain, such as relationship counselling, position education, device suggestion. The realisation that we know our bodies better than a text book by medical professionals' (Survey respondent)*

A critical narrative has emerged in this section. One respondent, in her late teens, gave a more hopeful account:

*'Sexual education at my school was fairly inclusive, and my teacher was not afraid to encourage people to be open with their partners on what they could/did not want to do before sex' (Survey respondent)*

Of note is that sex was contextualised within building a healthy communicative relationship, and this is a significant departure from the responses of most women who, if they received any sex education, found it reductionist and clinical.

## **Reproductive, Sexual and Maternal Health Services**

*'I'm sorry to say that I can't think of anything [good experiences]! Everything, from contraceptive provision to access to safe abortion to representative education has been a fight' (Survey respondent)*

Many women felt that reproductive advice and support was poor and that medical practitioners were insensitive. There were multiple examples of women having to fight for services and claim their legitimacy:

*'Eventually (after I married!) I managed to access an appointment at a pre-pregnancy clinic to help me find out important info[rmation] about getting pregnant, what medication I should stay on, should try to reduce and what the impact on me and the child could be. I was initially told that this service didn't exist in my area but after much investigation and pushing from a Consultant It suddenly was available'* (Survey respondent)

And:

*'[Doctor] suggested I would not make a good parent, [I was] told, 'you struggle to look after yourself, never mind a child. [I] had only certain contraceptives offered because someone like me would 'forget' to take the pill'* (Survey respondent)

There were varied experiences as women encountered multiple healthcare providers:

*'I've had doctors who were fine with prescribing me the contraceptive pill and potentially being sexually active, making no comments on my disability (considering how I've had doctors scoff at this, I take that as a win). I have a partner who is open to discussing how my physical disability might affect sex. We need to be included and consulted. We're a large portion of the population, yet we're still forgotten about and are often left in the dark on these matters ... ableism is often at the centre of this'* (Survey respondent)

And some women shared good experiences, for example:

*'My GP in Aberdeen was brilliant. He really listened and understood that I knew what I needed. He didn't treat me like a child and said that I was an expert in my own needs. That gave me the confidence to be open with him.*

*Thank you, NHS, <3 Without you, my life would be hell'* (Survey respondent)

## **Practical Access**

Practical access to service providers is still an issue for disabled women and a number cited examples of sexual health clinics being inaccessible, or difficult to access. One woman was offered a clinical meeting in a public corridor because treatment rooms were inaccessible.

Parking was also cited as a major issue, with sexual health clinics being difficult to get to. This was a major issue for women, who had often been told by their GP that they didn't have the reproductive expertise to advise, and so women were left with no access to this service.

Related to this was better access in disabled bathrooms which didn't understand the inter-sectioning need of disabled women, for example, one respondent called for:

*'Better toilet facilities for changing pads/tampons'* (Survey respondent)

This would include the design of the space, design of the toilet and equipment in the space for example, a bin for sanitary waste and access to sanitary products (it's usual to find sanitary vending machines in public bathrooms). Even if the building is accessible, there was some concern the clinical space might not be:

Q: *'What would make life better for disabled women?'*

*'Accessible sexual health clinics – the clinic might be accessible but what about the actual examination – is there a hoist? Can the women have her legs supported?'* (Survey respondent)

As important are accessible clinical spaces for pre-natal appointments. Access can be understood in terms of the physical environment, but also in terms of attitudes:

*'Doctors/midwives were generally patronising during my prenatal care appointments and the clinics were generally inaccessible. People have bad attitudes towards disabled people having sex and becoming parents'* (Survey respondent)

This, together with a lack of information and role models compound to make some disabled women feel that they don't belong in these spaces. In turn when information is available, our respondents called for it in accessible formats. Electronic formats were popular as they could be converted to spoken word, enlarged or translated with minimal effort, as Mo said:

*'Resources could be emailed, or a link provided. Very simple, shouldn't cost anything and would make the world of difference'* (Survey respondent)

## Contraception

There is growing awareness that women who choose not to have a child can be problematized, not just by society, but by medical professionals. Making choices about their own bodies, seems to be viewed as 'presumptive' and this is true too for disabled women:

*'Disabled women should not be treated any differently when trying to access contraception and other treatments to prevent pregnancy. I have found as an autistic person with chronic pain that I would much rather adopt than experience pregnancy (if I ever decided that I did want children, which I currently do not).'*

*However, my GPs refuse to accept that I am adamant in my views and getting birth control to help with my periods was a long and painful struggle'* (Survey respondent)

It seems implausible that a request for contraception should be denied or delayed. Further negotiating someone's views on parenthood, other than, I don't want to get pregnant, seems invasive. Equally significant, some women felt contraception was forced up on them:

*'I recently had a doctor tell me it would be awful for me to be pregnant and tried to force birth control on me even though religiously this is not ok. I've also had doctors fail to refer me when my period was missing for a decade as they felt there was no merit in getting to the bottom of this when I was in my 20s!'* (Survey respondent)

## Violence Against Disabled Women

Violence takes many forms and we reject notions of a hierarchy of violence: all violence should be challenged. In asking what would make life better? One respondent answered, *'Help to say no'*. Another outlined one problem she had had:

*'A partner pressuring me for sex when I was too ill'* (Survey respondent)

And this was expressed in distressing terms:

*'Male partners' lack of awareness of the need for consent'* (Survey respondent)

Some women had experienced violence within their relationships:

*'As someone who was sexually assaulted, it has taken me time to get around to addressing my own issues with sex and trust. I think as well as the clinical side of things, females, esp[ecially] disabled females need more information on emotional wellbeing, what is appropriate behaviour of men, safeguarding if a man is behaving in a manner which could lead to harm and also how we deserve to be mothers as much as anyone else'* (Survey respondent)

The above survey respondent also revealed that she had not been given sex education at school, which should also include education around positive relationships. This is not to suggest that better education would have removed this risk, for that the perpetrator needed the education, but to say that there were several stories of women feeling unable to seek support as an adult and a better education earlier on, could have given them some idea on what services were available.

### **Access to Services**

This section closes with a quote that gave the research time reason to pause and consider as it encapsulates so many of our themes:

*'I have 4 amazing children, they range from 1 to 17. Well, where do I start? I've had support all my life from my family and my Mum has been a massive part. She has helped me throughout my life. I don't know what I will do without her. When I was pregnant with my older daughter, I got told I shouldn't have children and should be sterilised, not just from one, but from a few people. This hurt me a lot by my Mum stood by me and helped me through every negative comment that I got. Over the years I've had a good few [Social Workers], some have been OK but others, they just looked right through me as if I was invisible and throughout I feel they're placing a label on me. When myself and the kids' Dad broke up I got told my kids might be taken from me .... EM What!!!! What because I'm disabled so I can't look after my babies? I've been doing it since I was 16 and I'm sure Not letting ANYONE tell me what to do. This has to stop.'* (Survey respondent)

### **Survey Findings from Women with Learning Disabilities**

Easy read surveys were developed to make the surveys accessible to all disabled women. Some respondents with learning disabilities filled these surveys in as groups, with support at times, as such where responses represent more than one respondent this has been demonstrated.

### **Menstruation and Periods**

Women with learning disabilities identified periods and menstruation as being of key concern in their reproductive lives. This was consistently brought up in the section of the survey 'Tell us 3 problems you have had'. A group of four women with learning disabilities detailed their feelings about menstruation:

*'People didn't talk to me about what I needed [in managing menstruation]'*

*'I didn't understand about periods and what to expect' and 'I didn't know what to do [with the pads], how often to change them or where to put them'*



(4 respondents)

Not having adequate information about menstruation, why menstruation occurs or how it could be managed featured across all survey responses from women with learning disabilities:

*'When I took my period I didn't know what was happening. I panicked when I saw the blood as I didn't know what was going on'*

(Survey respondent)

*'Things were not spoken about when we were growing up. We didn't get told about sex, periods or pregnancy'*

(2 respondents)

However, participants did also report positive experiences of menstruation and information about menstruation and where these responses these were almost always where mothers had informed their daughters in meaningful ways about periods and how to manage them and understand what they are.

### **Sex and sexual health education**

Survey responses from women with learning disabilities on sex and sexual health education centred around a lack of accessible information or any information at all. Women who had attended special or segregated information reported that sexual health education was poor:

*'Some schools overlook the importance of sex education. Some people think we are not able to understand and learn. No time is taken to support us to understand'* (Survey respondent)

*'Not good sexual health information at school'* (Survey respondent)

And in response to *'what would make life better for disabled women'*:

*'More one-to-one support. I was sitting on my own in sex ed class and there was a lot of text and writing. The material was not accessible to me'* (4 respondents)

Sex education can be difficult to provide. Those experiencing puberty can be confused and embarrassed about their bodies, largely due to hormonal shifts, and so talking about them in a mixed group can be very difficult. While this is true for all, women with learning disabilities can benefit from help, to understand what the sessions are for, what they will learn, and how they should act, for example, should they ask questions?

*'I did not get the right sex education at school. It was difficult to understand what was being shared and there was no time given to help us with this. I didn't want to say that I didn't understand, especially with this, it was embarrassing'* (Survey respondent)

It is fundamentally important that women find these learning opportunities accessible, as the information goes beyond puberty, and covers reproduction and relationships more broadly. Women with a learning disability may need additional support:

*'[I needed] more one-to-one support. I was sitting on my own in sex ed[ucation] class and there was a lot of text and writing. The material was not accessible to me'* (Survey respondent)



And from another respondent:

*'Any written information should be easy read and using pictures if necessary'* (Survey respondent)

It seems obvious that this learning be made accessible, but it is often organised differently from the rest of a school curriculum and normal accessibility rules may well not be considered. The survey did not specifically ask where sex education had been dominated by heterosexual sex and relationships, though one participant did raise this issue:

*'[I want] more support for disabled people in terms of sexuality – bisexual, gay, transgender, lesbian. This doesn't always get brought up with disabled people. They may be scared to say'* (Survey respondent)

Normalising difference is a key function of education and sex education is a useful opportunity to embrace diversity. As notions of non-binary gender identities are becoming more normative, so sex education in school is developing, and it would be useful to know if this was inclusive of disabled people.

Younger respondents communicated sex education experiences that were accessible. Women talked of having time to chat through issues, weekly sessions that allowed them to think of questions ready for the next week, and easy-read formats to help them engage.

## Contraception

Women didn't feel like early engagement with medical practitioners around contraception helped fill in the gaps left by sex education. Limited time to discuss issues, and with some women feeling that they were not viewed as legitimate users of contraceptive medication, impacted on the women who responded to our survey:

*'When I went to the doctors to ask about contraception, I was not given the opportunity to explore the different options. I was told what one I should take. I wasn't encouraged to ask questions or supported to understand all my options. After taking the contraception, my periods stopped, and I didn't know what was happening as this had never happened before. I felt really anxious. I wasn't told the side effects of contraception'* (Survey respondent)

Women experienced serious neglect, with only a small minority feeling they were supported to make an informed decision around contraception. Many women were given contraceptives that stopped periods without asking for this, suggesting that the medical aim wasn't to stop the ability to get pregnant, but women's adult bodies. In turn, some women reported that they were not informed about alternative contraceptives such as condoms that are useful for also protecting against STDs.

## Relationships

Sex education, is optimally delivered within a context of building positive relationships and friendships. Its absence from many special schools historically, has contributed to a current situation where many women feel there are significant gaps in their sex education and also in their knowledge about relationships:

*'Because we did not get the chance to learn what friendships and relationship should be like, we can become vulnerable to harm'* (Survey respondent)

And so a failing in the past has real and sometimes urgent consequences for women in the present. Useful at this point to reiterate that this can be done well, and there were examples of women who felt that they were able to navigate adult relationships:

*'Good experience with sex – lots of boyfriends and they were all nice'* (Survey respondent)

Education around relationships was really valued by women of all ages. Having a learning disability can be isolating particularly if the woman does not work, as this can be a great source of social networks. Women spoke of having less chance to talk through issues and ask questions of peers, and so knowledge gaps are likely to be larger, and persist for longer.

## Parenting

A key theme within the survey responses was the tension between needing help and the consequences of feeling able to say that help was needed. Women felt that as soon as they requested help, then their parenting was scrutinised, and that this scrutiny included aspects of their parenting out with their original request for help:

*'Our parenting should not be judged more harshly than others'* (Survey respondent)

Several of the women were worried about asking for help around parenting activities, for example:

*'[I want to] feel safe enough to say that we are struggling, without the fear of our children being taken away'* (Survey respondent)

Often nondisabled others (mothers, partners) were used as verification. The disabled women's view of being a good parent was not reliable enough for social workers or health care practitioners, unless it was corroborated by someone else, and this further undermined the confidence of mothers. Survey respondents with a learning disability emphasised the need for more support and understanding in parenting, this was desired in the form of accessible information, consistency in supportive services and a recognition that women with learning disabilities have a right to retain and parent their children. The fear of, and experience of, the removal of children into permanent care was present in survey responses. Women with learning disabilities feared that their children would be removed from them on the basis of their having a learning disability. Respondents were fearful of social and health care services and of asking for support when needed.

## Pregnancy

As with the other respondents to this research, there were positive and negative experiences around pregnancy and early motherhood. There were many more negative than positive stories:

*'I had no preparation about what to expect with the scan and giving birth or to start learning about the support my baby would need after the birth. And I didn't know who to talk to about this. I think I was given a section because I was hysterical during the birth as I was so scared. Looking back if I had been given the right support I would have been calmer and there may have been no need to have a section'* (Survey respondent)

Becky's quote was chosen because it covers a lot of themes. Mothers tended to feel that they hadn't been well informed about what to expect during their pregnancy and labour. Women felt that this lack of information, impacted on the likelihood that they had a section. A few women felt blamed

for stressing out their babies during labour. Further research on experiences of pregnancy and labour are required to further unpack this significant issue.

### **Support and Social Workers**

Women who struggled with parenthood, as discussed, felt unfairly scrutinised, there are aspects of the system that exacerbate this:

*'Social workers need to be more understanding. Support should be in place before any crisis happens. They should learn to listen to the parent. Don't keep swapping social workers who all have different ways of working. Continuity – one person'* (Survey respondent)

For women with a learning disability, and particularly for women who also experience mental distress, the changes in social workers were problematic. Julie's child was taken into protective care when they were a toddler, and the above respondent reported having had no support before this decision was made. Asking for help, especially in a situation like this where the consequences of not having help are so traumatic, requires trust between a parent and their social worker and this cannot be established with frequent change or a lack of consistent and accessible information.

### **Sexual violence**

The survey did not specifically ask about the experience of violence. Where women responded on this issue, they chose to respond to a question on 'problems'. We do not know if the women who did not discuss violence had experienced it but chose not to disclose. There were a few examples of gender-based violence written into the surveys. One respondent said:

*'Forced to have sex against my will – rape – reported to police and dealt with. Person still lives near me'* (Survey respondent)

The methodological limitations of a survey are apparent here as this quote prompts many questions that we were unable to follow up. Disabled women can struggle to leave home, and struggle to leave their community. They rarely have the socio-economic capital to choose where or how they live. So when a violent episode happens within their community, that trauma can be reinforced by their home, local streets, and the places that should make them feel safe.

### **Focus Group Findings from Women with Learning Disabilities**

The focus groups were an opportunity for women with learning disabilities to speak in more detail and with more time to express their feelings and experiences. While the survey responses were given anonymously, the focus groups were undertaken by Phillippa Wiseman and Jo Ferrie with 12 women with learning disabilities across central Scotland. As such, participants in the focus groups have been given pseudonyms (in line with feminist and emancipatory research principles) to maintain their anonymity and their geographic locations have been removed.

### **Menstruation and Periods**

Commensurate with the survey responses women with learning disabilities talked about a lack of meaningful or accessible information about menstruation as girls and as adults. Participants spoke about the informal ways in which they were told about their menstruation when they first got their period with, usually mothers, telling them that they had *'I got told it was the change to yir body'* (Sue 40s) and *'I just got told, don't go near any men now you've got them, that's what I got told'*

(Eileen 40s). Phrases such as *'the change of life'*, *'you're a woman now'* and *'everybody gets them'* or *'stay away from boys'* were used to explain to participants what periods were. Participants also said that this was the kind of information given by family members and by nurses or medical health professionals.

When asked by Phillipa or Jo, 'did anyone explain what a period is or what it's for?' Participants unanimously said no, all 12 focus group participants felt they weren't told why they menstruated or what it was for. When asked if they now knew as adults they also unanimously said no. Some women gave examples of what they thought a period was for or what they were told it was for:

*'I thought it was getting' rid ae bad blood in yer body'* (Eileen 40s)

Or:

*'I was told it was eggs coming off and they fall down'* (Sally 40s – 50s)

*'See I did'nae know that'* [In response to Sally] (Enid 60s)

One of the oldest participants spoke about beginning menstruation in a hospital setting and described how she wasn't given any information about her periods by the staff in the hospital. Enid (60s) talked about her treatment by staff in the long-stay hospital:

*'I was only eleven and she [the nurse] slapped me in the jaw and said why are you running about like that [bleeding] and I says 'I don't know what to do how do I stop it?' and she said 'don't be so silly go and get something on' and I thought what do you mean 'go and get something on?' and she pulled my hair and she took me to the toilet and she says 'here you've to put that on you stupid girl' and nobody had taught me about my periods'*

A lack of clear, accessible and medically relevant information impacted negatively on women with learning disabilities, which had medical implications for them knowing about what was 'normal' or 'abnormal' bleeding, clotting and most importantly participants were not aware that their menstrual cycles were related to conception or pregnancy. Participants were routinely told to *'stay away from boys'* but never explicitly told that the onset of menstruation might mean that they were able to get pregnant. Some participants intimated that it was through the focus group discussion that they were learning that menstruation and pregnancy were linked. Participants were not given clear and accessible, or sometimes any, information in school about menstruation, about available menstrual products, how to use them or how often to change them. Most women used menstrual pads given to them by their mothers or by school nurses, or menstrual/sanitary belts. Some women were given advice as to which menstrual products to use by asking a chemist:

*'A just asked them in the chemist'* (Judith 40s)

Two participants spoke about good information and support that they'd been given by parents or sisters, Sally (40s) and Karen (50s – 60s) talked about feeling that they'd been given good support by parents to get sanitary products.

All group participants said that they would have benefitted from better and more targeted information on menstruation and menstrual health and would have liked the same information that other girls and women got:

*'I would have liked the nurse to say to me you're taking your periods and you're a woman now like you all got' (Enid 60s)*

The focus group responses on menstruation points to a lack of meaningful information given to girls and women with learning disabilities about menstruation, how to manage menstruation and the function of menstruation. This was true of informal information given by parents and family members, medical professionals and schools.

## **Contraception**

Focus group participants discussed information given about contraception and birth control and the kinds of birth control they used. Most participants had used or were continuing to use in-situ birth control such as the contraceptive implant or the contraceptive injection.

*P: Did you get information about contraception?*

*'Not really, I'd heard about it when I was older, but I was unsure' (Sally 40s)*

*P: Were you told about different kinds of contraception?*

*'Mhhhm, the implant' (Sally 40s)*

*'The depo' (Karen 50s)*

*'Sterilisation' (Enid 60s)*

*P: Did you choose that Enid?*

*'No I got married and I was wanting to have children but because my mum's children got taken off her I decided when I got married I'd go to the doctors and get sterilised. I didn't want to get pregnant because I was frightened of the social and I wasn't good at walking, I was frightened I could drop the wean [baby] and I would get accused of hurting the wean so I decided it would be best to get sterilised but I hated myself because I wanted a wean but I knew it wouldn't be possible. I don't know what I'd do if the social took it off me' (Enid 60s)*

## **Sexual health education and sex**

Focus group participants reported poor sexual health education and information about sex overall. Participants asked how they were told or informed about sex and sexual health. Participants had varied responses, some couldn't remember, some were told by their mothers and some were given no sexual health or sex education in school:

*'She [mum] just told me to use pro...what's it called? Protection, aye protection. Otherwise you'll get pregnant' (Judith 40s)*

*P: Did your parents ever talk to you about sex?*

*'No' (Eileen 40s)*

Participants talked about sexual health education at school and the kind of information and education that they were given, some participants reported not being given any formal sex education in school or they couldn't remember what they have been told. Many participants talked about parents or siblings being the sources from which they received information about sex:

*'My mum!' (Jane 50s)*

*'Yeah it was my sister that told me' (Karen 50s – 60s)*

*'I learned about sex when I came out the hospital' (Enid 60s)*

*P: How old were you when you came out of hospital?*

*'I was 23 and I learned it off a lady, I was put in a day centre and she was retiring, and I just got attached to her and I asked her about it because I wanted to keep safe and she taught me all about it' (Enid 60s)*

When participants were asked about what kind of information they would have liked they often responded that they would have liked information about sexually transmitted infections and about consent and safety:

*'I wanted information about sexual diseases' (Sally 40s)*

*'Yeah same here' (Karen 50s)*

*'It's about keeping safe, you don't know who's caught something cause it's when people sleep with each other they get it the reason I know about this is because I watched it on telly and especially prostitutes do that' (Enid 60s)*

Participants from another focus group discussed their experiences of sexual health education and mentioned television being a source of sexual health and sex information:

*'My mum didn't tell me about sex. I learned about it myself. I watched telly. They tried to keep me away from boys. She said, 'they're only after one thing' (Pamela 50s)*

*J: And did you understand what she meant by that?*

*'No. I found that out through watching the telly'. (Pamela 50s)*

*'When they were talking to you about sex [sex education in school] they weren't talking to you about being a parent, they were teaching you about not getting pregnant' (Mhegan 50s)*

Sexual health information was often reported as poor or inaccessible. Participants got some information from parents but often this didn't include robust information about health, sexually transmitted infections, contraception or consent. Similarly, women felt they received poor information about routine reproductive health screenings such as smear tests or reproductive and breast cancers. Some of the women were involved in receiving training so that they could pass information on to other women with learning disabilities, although they did report that this should come from health professionals more routinely.

## **Menopause**

Like menstruation most participants felt they knew very little about menopause, what to expect or what it was despite several women being of menopausal age:

*P: How did you learn about menopause?*

*'Am no being funny, I don't even know what that is' (Sue 40s)*

*'Aye, it's when you're cold and then you go hot'* (Jane 50s)

*'Cold flushes and hot flushes'* (Sue 50s)

*P: Have any of you ever been told what it's for?*

*'Nup'* (Sue 50s)

*'Cause you're gettin' older, getting near fifty'* (Jane 50s)

The participants represented in the above discussion indicated that they wanted more information on menopause and that it was something they wanted to know about:

*'Aye, it'd be good for us tae have some'dy in talkin' to us about this'* (Sue 50s)

*'Some people don't understand properly, it'd be easier'* (Eileen 40s)

Participants in this discussion went on to talk about information given to them by medical health professionals and that they felt that their doctors weren't good at giving them information in a way that they understood or taking the time to explain information:

*'They dinnae explain nothin', I don't know about anybody else's but mine can't get me in the room quick enough, so he can get me out'* (Sue 40s)

*'Right, prescription and away ye go!'* (Jane 50s)

Participants from another focus group discussed their feelings about information on menopause:

*'Parents don't want to tell you stuff like [information about menopause], because they don't think you can understand. It's better for them? If they hide it away from you. They should be talking to me about it, to let me understand more. Because then you'd understand what is happening to you if you go all hot or sweaty or go in a mood. You know?'* (Jill 50s)

Overall participants in focus groups felt they received poor or no information about menopause, its health implications, symptoms or how to manage it. They felt that doctors weren't available to give information in an accessible way or to spend time with participants to inform them of reproductive health concerns that impacted on them. All of the three focus groups decided that they wanted to organise for a learning disability or specialist nurse to speak to them about menopause.

## **Pregnancy and Parenting**

Pregnancy and parenting were the most significant areas in which women with learning disabilities who participated in the focus groups felt they experienced inequality, a lack of information and discrimination. Echoing the survey responses, participants felt that they were given poor information on pregnancy, ante/postnatal information or accessible or meaningful information about how to manage having a baby.

Participants spoke about not being given helpful information by doctors:

*'Well when I went to see what was goin' on the doctor jus says to me 'well yer pregnant' and a went well is that all you're tellin' me? Can you no tell me a wee bit more?'* (Sue 50s)

Some participants reported negative experiences of giving birth:



*'I was having contractions and they left me, they kept giving me gas and air, but I was in that much pain and they weren't very helpful. I didn't know what was happening. My boy, because they whipped him out that fast, they put him in an incubator, and that was hard, because I got put to sleep and I didn't get to see him. He was stressed and I was stressed. They should have explained more, about what was going to happen'* (Alice 40s)

Participants discussed the need for better and more accessible information around pregnancy and birth including pain relief options, birth and delivery options and accessible easy read information for mothers with learning disabilities.

Parenting was a crucial topic for participants and discussions in focus groups overwhelmingly centred around fear of children being removed, the removal of children of women with learning disabilities into care, participants' children being adopted and the role of social workers and social services in their lives. All participants felt that women with learning disabilities are not given enough support to parent their children, they felt that they were not given enough information and that they felt it was inevitable that their children would be removed from their care. Of the seven women who had children in the focus groups, only two participants had retained the care of their children although they did feel that this had been threatened and questioned at various points:

*P: Do you feel there's barrier for women with learning disabilities being parents?*

*'Especially if social work are involved mhmm because they says I wis'nae a fit mother and his mum and dad were always say'n that I wis'nae a fit mother as well'* (Sue 50s)

*P: Do you think that's to do with having a learning disability... That they said that?*

*'Aye, I think so but it should'nae be any different for me'* (Sue 50s)

*'That's social work play'n it eh! (unclear) with people that's got learnin' disabilities'* (Eileen 40s)

*P: Can you explain a wee bit more?*

*'They just play'n it, they jus' say you're no fit tae look after your kids cause you've got a learnin' disability'* (Eileen 40s)

*J: Did any of you feel you got support from social work?*

All: (Laugh) ... *'you having a laugh?'* (unclear who speaker is)

*'Sometimes wit they do is they take the kids off you tae gi' ye help... 'cause I've had that experience eh'* (Eileen 40s)

*P: So, they remove the kids and give you help?*

*'No! They don't give you any help. They remove the kids and don't give you help at all'* (Eileen 40s)

A participant in another group discussed the threat of having her child removed:

*'Social worker said I wasn't fit to look after [son]. I lost my Nan and I lost my Ma, and then they started with the 'you're not fit enough'. I won my case with them. It was a scary thing. Because you never think for a minute that your weans can be taken off you. It's a bad situation. To have your weans taken, and you don't know where they've been taken? No. That's a bad situation'* (Alice 40s)

Participants grew increasingly upset during discussions about their children who had been taken into care and unanimously discussed the importance of support being given to women with learning disabilities to parent their children themselves and for their children to stay with them. They felt that they were unable to engage fully with social services because they didn't have appropriate support or have information in accessible formats. They felt unable to challenge assessments made about their parenting abilities; Judith said people with learning disabilities would have better experiences of social services:

*'if they would listen to people that's got learning difficulties and give you help' (40s).*

## **Sexual Violence**

Women with learning disabilities overwhelmingly reported experiences of sexual and intimate partner violence in institutional settings and by partners in home settings, participants also reported violence perpetrated by family members. Some participants reported rape and others reported physical and emotional violence by partners. In one of the focus groups when participants were discussing consent Sue (50s) reported being forced into having sex by a partner:

*'I got forced into it' (Sue 50s)*

*'Aye same, when I fell pregnant with my oldest they said they were going to get rid of it for me, that he would punch me' (Judith 40s)*

In another focus group participants intimated that they didn't feel like they always had a choice about whether to have sex or not:

*'[Men] though, they think because you've got a learning disability, that you're easy. That they can take advantage' (Mhegan 40s)*

Another participant talked about their experience of sexual violence by staff in institutional setting but didn't feel they wanted quotes to be used directly. While few direct quotes have been presented here, violence was an overwhelmingly common experience for women with learning disabilities who participated in the focus groups. They felt that their being seen to be an 'easy target' and not having been given good information about sex and relationships made them feel vulnerable in sexual situations. However, some participants were active in engaging and working with gender-based violence organisations in Scotland to train them in supporting women with learning disabilities. The disproportionate levels of violence experienced by women with learning disabilities and the consequences that this has for women's lives requires response from social and health care services. Research evidences that while nondisabled women's experiences of sexual and gender-based violence are routinely articulated by services and in social discourse as rape, while disabled women's experiences of sexual and gender-based violence are affirmed as 'abuse' (see Hollomotz 1999 and 2009). The use of differing language dehumanises the experiences of disabled women and perpetuates the assumption of lower social status. Commensurate language and responses (in law, by health and social care services and counselling services) should be used to reflect the fact that disabled women face equally brutal and negative consequences as nondisabled women (Hollomotz 1999, 102).

## **Summary of Findings**

The findings reported in this document reflect the wider findings reported in the accompanying policy document. Survey participants and focus group participants overwhelmingly reported

significant inequalities in reproductive health and rights. Disabled women understood themselves to be rights holders and that they should receive equal treatment. The survey data and focus group findings reveal that while some women did receive good and accessible reproductive and sexual health information, and some had good experiences, these were rare and often came from informal sources such as family members or support workers, however while it was positive that information was received it was rarely comprehensive.

Participants mainly discussed their exclusion from robust and routine information about sex, relationships, menstruation, health, menopause, pregnancy and parenting. The findings reveal that most of the inequalities and experiences documented in research over twenty years ago are still relevant now and have not been adequately addressed. The implications that these inequalities have on disabled women's health and wellbeing is pervasive; participants discussed poor relationships with medical health professionals and social care professionals and a lack of knowledge about their bodies and reproductive experiences. They often felt ignored or not listened to by the services that they interacted with and wanted better and more accessible information for disabled girls, in school, and as adult women. The fear of and experiences of having children removed caused anxiety, distress and worry for women and women with learning disabilities disproportionately experienced involvement with social workers and the removal of their children, permanently, in to care or in to adoptive families. This reinforces wider discriminatory social discourses around women with learning disabilities' capabilities and their status as mothers and carers.

Clear recommendations have been made, commensurate with the findings, in the Engender Scotland policy document. The findings from the qualitative research evidence a need for the rights of disabled women and girls, laid out in international and national equalities and human rights legislation, to be better implemented in health and social care services and practice, in education policy and practice and in the supportive services that work with disabled women in Scotland. As emphasised at the beginning of this report, disabled women have an equal and legal right to reproductive health and equality, to have and parent children and to make decisions and have choices over their reproductive experiences. To deny this is to deny disabled women their human rights, their humanity and their health and wellbeing. Systematic social and attitudinal change is needed to address the entrenched and institutionalised disablism that disabled women face. Crucially, disabled women need to be recognised as experts in their own lives and consulted about their needs to ensure equality in health and reproductive experiences and to affirm the equal status of disabled women in society.

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