

RESEARCH

Reproductive (In)Justice and Inequality in the Lives of Women with Intellectual Disabilities in Scotland

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This paper presents an empirical exploration of women with intellectual disabilities' experiences of reproductive (in)justice in Scotland. The findings build on feminist disability scholarship and call for recognition of women with intellectual disabilities' reproductive rights. By doing so we foreground the insights of women with intellectual disabilities in their own words, to confront that, despite significant global policy recognition of equality and human rights, there has been little impact on the lived experiences of women with intellectual disabilities in Scotland. This paper draws on the experiences of women with intellectual disabilities by focusing on their shared ontologies of inequality and by prioritising their words. The paper seeks to bring attention to the health inequalities that shape higher mortality rates for women with intellectual disabilities in Scotland and reconstruct a narrative of health parity that includes women's bodies and reproductive experiences. The paper argues that women with intellectual disabilities want and would benefit from life-long, accessible, and equitable sexual and reproductive health education around menstruation, contraceptive decision making, and menopause and that these are fundamental to realising rights to health and wellbeing.

Keywords: Scotland; Reproductive Rights; Health Inequalities; Intellectual Disabilities; Gender

Introduction

Disabled women's lives have received limited policy attention in the UK, limited visibility, and limited inclusion in mainstream feminist projects. Despite the increasing movement towards intersectionality and intersectional agendas, women with intellectual disabilities' reproductive health and wellbeing have remained invisible in mainstream feminist and health discourse (Bê 2019; Kallianes & Rubenfeld 1997). Women with intellectual disabilities have historically been excluded from information about reproduction in a society that increasingly supports relationships and sexual freedoms but continues to have difficulty accepting people with learning disabilities as parents (Ledger et al. 2016). Women with intellectual disabilities die, on average, 18 years younger than the general population in Scotland (O'Leary et al. 2018, see also Emerson & Hatton 2012; Glover & Ayub 2010; Heslop & Haughton 2018). In this paper, we argue that reproductive health inequalities, and their social determinants, contribute to this gendered inequality in health. We assert that socio-cultural assumptions, and legacies of psycho-emotional disablist practices (Reeve 2019), about the sexual citizenship of women with intellectual disabilities structure their exclusion from this sphere (Ignagni et al. 2016; Liddiard 2017; Lister 2002; Shildrick 2013).

While sexual and reproductive rights have come to be viewed through the lens of sexual citizenship (although not always for disabled people), health and wellbeing have limited inclusion in these conceptualisations. Citizenship is gendered, and women's claims to sexual and reproductive autonomy, their experiences of pregnancy, and motherhood have come to be viewed, by feminist citizenship scholars, through a rights-based narrative (Lister 2002). Exploring women with intellectual disabilities' health experiences as claims for sexual citizenship allows for the connection between intimate life and policy (Richardson 2000; see also Plummer 2011). To better challenge inequalities in wellbeing, a focus on women's reproductive citizenship and justice are required. There is a body of work exploring gender inequality and intellectual disability within the context of disablement more broadly (Hollomotz 2011; Kallianes & Rubenfeld 1997; McCarthy 2009; Sheldon 1999). Still, we argue there has been little empirical change in the lives of women with intellectual disabilities, locally and globally, in the past 20 years. A renewed debate and greater visibility of the wellbeing of women with intellectual disabilities is essential to achieving the rights of disabled women overall.

The reproductive rights of Scottish women with intellectual disabilities have been recognised in the Scottish Government's Keys to Life strategy (2019). The original 52 recommendations encapsulate a need to ensure the wellbeing, health, and equal citizenship of people with intellectual disabilities including rights to family life, support,

inclusion, and reproductive health. Despite an ongoing policy commitment to improving the lives of women with intellectual disabilities, inequalities remain systemic and entrenched. This paper explores the extent to which women with intellectual disabilities are prevented from autonomous decision making whilst simultaneously being subject to Western neoliberal processes of individualisation. Through these processes, their 'ability' to practice citizenship 'well' or parent along normative ableist lines, for example, is constructed as an individual problem rather than a structural one.

Reproductive Justice and Wellbeing

Scholarship examining disablement and marginalisation have been criticised for neglecting the intimate and reproductive lives of disabled people, and disabled women in particular (Kulick & Rydström 2015). In early disability feminist studies, Fine and Asch (1988) emphasised the need for 'societal transformation' in addition to levelling pre-existing playing fields. Thirty years on, these societal transformations have taken place in limited ways, and many of the inequalities disabled women faced in early calls for equality are still as relevant now.

Feminist disability scholarship has highlighted the lack of engagement with disabled women in mainstream feminist scholarship, identifying the absence of disabled women:

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: 76).

While disabled women have the same reproductive interests and desires as nondisabled women (Turner & Crane 2016), they are beginning from the point of being denied recognition as potential mothers and carers (Morris 2005). Disabled women do not start from the basis of fighting for the right to have freedom of choice over terminating a pregnancy (Kallianes & Rubenfeld 1997: 204). This legacy of inequality is demonstrated through the history of forced sterilisation enacted upon disabled women globally, and particularly women with intellectual disabilities (Sheldon 1999). The sterilisation and denial of reproductive freedoms of women with intellectual disabilities have been ongoing and destructive forces in their lives.

There is limited social research focusing on the menstrual or menopausal experiences of disabled women and girls (McCarthy 2009; McCarthy & Millard 2003; Rogers 2001), the barriers they face receiving comprehensive sexual health education (Sheldon 1999; see also Hollomotz 2011), and commensurate reproductive health information. Women with intellectual disabilities are persistently excluded from sexual citizenship, including information and knowledge about sex, sexual health, consent, and relationships. This disadvantages women with intellectual disabilities in recognising and reporting sexual violence (Dotson et al. 2003; Hollomotz 2011). Due to institutional living and heightened protectionism from family, women with intellectual disabilities are less able to 'practice' relationship building and have limited opportunities to meet people (Arias et al. 2009). These restrictions can make it challenging to identify abusive relationships and, when they do, powerless to report them (Hollomotz 2011).

Disabled women's reproductive rights are constrained by the assumption that disabled women are not sexual citizens. There is a lack of societal support for disabled women's roles as mothers and sexual agents and a lack of health care services that support disabled women (Kallianes & Rubenfeld 1997). Tilley et al. (2012) highlight poor access to routine health care services, such as reproductive health, breast cancer screenings (see also Brown 1996), and Pap Smear screenings (Dotson et al. 2003). Women with intellectual 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 (McCarthy 2009). Health professionals often direct information and questions to supporters, carers, and family members rather than to the person themselves, and so women can feel unclear about side effects of medication (Rodgers 2001). This denial of agency is especially salient concerning contraception decision making (McCarthy 2010) and sexually transmitted infections (STIs) and how to avoid them (Saxe & Flanagan 2014). Thus, women with intellectual disabilities are subject to taking medical direction or 'informed compliance rather than informed choice' (Stapleton, Kirkham & Thomas 2002: 639 in McCarthy 2009: 206).

There is evidence that contraceptive use is imposed on women with intellectual disabilities (Rowlands 2011): sometimes for medical reasons, to avoid pain or pregnancy; sometimes for social reasons around hygiene, to be 'safe'; and also despite no identified need to control menstruation (McCarthy 2009, 2010). The use of sterilisation might appear to be historical. Sterilisation now requires multiple layers of care and consent. However, the lack of informed consent around contraception (McCarthy 2010), and the over-subscription of long-term contraceptives, even during menopause suggests that 'reproductive control is not a historical institutional problem but very much a 'contemporary community based one' (Ledger et al. 2016: 714 in McCarthy 2009: 203). Constraints placed on decision-making echo legacies of structuring women with intellectual disabilities as incapable of practising normative ideals of citizenship, where citizenship is afforded to so-called autonomous, able-bodied, rational (often male) actors (Wiseman 2019). As Dotson et al. (2003) argue, sex can be a complex topic to raise with women with intellectual disabilities. Often information regarding sex, oral sex, and intercourse are not given to disabled women and are instead targeted at parents or caregivers 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 patronising stereotype that disabled adults are like children.

The sexual and reproductive lives of women with intellectual disabilities remain hidden under veils of the so-called private sphere whilst also not being prioritised in feminist academic scholarship, or feminist discourse, outside of disability studies. The findings presented here make visible the inherent nexus within which rights, policy, and intimate life exist (Wiseman 2019). Disabled women's fights for reproductive equality are ongoing, and systemic denial of these rights are commonplace globally (Dean et al. 2017). Women's reproductive lives have become entangled in what Saunders (2020) refers to as the 'idealised reproductive citizen', where normative neoliberal processes demand the regulation of 'othered' women's reproductive decision-making as neoliberalism extends itself from market concerns to everyday life. Within these processes, where disabled women are, at best, given very little attention, women with intellectual disabilities are invisible.

Human Rights and the Scottish Policy Context

International recognition of rights of disabled people to family life and reproductive freedom have been relatively recent; the right to family life was purposefully blocked from the Declaration of the Rights of Mentally Retarded Persons in the early 1970s (Van Trigt 2019). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN 2006), and Scottish policy, have increasingly recognised the need for greater inclusion. The 'Keys to Life' (Scottish Government 2013, 2019) formalise the need to meet international obligations to disabled people under the UNCRPD. The WHO (WHO 1946) constitution includes freedoms to control one's health and body, including sexual and reproductive rights, asserting entitlement to the highest attainable level of health (Molkizadeh et al. 2019). The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW 1979, Article 12) (UN 1979) states that appropriate services should be delivered inclusively with access to information and services including contraception, family planning advice, and pregnancy support while avoiding coercive or harmful socially constructed practices. While CEDAW recognises the rights of women in general, the UNCRPD explicitly protects the rights of disabled women. The UNCRPD emphasises that disabled women have the right to found families and to access equal information on sexual and reproductive health, to 'retain their fertility on an equal basis with others'. Similarly, the United Kingdom Equality Act (2010) protects and articulates the rights of disabled people to be treated equally.

Scotland's disability policy has aimed to challenge the social invisibility of the gendered realities of disablement, including the reproductive equality and health of women with intellectual disabilities. One area where this gap could be closed is around sex education. Sex education has been a contentious issue in the UK with protectionism defining the policy approach. Under-18s are viewed as vulnerable due to their 'legal' status as a child and should be protected from engagement with sex (see Daly et al. 2019). Adults with intellectual disabilities are framed as vulnerable, and despite society becoming more sexually progressive, a view of disabled people as childlike dominates decisions around access to sexual education (Bollinger & Cook 2019).

Scottish Relationship, Sexual-Health, and Parenthood Education

It is clear from the growing literature on disabled women that better relationship, sexual health and parenthood education (RSHP) is needed (Wolfe et al. 2019). At the very least, education on consent (Sullivan et al. 2013), relationships (Yau et al. 2009), and safety (Kijak 2013) have been highlighted (Brown & McCann 2018) to fulfil wide-held ambitions among adults with intellectual disabilities for passionate, intimate, and romantic relationships (Wheeler 2007).

The latest guidance from the Scottish Government, published in 2014, provides a significant shift towards informed and informing sex education in all schools. Guidance specifies inclusion for disabled people under article 24, while no detail is provided about what this is, schools can access resources (that are blocked to non-teachers so cannot be assessed here). Article 26 calls for adequate staff development to ensure inclusion as 'particularly important for those who work with those children and young people whom evidence indicates are more at risk of having poorer sexual health outcomes, such as those ... with additional support needs [ASN]'. In Scotland, ASN refers to any person whose needs require multi-agency support and typically include disabled people. The guidance goes on to state in article 53 that

Evidence has demonstrated that children and young people with a disability are less likely to have had education in part due to misconceptions that they are not or will not be sexually active or are not abused. Children and young people with a disability, including those with a learning disability ... must be included in RSHP lessons in order to develop their knowledge and understanding of healthy, safe, respectful and loving relationships.

This unambiguous directive is a major change, yet there is no evidence in the guidance that thought has been given to make sure these materials represent disabled young people. As Bollinger and Cook (2019) argue, disabled bodies need to appear explicitly in educational materials and scenarios to avoid 'othering' and excluding by omission.

Research Methods and Methodology

People with intellectual disabilities have faced a history of exclusion from social research due to the perception of being unable to articulate their thoughts or to have reliable views. Inclusive feminist research challenges oppression by constructing accessible and participatory research methodologies that result in 'enabling greater involvement for people with learning difficulties in the research process' (Chappell et al. 2001: 47) through research that is undertaken in collaboration with people with intellectual disabilities rather than on their behalf.

In researching the reproductive rights of women with intellectual disabilities, we begin from a feminist standpoint where women '*are the authoritative speakers of our experience*' (Smith 1990: 28; Ramazanoğlu & Holland 2011). We drew upon the work of Dorothy Smith (1990, 1987) and in particular the notion that 'to begin in experience is to begin outside of textually mediated discourse' (Smith 1991: 156). We focused on participants' knowledge and expertise of their own bodily and social realities in their own words. Beginning with experience, in feminist praxis, allows us to bring together the relational realities of disabled women's lives by putting the political, social, corporeal, and intimate in conversation with one another.

The findings were produced as part of a research project in collaboration with Engender Scotland in 2018. To ensure that women with intellectual disabilities were supported to take part in this project, we used inclusive research methods. We developed a qualitative questionnaire to reach as many women as possible. We worked with women with intellectual disabilities and with collaborators to create accessible questions and images for an easy read questionnaire. The open questionnaire made it possible for women to narrate their viewpoints and not be constrained by a 'tick-box' style questionnaire. The easy read questionnaire asked three broad questions: about problems, about what would make life better, and about good experiences.

Personal assistants, self-advocacy organisations, and supporters aided women to participate, which allowed us to include women from rural communities as well as urban areas in Scotland. Some women chose to fill in the questionnaires collectively. Where this has been the case, we make this clear in the findings.

A total of 21 women self-identified as having intellectual disabilities in the questionnaire responses, and a further 12 women took part in focus groups. The ranges in age were from 18 to 78 (where women reported age). We did not ask for demographic data in the questionnaire. Still, from the responses given, there was a mix of participants who lived independently in supported accommodation, with family members, women who were mothers, women who were in relationships, and women who had never had sexual relationships.

Focus Groups

Initially, single interviews were considered; however, women decided that they would rather take part in focus groups with other women that formed part of their women's groups or forums. Women chose this because they felt supported by one another and able to share their stories collectively. In practice, the focus groups enabled a shared process of storytelling, support, and active collectivist participation that delivered the feminist ontologies inherently bound in the project.

We met with participants and developed topic cards together that centred around the key themes of the research so that women could decide and prioritise which topics they wanted to discuss. These topics covered reproductive experiences across the life-course and tied in with the key issues listed in the questionnaire. Three focus groups took place with 12 women.

Participants were provided with accessible participant information sheets and consent information. The beginning, and end, of focus groups were spent negotiating the purpose of the research, the voluntary nature of participation, the protection of participants' identities and locations, and answering any questions that participants had. Institutional ethics procedures approved the research, and all participants names are anonymised through use of a pseudonym. Questionnaire participants were anonymised without pseudonym as agreed in the negotiation of confidentiality.

Data Analysis

The questionnaire data and focus group data have been analysed using thematic analysis (Braun & Clarke 2014) and using Nvivo 11 qualitative data analysis software. Thematic analysis identifies patterns in the data and allows for rich and flexible analysis, which complements a feminist epistemology (Braun & Clarke 2014; Ramazanoğlu & Holland 2011). The data were continuously read and reread to allow for the emergence of categories that could be grouped into themes (Charmaz 2006).

Findings

Experiences of RSHP Education

Barriers to RSHP education emerged as an overarching theme across the questionnaire and in focus groups. Younger and older participants reported an overwhelming lack of representation of girls and women with intellectual disabilities in the education that they did get if they were to receive RSHP education at all. Unable to rely on their schools or medical practitioners, many women reported that parents and mothers, in particular, could be important sources of sexual health education:

I learnt from my mum. It was a positive message about the right to have sex.
(Questionnaire respondent, age 28)

Some participants discussed that they were more informed and confident in their SRH rights due to the informal education that they received, usually from their mothers. These messages about their rights were positive and affirming and would go some ways to managing the exclusion from formal education.

Older women had received minimal information about sexual, reproductive, or relationship health, which then had impacted on their wellbeing throughout their lives. A lack of education was not only a lost opportunity but had damaging and avoidable health consequences. Older women with intellectual disabilities have not benefitted from relatively recent attitudinal, and policy, shifts. Women in the focus groups reported having limited access to RSHP education at school, and those who had lived as girls and young women in long-stay institutions had received none. The sex education they had received had focused exclusively on avoiding pregnancy:

My mum didn't tell me anything about sex. She just tried to keep me away from boys.

J: How did you come to know [about sex]?

From the telly.

(Ruth, 50s)

Older women found it hard to recall the sexual and reproductive health education that they might have received as girls. Most older women were not able to remember details, possibly, in part, due to not having had the benefit of access to online information (as girls). Older participants wanted sexual health education and information to be accessible to them, now, at this stage in their lives so that they could make informed choices about their intimate lives as older women.

Not being excluded from school RSHP classes is not the same as inclusion. Younger participants reported that they had attended sessions at school, but this resulted in complex issues in terms of accessibility or authority figures gatekeeping which elements of the resources were available 'for them'. One questionnaire respondent recorded a lack of any sexual or reproductive health education in school or from adult services later on saying that they had 'nobody to talk to about all of these things'. Young women with intellectual disabilities felt isolated and alienated in terms of their education—often not knowing where to go to get information or who to speak to. These narratives reflect entrenched social systems that either deny women access to knowledge about their own bodies (to constrain their reproductive potential) or to individualise the process of education, making it the responsibility of girls and women (and their families) rather than on the structures that are in place to provide equitable education. Participants felt excluded from RSHP education in general and often identified this exclusion:

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.

(Beth, 20s)

People with intellectual disabilities are routinely infantilised and have been subject to legacies of restriction from equal sexual and intimate citizenship (Hollomotz 2009; Thompson et al. 2014). Girl's and women's intimate citizenship is hidden through macro gender inequalities that locate women's lives in the so-called 'private' sphere. These intersecting inequalities compound to disadvantage girls and women with intellectual disabilities who are positioned as incapable of understanding their own bodies.

Experiences where participants had been removed from RSHP education or where information was inaccessible reaffirmed to participants that they were not considered to be equal citizens. This, in turn, shaped how they understood possibilities for their lives and futures, for having intimate relationships and the chance of becoming mothers:

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.

(Questionnaire respondent, 20s)

This section examined the broad impact of barriers to RSHP education experienced more chronically and acutely by older participants. There is a tension expressed between awareness of rights and missing experiences around knowledge and intimacies, together with an understanding of these being available to 'other' women. When recalling experiences of RSHP education, women frequently spoke of managing menstruation. The following section will turn to this specifically.

Menstrual Wellbeing

The relative absence of menstruation in social research reflects socio-cultural discourses that have relegated menstruation to the so-called private sphere (Moffat & Pickering 2019). While the experiences of marginal menstruators

are becoming more visible, the menstrual wellbeing of women with intellectual disabilities is almost entirely invisible in social research or feminist scholarship. Participants reported a lack of formative education on menstruation and as such experienced distress when their period began:

Nobody ever said what it [period] was or what caused it.
(Questionnaire participant, 30s)

Another questionnaire participant in her twenties reported

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

Cultural legacies of taboo around menstruation have amplified the menstrual invisibility of women with intellectual disabilities (Rodgers 2001). Participants who had decades of experience menstruating had limited knowledge about menstruation, its reproductive purpose, how to manage menstruation or menstrual pain, and how to identify issues or problems with their menstruation. Older participants who had spent time in institutional care had received very limited menstrual health information. The information they had access to was often from women in their families—mothers and sisters—and was constrained by social attitudes. In one of the focus groups, participants discussed what they knew or had been told about what menstruation was 'for':

I thought it was gettin' rid ae' bad blood in yer body.
(Eileen, 40s)
I was told it was eggs coming off and they fall down.
(Sally, 40s–50s)
See I did'nae know that, 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'.
[In response to Sally] (Enid, 60s)

Participants were not confident in stating what menstruation is 'for'. They were unclear of how their menstrual cycle was linked to pregnancy, how long they would menstruate for over the life course, and what the end of menstruation meant. Menstruation had not been part of their education as girls. No family member or professional had raised the issue beyond offering folk narratives relating to the end of girlhood and the beginning of womanhood with phrases such as, 'I got told it was the change of life, the change to your body' (Sue, 40s) and 'I got told don't go near men now that you've got them [periods]' (Eileen, 40s). Across the focus groups, women repeatedly referred to phrases such as 'the change of life', 'it means you're a woman now', and 'keep your legs shut!'.

Often the information that parents did give was underpinned by attempts to limit the 'risk' of pregnancy. While parents may have had caring intentions, paternalism constrained participants' agency over their menstrual wellbeing. Parents may have indicated to participants that they would experience embodied changes, but they did not provide their children with clear and accessible information that supported them to understand why they menstruated and how to identify changes in their menstrual health. Participants expressed that this made them more vulnerable to preventable health conditions:

P: Do you feel you would know what to do if you had any problems with your period?
Judith: I wouldn't even know what a problem would be? What do you mean?
P: Were you told about things like irregular bleeding, clotting, pain?
Judith: No, not ever, but oh yeah, I did have [blood] clots – lots of them, but I just carried on.
(Judith, 40s)

A lack of information extended to how to choose and use menstrual products. One primary source of information were pharmacists and, failing access to them, shop assistants. Participants sought information about what products to use, how long to use them for, and how to fit them onto underwear:

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

I didn't understand about periods and what to expect.

I didn't know what to do [with the pads], how often to change them or where to put them.
(A group of 4 women, ages 20s–30s)

Participants' ability to make informed choices about menstrual care were constrained, and they felt unable to perform 'correct' menstrual care for themselves. As Rodgers et al. (2006) have shown, women with intellectual disabilities

experience overwhelming 'management' of their menstruation by others, therefore giving them limited opportunities for engaging in their own menstrual care and demonstrating bodily autonomy, knowing how to identify changes in their menstruation and possible issues that warrant medical attention. Despite significant changes in RSHP education and increased social awareness of period poverty, menstrual provision in schools, and elevated awareness of human rights issues that speak to girls and women, younger women reported a lack of accessible education and support in menstrual management.

Contraception choice making

Like the other substantive areas raised in these findings, women felt that they had minimal information and knowledge about the range of contraceptives available. As a result, women's ability to make choices about contraception and family planning were not only restricted but actively guided towards hormonal contraceptive measures:

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.
(Mika, 20s)

Women with intellectual disabilities were more likely to use hormonal contraception, and this could also be used to end menstruation where 'this approach to menstrual suppression and fertility control could be replacing surgical interventions' (Rodgers et al. 2006: 370). The overwhelming use of hormonal contraception was reflected in focus group discussions:

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: Were you ever told about condoms?
No!!!
[Unanimously]
Nobody would ever want to have a conversation like that with women like us.
(Clare, 30s)

Enid's experience was the only one of coerced sterilisation, most likely due to her age and having lived in an institutional setting. The decision was a coerced one because Enid felt worried that her future children would be removed because of her impairment:

P: Did you choose that [sterilisation], Enid?
No I got married and I was wanting to have children, but I didn't want to get pregnant because I was frightened of the social [services] and I wasn't good at walking, I was frightened I could drop the wean [baby] and I would get accused of hurting it 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)

Experiences of contraceptive use were articulated through the lens of control and the absence of supported or informed decision making. Decisions over women's contraception were made on two bases: either to suppress menstruation or to avoid pregnancy risk. Younger questionnaire respondents were more likely to report better information about contraception but, again, this was almost always provided by family members. All of the younger questionnaire respondents also reported that they would benefit from more: more explicit information about contraception and how to use it and how it fits in with family planning for the future.

Autonomy, Information, and Reproductive Wellbeing

Women reported receiving very little information about cervical smear tests or breast health at any point in their lives. This had impacted, significantly, on the health of some of the older participants who had reported never having had cervical smear tests and then having to have colposcopy appointments to remove affected cervical tissue. Despite these

tests being established public health initiatives, self-advocacy organisations or women with intellectual disabilities, themselves, were active in supporting other women to have routine screenings:

I had bleeding there and then I had to get a surgery in the end because there was maybe cancer cells there.
(Karen, 50s)

After hearing what Karen had said in the focus group, Sally said that she'd never had a smear test and was going to go and get one:

I thought you needed to catch that cancer off someone? So I need to go and get that done [cervical smear test] now, and that's the next thing I need to do. (Sally, 40s)

Once given information, participants wanted to make sure that their reproductive wellbeing and health was being appropriately cared for. All participants (both younger and older) reported wanting more information about STIs and vaginal care. Older participants voiced that they were not aware that their hormonal contraception did not protect them against the risk of transmission, and some participants were informed through the focus group discussions with other women. One group asked us to organise sexual health classes for them, especially in relation to menopause.

Women who participated in the focus groups were in their 40s, 50s, and 60s, and while several had experienced, or were experiencing, menopause, they had limited knowledge of it:

I just want to learn what the menopause is, and I just want to understand.
(Liz, 50s)

J: Have you tried speaking to your GP about it?

No! Because he's a man!

(Liz, 50s)

I asked the doctor what it means, and all he said was 'your body goes through a change—you'll get all sweaty'.

(Ruth, 50s)

Like menstruation, participants wanted to know in detail what was happening to their bodies throughout menopause and how to understand and interpret changes, such as 'hot flushes', mood changes, or pain. Whether health professionals were giving this information or not, it was not in a way that participants found to be accessible or lasting. Male GPs were often cited as barriers to information about gendered health issues due to gendered power dynamics where women felt embarrassed or worried about talking to a man, especially men who were felt to be in positions of authority. When discussing menopause, participants linked their lack of knowledge in later life to information being withheld by parents as younger women:

Your mum and dad don't want to tell you about things like that because they think because you've got a learning disability you don't understand! They hide it away from you because it's better for them.

J: How does that make you feel?

They should be letting me know what's happening to me.

(Elsie, 40s)

While earlier sections explored how younger women felt empowered by family members, older participants experienced parents and families as gatekeepers to bodily autonomy. Participants reported that their parents felt that having an intellectual disability was in opposition to informed sexual citizenship. This opposition was experienced as exclusion in formal education, misinformation, or withheld information by parents and families and through difficult relationships with health professionals.

P: What would help you with managing these things?

Speaking to a doctor or a nurse.

(Judith, 40s)

Doctors are useless, and they don't care about us.

(Eileen, 40s)

I can tell, my doctor just thinks I'm stupid—I'm nothing to him.

(Clare, 30s)

Questionnaire participants also reported a lack of communication with health professionals and wrote about feeling dismissed by doctors based on intellectual disability:

A lot of people without learning disabilities, like your doctor, they're talking to people with a learning disability not that sensitive. Some people would say 'right they've got a learning disability, so no use talking to them...

what's the use explaining things to them' but we're human, and we've got a brain, and we've got thoughts, and we hurt, and we can speak. I mean we've got everything else what a person's got.
(Lena, 20s)

Participants felt they were not afforded their rights because they had an intellectual disability. Differential health outcomes for women with intellectual disabilities are, in part, a result of systemic structural inequality (Emerson & Hatton 2012) that produce lasting health inequalities. For women with intellectual disabilities, this intersects with significant inequalities relating to sexual and reproductive health.

Conclusion

This paper has examined the lives of women with intellectual disabilities in Scotland, their experiences of reproductive rights and inequality and the consequences that these inequalities have on health and wellbeing. By beginning with the narratives of women with intellectual disabilities, this paper addresses the invisibility of this group of women from mainstream feminist narratives of reproductive justice. Locating reproductive inequality within the myriad causes that lead to early and preventable deaths of women with learning disabilities is essential to building an intersectional feminism that includes disabled women.

Women with intellectual disabilities live shorter lives in Scotland than their male counterparts and the general population; their reproductive wellbeing continues to remain hidden in both everyday discourse and policy. This invisibility contributes to the causes that underlie these shortened lives and devaluing of the reproductive lives of women with intellectual disabilities. A commitment to challenging the unequal power relations in society that make these gendered inequalities possible and the socio-attitudinal processes that devalue the lives of people with intellectual disabilities are essential to realising rights. There is also a need to initiate a number of practical changes that action the robust policy provision that already exists.

The findings presented evidence a need to ensure that RSHP education be accessible to women with intellectual disabilities at all stages of their lives. This is particularly salient in the context of reliance on individualised and informal education and support work undertaken in the 'private' sphere through support networks, self-advocates, and family members, and almost always by women. The overwhelming outcome of a lack of inclusive information was that women felt they were restricted from making decisions about their own bodies. A lack of commitment by health and education professionals, and sometimes family members, to recognising and establishing the importance of supported decision making and informed consent rendered women unable to meaningfully participate in their own citizenship.

Choice and agency are shown to be constrained in making decisions around contraception, and, as the focus group data shows in detail, disabled women are often encouraged to use hormonal 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). Failure to do so amounts to the claim that consent is at best 'informed compliance' (Stapleton et al. 2002: 639). This indicates that the rights of women with intellectual disabilities to 'retain their fertility' on a par with others is diminished. Not only does this impact on the ability to make informed choices about her future but has the potential of placing women with intellectual disabilities at higher risk of STIs (Dotson et al. 2003). Women with intellectual disabilities are denied comprehensive discussions about condom use because, in part, they are viewed as outside of idealised ableist constructions of sexual citizenship and reproductive value. As Saunders (2020) maintains, it is a 'normative neoliberalism' that produces expectations that women are responsible for their own reproductive wellbeing, despite being denied appropriate resources. Whereas, prioritising reproductive justice can 'shift the focus from neoliberal notions of individual choice to understand reproductive decisions as connected to the social world and other people, and therefore as facilitated or constrained based on access to resources' (Saunders 2020: 5).

Much of the constraint on choice making, and processes of control enacted by others, was underpinned by attempts to minimise risk of pregnancy, which reinforces dominant discourses around the unsuitability of women with intellectual disabilities as mothers. These experiences also reflect the lack of rigorous application of human rights legislation and integrated policies to the provision of reproductive care and reflect ableist sexual health provision that does not meet the needs of disabled women. Further still, they demonstrate the ways in which policies of enforced sterilisation take new forms and are woven into contemporary processes that constrain women with intellectual disabilities' ability to become mothers.

Changes in policy and practice are urgently required to address the inequalities in health and wellbeing experienced by women with intellectual disabilities in Scotland. As indicated in the findings, participants discussed a lack of inclusion in routine reproductive health screenings or information on their sexual and reproductive health. As such, commensurate and accessible information is required to meet the needs of women with intellectual disabilities and to provide the means for women to make informed decisions about their reproductive and sexual health and wellbeing.

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Competing Interests

The authors have no competing interests to declare.

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