ENGENDER

OUR BODIES, OUR RIGHTS:

Identifying and removing barriers to disabled women's reproductive rights in Scotland

Inclusion Scotland
Disabled People's Organisation
Our voices ▪ Our choices

People First
(Scotland)

CONTENTS

"For women with disabilities, disability inclusion and gender equality cannot be achieved without addressing their sexual and reproductive health and rights."

UN Special Rapporteur on the Rights of Persons with Disabilities, 2017.[1]

"Because I have a disability people felt I didn't have a right to a sex life. They made me feel self-conscious. I felt I had a right – we all have a right to be treated the same."

Survey response from a woman with a learning disability, 2018.

Image provided by CHANGE (changepeople.org) with our thanks

DISABLED WOMEN'S REPRODUCTIVE RIGHTS IN SCOTLAND

There has been very little systematic research into disabled women's reproductive rights in Scotland. However, qualitative evidence gathered by Engender over a number of years suggested to us that their reproductive, sexual and maternal health was being overlooked by the very systems and services that should have been enabling their wellbeing.

TERMINOLOGY

Engender, along with disabled people's organisations in Scotland, use the term 'disabled women' rather than 'women with disabilities' as we recognise that it is the failure of society to remove barriers to participation which makes someone disabled. We use the term impairments rather than disabilities to describe conditions, illnesses and injuries which affect disabled people.

Where we are quoting from surveys or focus groups, we have used the language provided by the person we are quoting.

In Engender's regular engagement and consultation with women across Scotland, the discrimination faced by disabled women and girls regarding their reproductive, sexual and parental rights has emerged as a key theme. Women spoke to us of fears of children being removed into care due to stigma and stereotyping, and we heard stories of forced sterilisations and terminations, failures of maternity services, and pervasive violence. All of these issues have deep and damaging impacts on the lives of disabled women and girls.

So since 2013, Engender has been working with disabled women and disabled people's organisations on a project to discuss the key issues facing women and girls in Scotland, and to enable a deeper and richer conversation about reproductive rights.

[1] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities

The overall aims of this project, as determined by the project advisory group, were:

- to find out more about disabled women's experiences of reproductive and parenting services
- to find out what difficulties disabled women have in using services
- to find out what good experiences disabled women have in using services
- to find out when disabled women feel they are treated badly because they are disabled
- to share what we have learned with health and social care professionals and policy-makers to help them improve services
- to share the views and experiences of disabled women.

In order to find out this information, the project ran consultation events, surveys and workshops, and focus groups, as well as doing research on relevant academic papers, similar projects which have taken place, and current Government strategies, frameworks and standards. This report summarises what women have told us about their experiences of reproductive, sexual and parental rights, and makes recommendations to the Scottish Government and other bodies. Throughout the report you will see quotes from women who took part in project activities.

> *"I think disabled women need more support from the NHS and social care to look after their bodies and to parent their children. Society needs to be more open about disability and sex."*
>
> **Anonymous survey response**

Our key finding is that women's reproductive, sexual and parental rights are being undermined by systems. Gaps in enjoyment of rights are due to lack of knowledge, embedded stigma, and a huge gap in quality and accessible services within Scotland's social care, child protection, education, and healthcare systems. We also found that women with multiple impairments, and disabled women from other marginalised groups (including BME, LGBT, refugee, asylum-seeking, migrant, minority faith, younger, older, care-experienced, rural and low-income women) are all likely to face additional barriers to accessing their reproductive, sexual and parental rights.

STIGMA AND STEREOTYPING

Culturally ingrained stereotyping and negative assumptions about disabled women play a huge role in the systemic failure to protect their reproductive rights. It is often assumed that disabled women and girls do not need to access to information or services regarding their reproductive and sexual health. Misconceptions about their

needs, intentions and capacities regarding sex, relationships and motherhood influence the actions of families, service providers and legal representatives, and perpetuate stereotypes that lead to lack of autonomy and the breach of a wide range of human rights.

> *"There should be more acceptance that disabled people have sex. Disabled people have the same feelings as everyone else."*
>
> **Survey response from a person with a learning disability**

The extent to which this stereotyping of disabled women underpins negative outcomes is overwhelming.[2] In this report we explore this key theme in terms of parental rights, training and education, health and social care services, and violence against disabled women. We make recommendations in each of these areas. The actions needed from decision makers and service providers to erode stigma as a barrier to good reproductive health for disabled women must also be linked to wider initiatives regarding disability rights.

HUMAN RIGHTS

The Scottish Government is obligated to respect, protect and fulfil rights related to the sexual and reproductive health of disabled women and girls under various UN human rights treaties and Article 8 of the Human Rights Act.[3] Amongst others, the rights to life, health, privacy, education and family life all squarely relate to women's reproductive and sexual health.

Particularly relevant articles and commentary include:

- Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD), under which disabled people have the right to gender-sensitive sexual and reproductive health services of the same range, quality and affordability as non-disabled people
- Article 16 of the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW), under which all women have the right to freely decide the number and spacing of children, and to information and means to enable this
- General Comment No. 22 from the Committee on Economic, Social and Cultural Rights, which states that barriers to contraception and abortion, and lack of accessible reproductive and sexual health services violate the right to health[4]

[2] Engender engagement events with disabled women 2013-18
[3] Article 8 Human Rights Act 1998
[4] Economic and Social Council (2016) General Comment No. 22 on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)

- CEDAW Committee General Recommendation No. 24, which recommends special measures to ensure that disabled women have equal access to reproductive healthcare services.[5]

Nearly all relevant Scottish Government policy frameworks, however, make no or very little reference to disabled people's sexual and reproductive health. They are also almost entirely **GENDER BLIND**. Reproductive and sexual health are not mentioned in its key strategy for disabled people, which is explicitly geared towards delivering the rights articulated in the CRPD.

GENDER BLIND

Gender blind projects, programmes, policies and attitudes do not take into account the diverse needs of different genders, and therefore cannot challenge gender inequality.

A key principle of both reproductive and disability rights is that individuals are able to exercise autonomy and freely make decisions about their own lives. As set out in respective sections of this report, this hinges on access to quality and accessible social care, education and health services for disabled women and girls. At present, however, the lack of policy direction and integrated gender analysis on disabled women's reproductive rights is reflected in negligible support and outcomes that can be devastating to women's lives.

A note on this paper

Please note that this is a scoping paper that touches on numerous policy areas in which Engender has not undertaken extensive policy work. Many issues raised during the project and referenced here are therefore not explored in detail. Rather, our intention is to indicate the extent and breadth of these issues and to highlight the lack of needed knowledge and action regarding disabled women's reproductive, sexual and maternal health in Scotland.

Many thanks to the many disabled women, practitioners, advocates and third sector colleagues who have contributed to our discussion events and the findings of this report.

[5] Division for the advancement of women (1999) CEDAW General Recommendation No.24: Article 12 of the Convention (Women and Health)

PARENTAL RIGHTS

This section explores issues that disabled women face in the area of parental rights.

IT EXAMINES:

- the lack of data which exists around experiences of disabled parents
- issues facing disabled parents whose children are taken into care
- the failure of Scottish Government frameworks to take into account disabled parents.

AND RECOMMENDS:

Scottish Government, care and child protection agencies should work together to:

- Establish the number of disabled parents in Scotland and disaggregate data collection by gender and by impairments
- Commission gendered research into disabled parents' experiences, including for those who are not in contact with social care services
- Ensure that refreshed national parenting, child protection and disability rights policy explicitly addresses the support needs and contexts of disabled mothers
- Collect and publish gender-disaggregated data on parental disability when referrals are made to the Children's Hearing System on grounds of 'lack of parental care'
- Explore statutory underpinning for the good practice guidelines for supporting learning disabled parents, and integrate them across wider parenting, social care and child protection frameworks
- Review the Mental Health and Care (Scotland) Act (2003) and remove learning disabled people from the definition of people with a mental disorder.

PARENTAL RIGHTS

Disabled women in Scotland report feeling routinely subject to unfair scrutiny and judgement regarding parenting.[6] This is largely due to negative assumptions about their ability to cope from service providers, relating to both practical tasks and cognitive and emotional skills. Learning disabled women are faced with particular forms of discrimination as potential parents and during parenthood, and are extremely vulnerable to abusive practices that breach disabled women's reproductive rights (see later chapters).

Many challenges faced by disabled women are a direct result of inaccessible approaches within service provision, and can be overcome with appropriate parenting support. However, ingrained responses from service providers, institutionalised discrimination, and lack of support structures lead to disabled women's children being referred to the child protection system and unnecessarily placed in state care.[7]

There is no readily available research or data regarding disabled women and their experiences of social care or child protection systems in Scotland. There is a small amount of related information and media coverage from England, but this is mostly dated and contains very little gender analysis.
The information set out below is therefore intended to indicate both the scale and lack of clarity surrounding parenting support issues for disabled women, and the need for related policy focus in Scotland.

> *"I did not get any support throughout my pregnancy. I was really worried and anxious the whole time I was pregnant as I didn't know anything about what was going to happen with the birth... I had no support about what to expect in child birth. I ended up getting a section but I had never heard of a section before this and I didn't know what it was. 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.*
>
> *When my baby was born he had to go into an incubator. Although he was a healthy weight the doctors told me the reason for this was because he was so uptight with all the stress coming from me."*
>
> **Survey response from member of People First Women's Group.**

[6] Engender engagement events with disabled women 2013-18
[7] National Centre for Disabled Parents (2004) They said what? Some common myths about disabled parents and community care legislation

Disabled parents: a hidden population

The number of disabled parents in Scotland and the UK is unknown. Given the lack of dedicated statistics, very limited research has extrapolated information from population surveys aimed at other purposes.[8]

- In 2006, the Social Care Institute for Excellence used Labour Force Survey figures to estimate there were around 1.7 million disabled parents in England, Scotland and Wales[9]
- A Labour Force Survey from 2005 estimated that 15% of parents experience a disability when their children are still minors[10]
- In 2008, researchers at Bristol University estimated that there were 53,000 parents with a learning disability in England.[11] Another study from 1997 found that there could be 250,000 parents with learning difficulties known to health and social services agencies in the UK[12]
- Most recent statistics regarding disability demographics published by UK Government (Disability Prevalence 2011/12 and Family Resources Survey 2016/17) and Scottish Government (2011 Census and Scottish Health Survey 2016) do not include information about disabled people as parents
- Scottish Government's 2013 Disability Evidence Review does not consider parenthood.[13]

> *"I never got much support with parenting. I just had to get on with it myself, and got some help from my mum. I didn't get the guidance I needed and felt miserable. I didn't get any sex education – I was at a special school. Once I got married it was an eye opener. I was then abused verbally and mentally. I never knew anything about contraception. I didn't intend to get pregnant."*
>
> **Survey response from a disabled mother.**

The Scottish Commission for Learning Disability (SCLD) concludes that this data gap is likely to have a negative impact on the availability and breadth of parenting support services.[14] In line with what we have been repeatedly told by disabled

[8] Olsen and Wates (2003) Disabled parents – examining research assumptions
[9] Social Care Institute for Excellence (2006) Supporting disabled parents and parents with additional support needs
[10] Carvalho (2013) Parenting and disability
[11] Bristol University (2008) Facts and figures about parents with learning disabilities in England
[12] McGaw (1997) Practical support for parents with learning disabilities
[13] Scottish Government (2013) Scottish Government equality outcomes: disability evidence review
[14] Scottish Commission for Learning Disability (2016) Supporting parents with learning disabilities in Scotland: challenges and opportunities

women,[15] this conclusion can be broadened to the population of disabled parents more broadly.

Disabled parents are described by researchers and advocates as an invisible or hidden population, and services as suffering from a "yawning support gap".[16] Almost nothing is known about the needs and experiences of disabled parents who are not in contact with social care services. In turn, gender issues are hidden within the majority of work that has been undertaken to examine and support disabled parents. The need to understand disabled mother's experiences is therefore urgent.

Furthermore, it is likely that women with multiple impairments, and disabled women from other marginalised communities will face additional embedded discrimination and experience multiple disadvantage and stigma with regards to their parental rights.

Data related to disabled parenting and child protection is even scarcer. Again, however, qualitative evidence from disabled women and a small amount of dated research tell us that stigma, and minimal direction and support for practitioners, lead to children of disabled women being taken into care.

- The English National Survey of Adults with Learning Disabilities, 2003/04 showed that 60% of mothers (who were living alone or with a partner) did not live with their children of under 18 years of age[17]
- Parents with learning disabilities are up to 50 times more likely to have their children removed from them and placed in care[18]
- A study from 2005 showed wide variation between English local authority areas regarding care proceedings involving learning disabled parents[19]
- High profile child protection case law includes women who have suffered from stroke, visual impairment and mild learning disabilities[20]
- There is no data to be found regarding women with physical and sensory impairments and child protection systems in Scotland or the UK.

Media coverage and literature highlight cases whereby children have been pre-emptively placed in care solely on the basis of their mother's disability, despite no evidence of neglect, abuse or parental incompetence.[21] In line with this, orders

[15] Engender engagement events with disabled women 2013-18
[16] Research in Practice (2003) Disabled Parents – examining research assumptions; Booth (2000) Parents with learning difficulties, child protection and the courts
[17] Bristol University (2008) Facts and figures about parents with learning disabilities in England
[18] The Baring Foundation (2006) Finding the right support? A review of issues and positive practice in supporting parents with learning disabilities and their children
[19] Booth et al. (2005) Care proceedings and parents with learning difficulties
[20] Carvalho (2013) Parenting and disability
[21] Quarmby (2011) Scapegoat: why are we failing disabled people

removing children from disabled mothers have subsequently been overturned on grounds that include infringement of the right to family life, lack of fair assessment, and discrimination under the Equality Act.[22] More commonly, however, mothers are separated from their children because courts do not recognise that women lack appropriate infrastructure and support.

In the context of austerity, public sector cuts and lack of access to legal aid, independent advocacy and other support services are likely to act as further barriers to justice for disabled mothers.[23]

All of this demonstrates the need for a targeted focus to uncover the extent to which disabled women's parental rights are breached in Scotland and to tackle the driving causes in policy and practice.

> *"My child was removed because of my mental health. Now looked after permanently. Had no support to keep my child, or I could still have my child with me. I had problems with social workers – I really struggle to communicate and put my point forward to them. Need help to do this."*
>
> **Survey response from a woman with learning disabilities.**

Scottish Government legislative and policy frameworks

Many relevant Scottish Government policy frameworks make no or very little reference to disabled parents. Astonishingly, neither the Scottish Government's Disability Delivery Plan[24] nor National Parenting Strategy[25] address disabled parenting. The latter, which is focused on outcomes for children, includes one brief reference to consultation with parents who have support needs of their own, but no mention of what they said. The Pregnancy and Parenthood in Young People Strategy is aimed at supporting young parents, and commits to commission research on the support needed by particular groups, including young disabled people.[26] However, details on this are yet to emerge. 'Getting it right for every child' (GIRFEC), Scotland's overarching framework to improving outcomes for children, includes a focus on preventative action and flexible support tailored to the needs of families, but GIRFEC policy documents do not address parental disability.[27]

[22] Carvalho (2013) Parenting and disability
[23] Community care: http://www.communitycare.co.uk/2011/09/23/supporting-learning-disabled-parents-to-keep-their-children/ (accessed 24/7/18)
[24] Scottish Government (2016) A fairer Scotland for disabled people
[25] Scottish Government (2012) National parenting strategy: Making a positive difference to children and young people through parenting
[26] Scottish Government (2016) Pregnancy and parenthood in young people strategy
[27] Scottish Government 'GIRFEC' webpages: https://www.gov.scot/Topics/People/Young-People/gettingitright (accessed 24/7/18)

The National Guidance for Child Protection in Scotland stipulates that Child Protection Committees must link with learning disability services, and that adult services for disabled people should take stock of children's needs. The section on disability as an indicator of risk does recommend full assessment of the support needed by disabled carers to fulfil their parenting responsibilities, and notes that joint working between specialist disability and child protection services will be required. However, its 'key messages for practice' focus exclusively on disabled children.[28] Disabled mothers tell us that it is precisely this lack of joined-up working that causes significant problems to develop.

In Scotland, the primary ground for referral to the Children's Hearing System is 'lack of parental care', but further breakdown is not publicly available. In 2015/16, 13,688 children and young people were referred to the Children's Reporter[29] on non-offence grounds under section 67 of the Children's Hearings (Scotland) Act 2011. Of these cases, 5,606 were due to lack of parental care.[30] This data was collected individually from local authorities for the purposes of this report. There is no information about parental disability within the statistical analysis released.

Framework for learning disabled parents

The Scottish Government's national learning disability strategy does, however, consider the support needs of disabled parents.[31] It recognises that disproportionate numbers of learning disabled parents have their children removed, and that the right of a child not to be separated from their parents on the basis of disability (under Article 23 of CRPD)[32] is sometimes not upheld. Unfortunately, however, it does not indicate how this is known, nor the extent of the problem. It finds that implementation of the Scottish Good Practice Guidelines "is at best patchy" and recommends access to local supported parenting services for all parents with learning disabilities by 2014.[33] Disabled women in Scotland confirm that this has not yet been achieved.[34]

The updated Good Practice guidelines reiterate that children have "the right to receive the necessary support to remain living with their parents, wherever possible", that outcomes for children are better when they are within their own families where

[28] Scottish Government (2010) National Guidance for Child Protection in Scotland
[29] The Scottish Children's Reporter Administration (SCRA)
[30] Scottish Children's Reporter (2016) Statistical Analysis 2015/16
[31] Scottish Government (2013) The keys to life: improving quality of life for people with learning disabilities
[32] The UN Convention on the Rights of Persons with Disabilities
[33] "Scottish Government Task Group is currently looking to examine the numbers of parents with learning disabilities whose children are removed from their care. There are significant challenges with data collection in this area including parents not being identified as having a learning disability and data on parental learning disability not being collected. The report 'Supporting Parents with Learning Disabilities in Scotland: Challenges and Opportunities' gives an overview of the landscape of services for parents with learning disabilities in Scotland and challenges with data collection. https://www.scld.org.uk/wp-content/uploads/2016/11/Parenting-Report-FINAL-14.11.16.pdf
[34] Engender engagement events with disabled women 2013-18

that can be achieved, and that support should therefore be aimed at keeping families together, including when child protection measures are needed.[35] They stress the need for multi-agency working, and set out why adult and children's services, and health and social services should improve co-ordination and communication to prevent children being removed into care.

> *"We are treated like children, it's almost as if we are not expected to have a relationship."*
>
> **Survey response from member of People First Women's Group.**

However, none of this is reflected in other Scottish Government parenting, child protection and disability rights policy, and is underrepresented across care sector regulatory and practice frameworks. Nor do respective strategy, policy and guidance documents on learning disability take account of gender equality or women's experiences of accessing services and support.

It is therefore entirely unsurprising that disabled women and practitioners tell us that major problems persist. There is a clear need to ensure that parents with physical and sensory impairments are adequately supported in parenting roles, and that existing policy and guidelines for learning disabled parents are fully implemented.

[35] Scottish Consortium for Learning Disability (2015) Supported Parenting: Refreshed Scottish good practice guidelines for supporting parents with a learning disability

TRAINING AND EDUCATION

This section explores how training and education should better cater for disabled women and girls.

IT EXAMINES:

- the detrimental impact of stereotyping and assumptions made by social care, health and education professionals and carers
- the importance of comprehensive and accessible sex and relationship education which has a strong gender analysis
- the way in which disabled women facing multiple barriers to equality are further discriminated against in sex and relationship education.

AND RECOMMENDS:

Scottish Government, health boards, integrated joint boards, local authorities and professional and regulatory bodies across health, care and education sectors should work together to:

- Develop and deliver continuing intersectional and co-designed professional development (CPD) programmes on disabled women's reproductive, parental, sexual and maternal health and rights for:
  - Trainees and practitioners in health and social care services, including social workers and workers in residential care settings
  - Trainee, newly qualified and practising teachers with regard to delivery of RSHP
- Create best practice guidelines, including a guide to standard pathways, for service providers regarding disabled women's sexual, reproductive and maternal health
- Create a central resource bank for social workers, social care practitioners and frontline staff including easy-read texts, to support informed decision-making around sexual, reproductive and maternal health

- Provide support and resources similar to those given to social care staff for parents and unpaid carers of disabled women and girls regarding their sexual and reproductive health, and parental rights
- Work with the Health and Social Care Alliance to improve promotion and awareness of health and wellbeing information tools such as ALISS.

Scottish Government, Education Scotland and local authorities should work together to:

- Introduce mandatory, age-appropriate, and inclusive Relationships, Sexual Health and Parenthood education (RSHP) in school curricula, using resources designed in collaboration with disabled women and girls
- Undertake an intersectional development programme on the reproductive and sexual health needs of young women, girls and disabled students
- Create national standards for RSHP that explicitly meet the needs of disabled women and girls
- Create a central resource bank of accessible and gendered resources for use in RSHP by teachers and students with additional support needs
- Create a national network of RHSP workers specialising in disability who can share good practice across Scotland.

TRAINING AND EDUCATION

Lack of knowledge and access to information acts as a barrier to disabled women's reproductive rights in two key ways. Training, guidance and support for professionals within social care, health and education services, and for family members and others who support disabled people, is extremely thin on the ground. This has resulted in a huge knowledge gap that underpins many of the issues outlined elsewhere in this report regarding disabled women's reproductive, sexual and maternal health. Secondly, access to inclusive and targeted sex and relationships education for disabled young women and girls is also almost entirely absent from mainstream and specialist education, with devastating implications for disabled women.

Service providers and carers

False assumptions and stereotyping regarding disabled women's sexuality, and desire and capacity to have intimate relationships and/or children are routinely made by practitioners and carers.[36] Disabled women have similar patterns of sexual behaviour as their peers, but often lack autonomy and privacy with regard to sex and relationships.[37] This means that their sexuality, gender identity and gender expression are often denied or heavily restricted. Young and learning disabled women are particularly affected by this lack of autonomy.

> *"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."*
>
> **Anonymous survey response.**

All of this is echoed in a recent report by the Scottish Commission for Learning Disability (SCLD), on empowerment through education and the experiences of learning disabled people in Scotland. It identifies training for families and professionals as a key action to overcome existing barriers to safe and healthy relationships. Likewise, disabled women and practitioners point to lack of knowledge and resources as a critical barrier to good reproductive and sexual health for women with physical and sensory impairments.

[36] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities
[37] WWDA (2016) Position statement 4: Sexual and reproductive rights

Health and social care

Healthcare and social work professionals often lack the training to work effectively with disabled women, both pre-practice and during practice, and lack knowledge of their rights. This leads to poor decisions and outcomes, and to misunderstandings around shared decision making and use of legal guardianship. Many social workers do not receive even general sexual health training, and whilst resources regarding disabled women's reproductive, sexual and maternal health may be available, they are hard to find or not available in appropriate formats. Service provision across Scotland lacks consistency, with local authorities following different policies, support services not universally available to disabled women who require them and support outcomes varying widely.[38]

Teaching

Teachers and others in the education workforce rarely receive training to deliver Relationships, Sexual Health and Parenthood education (RSHP), especially to disabled students. It is therefore not surprising that the specific gendered needs and experiences of disabled young women and girls are not addressed. Targeted training that has been co-designed by disabled women and girls is sorely needed within initial teacher education (ITE), continuing professional development and probationary programmes for newly qualified teachers. In Scotland, the SCLD identify high quality training courses for staff, including with regards to disability, gender and becoming a parent as a vital and missing component in current delivery of RSHP.[39]

> *"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 response from member of People First Women's Group.**

Carers

Paid and unpaid carers, including parents, foster carers and staff in residential care homes, also often lack the necessary knowledge and information to help ensure that the reproductive health needs of disabled women and girls are met. There is a lack of guidance and support on how to talk about sex and relationships with disabled young women and girls, including with regard to menstruation and puberty.[40] This makes it more difficult for carers to enable informed decision-making and reproductive health choices, for example with regards to contraception, smear tests,

[38] Engender stakeholder event on social care, June 2018
[39] Scottish Commission for Learning Disability (2018) Safe and healthy relationships: empowering and supporting people with learning disabilities through education
[40] Engender engagement with disabled women, 2013-2018

fertility and pregnancy. In turn, this makes women more vulnerable to unwanted pregnancy, harm and abuse.

Later sections of this report provide further details on harmful outcomes that stem from lack of knowledge amongst carers and service providers, and lack of privacy and autonomy for disabled women.

There is clear and urgent need for vastly improved training for health, social care and education professionals regarding the reproductive and sexual health and rights of disabled women, as well as access to information and support for unpaid carers in the community.

> *"Sex Education - yes in schools and then when you're older. Support workers asking if you want to meet someone and helping you with relationships. Nobody has ever asked if I want to get married or have children and I need information on this please."*
>
> **Anonymous survey response.**

Sex and relationships education

Inclusive and accessible sex and relationships education (SRE) for disabled young women and girls is vital to prevent negative or extremely harmful outcomes. However, access to such SRE is a major issue throughout the world. It is often not available in special education settings, and mainstream programmes rarely address disabled women's distinct sexual and reproductive health needs. Meanwhile, the limited research, societal understanding , discourse and resources regarding SRE for disabled students that does exist is not adequately gendered. Consequently, disabled women and girls face multiple barriers in making informed decisions about their own bodies, health and lives.[41]

All of these factors lead to unintended pregnancies, poor sexual health outcomes, negative impacts on education, and abusive practices. For instance, one targeted study showed that 40% of female pupils from a specialist school for learning disabled children in Wolverhampton became teenage mothers within 18 months of leaving education.[42] This is higher than motherhood incidence for non-disabled teenagers in Wolverhampton.[43] We acknowledge that there are a range of factors underlying this difference, which includes both access to SRE information and healthcare services, but also discriminatory attitudes and assumptions about

[41] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities
[42] Heer (2008) Teenagers, pregnancy, learning disabilities: Wolverhampton City in context
[43] Office of National Statistics (2001 – present), Conceptions to women aged under 18 datasets

disabled women's capacity to study, and to participate in training and paid work.[44] There is evidence that targeted and accessible SRE leads to improved outcomes for disabled young people abounds.[45].

> *"I did not get the right sexual 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 response from member of People First Women's Group.**

Scottish Government Relationships, Sexual Health and Parenthood education

The Scottish Government programme of Relationships, Sexual Health and Parenthood education (RSHP) is not currently accessible, inclusive or adequately gendered. In 2013, the UN CEDAW Committee[46] called on UK and devolved governments to make inclusive education on sexual and reproductive rights mandatory in schools, under their international human rights obligations.[47] This has not yet been achieved.

> *"I needed 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."*
>
> **Survey response from a woman with a learning disability.**

Revised RSHP guidance from 2014 recognises that disabled children and young people are less likely to receive RSHP and are vulnerable to exploitation and abuse. It also stipulates that accessible resources must be made available to ensure that disabled students have access to quality sex and relationships education.[48] However, relevant teaching aids are not easy to find, accessible or adequately tailored to the needs of disabled women and girls. Practitioners state that a lack of consistent provision and implementation of RSHP across Scotland is amplified for disabled students. Individual teachers, schools and local authorities may have developed good practice

[44] Leonard Cheshire (March 2014) Realising the Rights of women and girls with disabilities
[45] Scottish Government (2014) National Guidance for Child Protection in Scotland, Additional Notes for Practitioners: Protecting Disabled Children from Abuse and Neglect; Barnardo's (2015) Unprotected, overprotected: meeting the needs of young people with learning disabilities who experience, or are at risk of, sexual exploitation
[46] UN Convention on the Elimination of all forms Discrimination Against Women
[47] CEDAW (2013) Concluding observations on the seventh periodic report of the United Kingdom of Great Britain and Northern Ireland
[48] Scottish Government (2014) Conduct of Relationships, Sexual Health and Parenthood Education in Schools

on delivering RSHP to girls and young women with additional support needs, but sharing and promoting this across Scotland is not prioritised or resourced at policy level.[49]

Furthermore, parents can still opt children out of RSHP, without the child's consent, in contravention of their rights. This is likely to be particularly common amongst parents of disabled children, although the extent of this in Scotland is not known.

Lack of gender analysis

The 2014 RSHP guidance does not refer to the needs or experiences of young women or girls, but advocates for a gender neutral approach to challenging negative gender norms and to questioning gender stereotyping and gender inequality. Conversely, however, it is vital that women and girls' experiences and perspectives are taken into account in the design of RSHP curricula and resources. It should go without saying that the needs and concerns of disabled young women and girls differ from those of disabled young men and boys, and that these must be embedded in accessible sex and relationships education.

Crucial gender issues regarding, for example, sexual violence, consent, domestic abuse and coercive control, and access to safe abortion must be addressed in the context of gender inequality and its wider implications in Scotland. In turn, gender inequality issues that impact on women's reproductive and sexual rights and health must be considered through the lens of respective disabilities and impairments in RSHP curricula.

For instance, learning disabled women face a particular set of challenges with regard to sex and relationships on account of their gender. This is highlighted by the SCLD in a recent report, along with the poorer sexual health outcomes and levels of knowledge that are experienced by learning disabled women as compared with their male peers, and the need for this to be addressed in RSHP curricula.[50]

Multiple inequalities

Access to education issues are even more pronounced for particular groups of disabled women and girls, including those with multiple impairments, those who live in poverty or are homeless, and those in institutional care, juvenile and correctional facilities. Access to information for many girls and young women with severe impairments is completely controlled by paid or unpaid carers. Girls and young women in such situations are at heightened risk of sexual ill-health and abuse.

[49] Engender engagement and stakeholder events, 2013-2018
[50] Scottish Commission for Learning Disability (2018) Safe and healthy relationships: empowering and supporting people with learning disabilities through education

This risk is also heightened for deaf or deaf-blind women, who are traditionally excluded from all mainstream education.[51]

Additional barriers to education for disabled young women from BME, refugee and asylum-seeking communities are likely to compound their lack of access to RSHP education, and information that is relevant to LGBT disabled young people is scarce.

> *"There should be 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 response from a person with a learning disability.**

These barriers are documented in literature from the UK and more widely. However, very little is known about the experiences of marginalised groups of disabled women in Scotland. This should be addressed as part of a wider development programme on the needs and experiences of young women, girls and disabled students regarding their reproductive and sexual health.

[51] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities

REPRODUCTIVE, SEXUAL AND MATERNAL HEALTH SERVICES

This section explores disabled women's experiences of services relating to reproductive health.

IT EXPLORES:

- The infantalising treatment experienced by many disabled and learning-disabled women accessing reproductive healthcare
- Failures to provide accessible information and services to women and girls
- Lack of consent and autonomy concerning reproduction, including forced sterilisation, access to abortion, and decisions regarding contraception
- The failure of Scottish Government policies to include the experiences and needs of disabled women in reproductive, sexual and maternal health frameworks and strategies.

AND RECOMMENDS:

Scottish Government, health and social care bodies should work together to:

- Establish a ministerial working group to carry out an intersectional review of disabled women's access to reproductive, sexual and maternal health services and information
- Build the capacity of health and social care professionals about disabled women's sexual and reproductive health needs through development of continuing professional development resources
- Create a disabled women's reference group to advise on the planning of reproductive, sexual and maternal health services, infrastructure, and new and improved accessible resources
- Ensure that reproductive, sexual, maternal and perinatal health services are resourced with specialist equipment and accessible signage

- Ensure transport options to NHS services, including non-acute services are well funded and promote awareness of these services
- Introduce Routine Enquiry forms on sexual health with all service users at every appointment/care plan/review or informal chat
- Create a pool of NHS language and BSL interpreters to work with disabled women accessing reproductive, sexual, maternal and perinatal health services
- Extend the definition of an advocate to include independent support people may require to increase options for attending health services that may be sensitive.

Scottish Government and health bodies should work together to:

- Develop clear protocols to eliminate harmful forced practices regarding disabled women and girls' reproductive rights and health across health, care and legal sectors
- Create and implement checks and accessible consent processes to guarantee free, prior and informed consent and shared decision making in all reproductive and sexual health operations and treatments
- Decriminalise abortion in Scotland and ensure equality of access to abortion for disabled women with a national standards framework
- Mandate data collection regarding disability on women presenting for and proceeding to abortion, whilst protecting anonymity with regards to public release
- Update relevant strategies, policy frameworks and service standards to reflect the reproductive, sexual and maternal health needs of disabled women and girls
- Undertake research to fill substantial knowledge gaps regarding disabled women's reproductive, sexual and maternal health to inform future policy and practice.

REPRODUCTIVE, SEXUAL AND MATERNAL HEALTH SERVICES

Disabled women's access to reproductive and sexual health services is similarly undermined by lack of knowledge, information and inclusivity. Health and social care workers often unknowingly perpetuate negative stereotypes, and view disabled women and girls solely through the lens of their impairments.[52] This is partly due to the dearth of information relating to their reproductive and sexual health needs and the types of practical and social support that are required.

> *"I'm afraid nearly all my experiences have been poor. Saying this lately my GP has signposted me to family planning and told me my choices of contraceptive is up to me. I also had a gynaecologist who told me my sex life should be enjoyable and gave advice about how to overcome physical pain and difficulty coming from my illness."*
>
> **Survey response to question 'tell us about any good experiences you have had'.**

Women at our consultation events have described infantalising treatment based on their gender within Scotland's healthcare system, and experiences where doctors and other practitioners have made assumptions about their fertility, capacity and desire to parent. Many women related negative comments made with regards to pregnancy and maternity, including assumptions that their pregnancies were unplanned or a bad idea.

In the UK and more widely, disabled women also live with the legacy of historical social resistance to disabled women becoming mothers, which borders on a form of eugenics.[53] Later sections of this report further explore the harmful and forced practices experienced by disabled women and girls such as non-consensual sterilisation and forced terminations. Related stigma persists and is particularly strong for women and girls with learning disabilities.[54]

Access to reproductive, sexual and maternal health

Disabled women's limited access to sexual, reproductive and maternal healthcare services cuts across a large number of primary and secondary health and social care

[52] Engender engagement with disabled women, 2013-2018; United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities
[53] Tilley et al. (2012) The silence is roaring: sterilisation, reproductive rights and women with intellectual disabilities
[54] Engender engagement with disabled women 2013-2018; United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities

sectors. Examples of resources and good practice exist within some of these sectors, such as the Royal College of Nursing guidance on pregnancy and disability.[55] However, inadequate co-ordination and integration across services means that these can only have a limited impact on outcomes for disabled women. This is reflected in research that sets out negative perinatal and maternal experiences and poorer health outcomes for disabled women, as compared with non-disabled peers,[56] as well as abundant anecdotal evidence from women and practitioners in Scotland.[57]

> *"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 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 response from member of People First Women's Group.**

Practical access

Another key barrier is a widespread lack of available or affordable equipment, and practical aids that have been designed in partnership with disabled women. For instance, women with different impairments have specific physical needs regarding childbirth, breastfeeding, menstruation and childcare. Visually impaired women are often unable to access services because of poor signage coupled with a lack of assistance.

A wide range of economic, cultural, physical and institutional barriers impede or preclude access to reproductive, health and maternal health services for many women. These include:

- Inaccessible venues
- Lack of information and signage in accessible formats
- Lack of accessible transport
- Lack of appropriate equipment
- Non-inclusive and inflexible service policies
- Lack of skilled workers

[55] Royal College of Nursing (2007) Pregnancy and disability: RCN guidance for midwives and nurses
[56] Birthrights (2018) Experience of disabled women during pregnancy, childbirth and early parenting
[57] Engender engagement and roundtable events, 2013-2018

- Pervasive stereotypes that disabled women are asexual or hypersexual
- Discriminatory attitudes amongst service providers
- Communication barriers, including lack of BSL
- Relatives and caregivers acting as gatekeepers to information or giving inaccurate information
- Lack of signposting to reproductive and sexual health services
- Lack of joined-up and preventative working across health and social care services
- Lack of privacy and autonomy in care homes or community care.

> *"Better toilet facilities for changing pads/tampons. Same with baby changing facilities. Make them adjustable height so someone in a wheelchair can change their baby's nappy."*
>
> **Anonymous survey response.**

Disabled women report that these barriers apply to a wide range of reproductive, sexual, perinatal and maternal health issues and services, including:

> *"For those of us with asperger's and autism, infinitely more education to teach us about our right to autonomy: that it's okay that something doesn't feel right or nice to us and to say no to that happening, no matter how "normal" it might be to others. For GPs, learning to listen to the content of what an asperger's or autistic woman is saying, not the tone. It is immensely hard to get anyone to listen or help when you don't give the verbal or facial cues to convey the level of emotional of physical distress you're suffering."*
>
> **Anonymous survey response.**

- Menstrual management
- Contraception
- Abortion care
- Sexual health management
- Gynaecological services
- Midwifery
- Perinatal and maternity services
- Breast and cervical cancer screening
- Menopause
- Assisted reproductive technologies
- Support for parents regarding disabled girls' reproductive health.

These lists are not comprehensive but indicative, and it is beyond the scope of this paper to explore the issues in detail. Rather, our intention is to indicate the scale of the problem and to highlight the limited extent of knowledge and action regarding the reproductive and sexual health needs of disabled women in Scotland.

Care services

Social care sectors also have a significant role in ensuring disabled women are able to access appropriate reproductive, sexual and maternal health services, and to identify emerging issues before problems or crises develop. At the same time, lack of privacy and autonomy for disabled women with severe care needs can affect their access to sensitive medical appointments and services. However, these considerations are not systematically addressed by regulatory or professional bodies.

Multiple inequalities

Barriers to broader aspects of physical and mental health for women facing multiple inequalities in Scotland, suggest that detailed intersectional evidence regarding disabled women's experiences of reproductive, sexual and maternal health services is urgently needed.[58]

The issues and barriers touched on here are often compounded for disabled and care-experienced women within other groups that experience poorer health outcomes, face further discrimination, or have particular needs. These groups include women in rural areas, older Indian, Pakistani and Bangladeshi women,[59] LGBT women, migrant, refugee and asylum-seeking women,[60] and adolescent girls, whose mental health is poorer than that of boys.[61]

> *"I recently had a doctor tell me it would be awful for me to be pregnant and try to force birth control on me even though religiously this is not ok for me. 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!"*
>
> **Anonymous survey response.**

Harmful practices to control disabled women's reproductive choices have been commonplace throughout the world. Forced or coerced sterilisation, abortion, and use of long-term contraception continue to this day. Disabled women and girls may also be given misleading or false information about sex and reproductive health by healthcare workers, family or carers. Young women and girls especially are affected by routine decisions regarding their reproductive health made by families, legal representatives, and service providers.

[58] Engender (2018) CEDAW shadow report
[59] EHRC (2016) Is Scotland Fairer: The state of equality and human rights 2015
[60] Strathclyde University (2016) What do you mean, I have a right to health? Participatory action research on health and human rights
[61] SAMH (2017) Going to be all right? A report on the mental health of young people in Scotland

This clearly violates disabled women's human rights to health, privacy and family life. There is lack of clarity regarding the degree to which these practices continue in the UK, but women in Scotland report that they have been encouraged to terminate their pregnancies or be sterilised by health and social care workers.[62] Practitioners in Scotland confirm that disabled women are often subject to operations and treatments regarding their sexual and reproductive health, such as forced sterilisation, without providing informed consent even when this is possible.[63] Linked to this, parents and carers often do not have access to full information in order to make informed decisions in the interests of the person they support.

The Adults with Incapacity (Scotland) Act 2000 introduced a legal framework in which capacity is presumed, with support for people to make decisions where possible. Where such capacity is deemed to be lacking, procedures should ensure that decisions are taken in that person's best interests, with the assumption of supported decision making as routine. Given the testimonies of disabled women and practitioners regarding consent issues, clearly such procedures must be strengthened with regards to disabled women's reproductive rights and health. Health and social care regulators must also take steps to ensure that more subtle forms of coerced harmful practices are eliminated from practice in Scotland.

Sterilisation

Disabled women and girls are still subject to forced or coerced sterilisation to control menstrual cycles, to prevent pregnancy as a result of sexual abuse, and because of misconceptions and discriminatory attitudes about disabled women's parenting abilities.[64] This is clearly an abusive practice that breaches disabled women's human rights. Women with learning disabilities, as well as those in institutional care, are particularly vulnerable to forced sterilisation.

There is lack of clarity regarding the degree to which these human rights violations continue in the UK. However, relatively recent studies relating to England and Wales demonstrate the need for focussed investigation. They find that:

- 73 referrals for sterilisation were made to the Official Solicitors in England and Wales between 1988 and 1999
- Of the 73 cases, only three concerned men
- The individuals were between 12 and 41 years old
- Over half of 274 family members participating in a study would or had consider(ed) sterilisation for their child

[62] Engender engagement with disabled women, 2013-2018
[63] Engender stakeholder event on health, 2018
[64] Tilley et al. (2012) The silence is roaring: sterilisation, reproductive rights and women with intellectual disabilities

- Almost all requests for sterilisation refer to coping with menstruation.[65]

Abortion

Access to abortion for disabled women in Scotland is shaped and potentially undermined by discrimination and stereotyping. Disabled women report frequently facing pressure to terminate their pregnancies, from doctors, guardians, social service workers, parents and carers.[66] Much of this pressure stems from misconceptions about their roles in society, their abilities and even the inheritability of certain impairments or conditions. Lack of autonomy, privacy and access to relevant sex and relationships education may also affect the ability of disabled women to access abortion when required.

> *"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, many 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."*
>
> **Anonymous survey response.**

Unfortunately, however, our understanding of disabled women's experiences is extremely limited. The notification of abortion is mandated under the 1967 Abortion Act, but disability is not included amongst statutory data collection requirements. Research into disabled women's experiences of accessing abortion, as well as data collection on the incidence of abortion amongst disabled women is needed.

This also highlights fundamental flaws in Scotland's legal abortion framework and care system. Abortion is not legal on request, but requires the consent of two doctors. As repeatedly reported to us, this involvement of practitioners in women's decision-making has significant implications for disabled women. Access to abortion care and process across regional health boards is also inconsistent. Abortion should be decriminalised in Scotland and provision regulated in line with all other healthcare. A national framework should be established to standardise and monitor access of abortion, regardless of intersecting inequalities including disability, age, care-experience, geography and financial status.[67]

[65] Tilley et al. (2012) The silence is roaring: sterilisation, reproductive rights and women with intellectual disabilities
[66] Engender engagement with disabled women, 2013-2018
[67] Engender (2016) Our bodies, our choice: The case for a Scottish approach to abortion

Contraception

Disabled women and girls also lack autonomy regarding contraception, and are more likely to be prescribed long-acting contraceptives than non-disabled peers. Decisions are often made by caregivers or service providers on the basis of convenience. Furthermore, contraception is prescribed earlier and continues later than for non-disabled women, despite the risk of long-term health implications and lack of oversight.[68]

> *"Eventually (after I married!) I managed to access an appointment at a pre-pregnancy clinic to help me find out important info about getting pregnant, what medication I should stay on, should try to reduce and what the impact on me and the child could me. 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 response to question 'tell us about any good experiences you have had'.**

Scottish Government policy frameworks

There are a number of relevant Scottish Government health strategies, policy frameworks, and service standards in which the reproductive and sexual health needs of disabled women are entirely, or almost entirely, absent. Indeed, some health policy frameworks do not take account of gender or disability at all. Others recognise issues for disabled people but do not clearly set out action to tackle these. Here we set out some of those specific strategies, frameworks and standards.

Sexual Health and Blood Borne Virus Framework 2015-2020[69]

Despite describing the sexual health of disabled people as a "more recent issue", the Sexual Health and BBV Framework recognises that people with long-term impairments or illnesses are more likely to be negatively impacted by sexual health and wellbeing issues. It does not, however, refer to any of the wide-ranging sexual health issues experienced by disabled women, nor indeed include adequate gender analysis more broadly. It does not set out how the "recent issue" of disabled people's sexual health will be addressed.

Sexual health service standards[70]

Scotland's sexual health service standards, which date to 2008, do not refer to disabled people or women. A national review of these standards undertaken in 2011 found that disabled people are amongst those most affected by "undesirable

[68] Tilley et al. (2012) The silence is roaring: sterilisation, reproductive rights and women with intellectual disabilities
[69] Scottish Government (2015) Sexual health and blood borne virus framework 2015-2020
[70] NHS Quality Improvement Scotland (2008) Standards: Sexual health services

consequences of sexuality", but no strategic steps appear to have been taken to address this.[71]

The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland[72]

Scotland's maternity and neonatal care framework finds that there is a lack of good quality evidence around care for disabled women, and therefore "a need to include these populations of women in research on maternity services both in terms of collecting evidence on their views and experiences and development of interventions." It does not, however, commit to undertaking or commissioning such research.

Mental health strategy 2017-2027[73]

Good mental and physical health are clearly intertwined. Some of the reproductive, sexual and maternal health issues set out in this report, including with regard to violence against disabled women, have clear and egregious implications in terms of disabled women's mental health and wellbeing. However, reproductive and sexual health is not covered by the strategy and very little gender analysis is included throughout.

> *"Stop treating us like we are a) like able bodied people. B) we don't know what we're talking about because we don't have a medical education, we are often more knowledgeable on our condition than the professional c) easier access to mental health services."*
>
> **Anonymous survey response.**

Health and social care standards[74]

Unlike the previous National Care Standards, Scottish Government's updated Health and Social Care Standards do not include guidance related to reproductive, sexual or maternal health.

Although the Scottish Government's new National Care Standards take a rights based approach, they are generic to all services and do not include guidance related to any specific condition or service area including reproductive, sexual or maternal health. It is unclear how these standards will be monitored in a sufficiently gendered way and/or relate to other policies such as the sexual health standards.

[71] Healthcare Improvement Scotland (2011) Improving sexual health services in Scotland
[72] Scottish Government (2017) The best start: A five-year forward plan for maternity and neonatal care in Scotland
[73] Scottish Government (2017) Mental health strategy: 2017-2027
[74] Scottish Government (2017) Health and social care standards: my support, my life

VIOLENCE AGAINST DISABLED WOMEN

This section discusses the importance of sexual and reproductive rights in tackling violence against disabled women and girls.

IT EXPLORES:

- The prevalence of violence against disabled women and girls
- The need for accessible services for women who have experienced violence, and the interlinking between services.

AND RECOMMENDS:

Scottish Government and health bodies should work together to:

- Ensure that disabled women and girls' specific experiences are reflected in Equally Safe and its action plan
- Develop continuing professional development (CPD) resources for medical professionals around the needs of disabled women who report experiencing domestic abuse or sexual violence
- Improve working relationships, including referral pathways, between disabled people's or disabled women's organisations and rape crisis centres and women's aid groups, including to increase the accessibility of refuge provision
- Improve provision of appropriate equipment, procedures and accessible information within healthcare services regarding violence against disabled women.

VIOLENCE AGAINST DISABLED WOMEN

Disabled women's lack of reproductive control contributes to an increased risk of sexual violence, abuse and coercion. Pervasive discrimination, negative attitudes, lack of knowledge and poor access to services feed into this. For instance, some young disabled women report that the experience of stigma around disability makes them more likely to accept a partner who might mistreat them.[75]

> *"I was forced to have sex against my will – rape – reported to police and dealt with. Person still lives near me."*
>
> **Survey response from a woman with learning disabilities.**

Incidence of violence against disabled women

The extent of violence against disabled women in Scotland is not known, but one small-scale survey conducted in Glasgow showed that 73% of participating disabled women had experienced domestic abuse and 43% had been sexually assaulted.[76] Studies from elsewhere in the UK find that disabled women are up to twice as likely to experience sexual violence and partner abuse as non-disabled women.[77]

> *"As someone who was sexually assaulted, it has taken me time to get around to addressing my own issues with sex and trust. I did not receive any sex education at school. I think as well as the clinical side of things females especially 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!"*
>
> **Anonymous survey response.**

Evidence generated in North America and Australia highlights both the extent of the problem globally and the need for an increased focus on disabled women's safety in Scotland. Statistics from that research include:

- Reported rates of sexual violence among disabled women range from 51% - 79%

[75] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities
[76] Wise Women (2015) Daisie project: violence against disabled women survey
[77] ONS (2018) Women most at risk of experiencing partner abuse in England and Wales: years ending March 2015 to 2017; Balderston (2013) Victimised again? Intersectionality and injustice in disabled women's lives after hate crime and rape

- 90% of learning disabled women have been subjected to sexual abuse, with 68% experiencing sexual abuse before turning 18
- 20% of disabled women have experienced unwanted sex compared to 8.2% of non-disabled women.[78]

International evidence suggests that disabled women and girls from BME, LGBT or minority faith communities in Scotland, as well as those from deprived areas, may be at even greater risk of sexual abuse,[79] as are women and girls with sensory or learning disabilities.[80]

Access to services

For many women, reporting sexual violence leads to investigation and medical procedures that are intrusive, inaccessible and traumatic. Disabled women may be especially disinclined to report sexual abuse because of discrimination and negative assumptions related to their impairments, communication barriers, or lacking equipment and specialist knowledge required to meet their needs.

> *"I'm sorry to say that I can't think of a thing! Everything, from contraceptive provision to access to safe abortion to representative sex education has been a fight."*
>
> **Survey response to question 'tell us about any good experiences you have had'**

Experiencing domestic abuse often compromises access to health services, with specific implications in terms of reproductive and maternal health for disabled women. Over 30% of domestic abuse begins during pregnancy and can escalate for those in existing abusive relationships, with hugely damaging impacts on maternal and infant health. Women in abusive relationships and disabled women are more likely to have delayed access to maternity services, which is particularly concerning given that disabled women can be susceptible to particular pregnancy complications.[81]

Evidently, this violence, abuse and mistreatment undermines disabled women's reproductive rights and has severe and long-lasting impacts on their reproductive and sexual health.

[78] United Nations General Assembly (2017) Sexual and reproductive health and rights of girls and young women with disabilities
[79] ibid
[80] Sightsavers (2017) Submission to the study on the sexual and reproductive health and rights of girls with disabilities
[81] Breckenridge et. al (2014) Access and utilisation of maternity care for disabled women who experience domestic abuse: a systematic review

RECOMMENDATIONS

PARENTAL RIGHTS

Scottish Government, care and child protection agencies should work together to:

- Establish the number of disabled parents in Scotland and disaggregate data collection by gender and by impairments
- Commission gendered research into disabled parents' experiences, including for those who are not in contact with social care services
- Ensure that refreshed national parenting, child protection and disability rights policy explicitly addresses the support needs and contexts of disabled mothers
- Collect and publish gender-disaggregated data on parental disability when referrals are made to the Children's Hearing System on grounds of 'lack of parental care'
- Explore statutory underpinning for the good practice guidelines for supporting learning disabled parents, and integrate them across wider parenting, social care and child protection frameworks
- Review the Mental Health and Care (Scotland) Act (2003) and remove learning disabled people from the definition of people with a mental disorder.

TRAINING AND EDUCATION

Scottish Government, health boards, integrated joint boards, local authorities and professional and regulatory bodies across health, care and education sectors should work together to:

- Develop and deliver continuing intersectional and co-designed professional development (CPD) programmes on disabled women's reproductive, parental, sexual and maternal health and rights for:
  - Trainees and practitioners in health and social care services, including social workers and workers in residential care settings
  - Trainee, newly qualified and practising teachers with regard to delivery of RSHP

- Create best practice guidelines, including a guide to standard pathways, for service providers regarding disabled women's sexual, reproductive and maternal health
- Create a central resource bank for social workers, social care practitioners and frontline staff. including easy-read texts, to support informed decision-making around sexual, reproductive and maternal health
- Provide support and resources similar to those given to social care staff for parents and unpaid carers of disabled women and girls regarding their sexual and reproductive health, and parental rights
- Work with the Health and Social Care Alliance to improve promotion and awareness of health and wellbeing information tools such as ALISS.

Scottish Government, Education Scotland and local authorities should work together to:

- Introduce mandatory, age-appropriate, and inclusive RSHP in school curricula, using resources designed in collaboration with disabled women and girls
- Undertake an intersectional development programme on the reproductive and sexual health needs of young women, girls and disabled students
- Create national standards for RSHP that explicitly meet the needs of disabled women and girls
- Create a central resource bank of accessible and gendered resources for use in RSHP by teachers and students with additional support needs
- Create a national network of RHSP workers specialising in disability who can share good practice across Scotland.

REPRODUCTIVE, SEXUAL AND MATERNAL HEALTH SERVICES

Scottish Government, health and social care bodies should work together to:

- Establish a ministerial working group to carry out an intersectional

review of disabled women's access to reproductive, sexual and maternal health services and information

- Build the capacity of health and social care professionals about disabled women's sexual and reproductive health needs through development of continuing professional development resources
- Create a disabled women's reference group to advise on the planning of reproductive, sexual and maternal health services, infrastructure, and new and improved accessible resources
- Ensure that reproductive, sexual, maternal and perinatal health services are resourced with specialist equipment and accessible signage
- Ensure transport options to NHS services, including non-acute services are well funded and promote awareness of these services
- Introduce Routine Enquiry forms on sexual health with all service users at every appointment/care plan/review or informal chat
- Create a pool of NHS language and BSL interpreters to work with disabled women accessing reproductive, sexual, maternal and perinatal health services
- Extend the definition of an advocate to include independent support people may require to increase options for attending health services that may be sensitive.

Scottish Government and health bodies should work together to:

- Develop clear protocols to eliminate harmful forced practices regarding disabled women and girls' reproductive rights and health across health, care and legal sectors
- Create and implement checks and accessible consent processes to guarantee free, prior and informed consent and shared decision making in all reproductive and sexual health operations and treatments
- Decriminalise abortion in Scotland and ensure equality of access to abortion for disabled women with a national standards framework
- Mandate data collection regarding disability on women presenting for and proceeding to abortion, whilst protecting anonymity with regards to public release

- Update relevant strategies, policy frameworks and service standards to reflect the reproductive, sexual and maternal health needs of disabled women and girls
- Undertake research to fill substantial knowledge gaps regarding disabled women's reproductive, sexual and maternal health to inform future policy and practice.

VIOLENCE AGAINST DISABLED WOMEN

Scottish Government and health bodies should work together to:

- Ensure that disabled women and girls' specific experiences are reflected in Equally Safe and its action plan.
- Develop continuing professional development (CPD) resources for medical professionals around the needs of disabled women who report experiencing domestic abuse or sexual violence
- Improve working relationships, including referral pathways, between disabled people's or disabled women's organisations and rape crisis centres and women's aid groups, including to increase the accessibility of refuge provision
- Improve provision of appropriate equipment, procedures and accessible information within healthcare services regarding violence against disabled women.

Engender is Scotland's feminist organisation. We work for women's economic, political, and social equality with men.
Engender is a Scottish charity (SC029053) and a company limited by guarantee (SC 286639).

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