






Menstruation and learning disability across the life course: Using a two-part scoping exercise to co-produce research priorities

Sarah Earle¹  | Susan Ledger²  | Victoria Newton²  | Lorna Rouse²  | Elizabeth Tilley² 

¹School of Social Sciences, Nottingham Trent University, Nottingham, UK

²School of Health, Wellbeing and Social Care, Faculty of Wellbeing, Education and Language Studies, The Open University, Walton Hall, UK

Correspondence

Elizabeth Tilley, School of Health, Wellbeing and Social Care, Faculty of Wellbeing, Education and Language Studies, The Open University, Walton Hall MK7 6AA, UK.
Email: elizabeth.tilley@open.ac.uk

Abstract

Background: Across the life course, women and girls with learning disabilities and their carers report difficulties in accessing information and support with menstruation, yet their experiences are often overlooked in initiatives to improve menstrual health and wellbeing. Our aim was to collaborate with women with learning disabilities to co-produce future research priorities in a UK context.

Methods: We undertook a two-part scoping exercise to explore what is known about this topic from a life course perspective, beginning pre-menarche and extending to post-menopause support. This combined a rapid scoping review of the literature since 1980 with a stakeholder consultation where people with learning disabilities, family carers, advocacy groups and staff working across education, health and social care were invited to share their experiences of menstruation support.

Findings: UK and international literature provided insight across five narrative themes. Seventy stakeholders took part in our consultation, enabling the identification of five key themes. Findings across both highlight examples of supportive practice and valued resources alongside enduring health inequalities and barriers to menstruation support faced by women and girls with learning disabilities across the life course.

Conclusion: Our scoping exercise identified multiple gaps in research and practice, ongoing reproductive health inequalities and a need for improved access to peer support, resources and training that take a life course approach. The scoping exercise indicates the need for further empirical research on menstruation and learning disability, with a particular focus on collating people's lived experiences.

KEYWORDS

health, learning (intellectual) disabilities, menstruation

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Authors. *British Journal of Learning Disabilities* published by John Wiley & Sons Ltd.

Accessible summary

- We wanted to find out what support and information is available to girls and women with learning disabilities about periods (also called 'menstruation') over a lifetime.
- This was to help us work out what new research might be needed in the future.
- Our team included women with and without learning disabilities. We are based in the United Kingdom.
- We read lots of articles, from the United Kingdom and around the world.
- We spoke to lots of people who care about this issue and know about it. This included women with learning disabilities, family carers, advocacy groups and staff working in education, health and social care settings.
- There is not enough guidance about periods for girls and women with learning disabilities.
- A lot more research is needed about how to support women with learning disabilities with their periods, over their whole life.
- This must also include women with profound and multiple learning disabilities and women from minority ethnic communities.
- Our work showed that we need to hear much more from women with learning disabilities themselves.

1 | BACKGROUND

Internationally and in the United Kingdom, menstruation and improving menstrual health is increasingly recognised as an important area of healthcare (Barrington et al., 2021). The World Health Organisation recently called for menstrual health to be addressed from pre-menarche to post-menopause (World Health Organisation, 2022). In the United Kingdom, there has also been increased political and societal attention on menstrual health throughout the life course (All-Wales Menopause Task and Finish Group, 2023; Department of Health and Social Care, 2022a; The Scottish Parliament, 2023). The policy paper *Women's Health Strategy for England* outlines ambitions relating to menstrual health, including increasing awareness and understanding, access to high-quality personalised care for all and ensuring that everyone is well informed about menopause (Department of Health and Social Care, 2022b). However, questions have been raised over whether women and girls¹ with disabilities, including those with learning disabilities, have equal access to information and support for menstrual wellbeing across the life course (McAteer, 2022; Steele & Goldblatt, 2020; Wilbur et al., 2019).

In the United Kingdom, an estimated 1.5 million people have learning disabilities (Office for National Statistics, 2020). The limited existing research into menstruation and learning disability (including people with learning disability and autism) indicates that this population may experience heightened challenges in

managing menstrual health across the life course (Cooper et al., 2019; Office for Health Improvement and Disparities, 2023a, 2023b) including difficulty understanding and managing menstruation and different patterns of menstruation such as earlier menarche or menopause for those with specific genetic syndromes (Butler et al., 2002; Carr & Hollins, 1995; McCarthy, 2009b; Rodgers et al., 2006).

Access to menstrual health information and support may be more problematic for women with learning disabilities reflecting wider healthcare barriers and inequalities (Emerson, et al., 2016; Glover et al., 2017). Concerns have been raised about the overuse of contraception to manage or suppress menstruation (Rodgers, 1999) and healthcare professionals have described different approaches to problematic menstruation when a person has a learning disability, including delays caused by addressing the capacity to consent to treatment and diagnostic overshadowing (McKinlay et al., 1996; Rodgers, 1999; Wishart et al., 1998). More recently, McAteer has argued that the lack of research and awareness on menopause for this population may be impacting the quality of care that they receive (McAteer, 2022). This is further supported by an international review of the literature on menopause and learning disability which identified that the experiences of women themselves are poorly documented in existing research (Moore et al., 2023). The UK's guidance on managing menstrual health problems does not specifically address the needs of, or interventions for, people with learning disabilities and their carers (National Institute of Health and Care Excellence [NICE], 2019).

Despite continuing calls for further research and interventions over the last two decades, there has been no recent review of the

¹We use 'women and girls' to reflect the terms most commonly found in our scoping exercise, but acknowledge that not everyone who menstruates will identify as such.

international evidence from a life course perspective. To address this and to identify the priorities for future research in a UK context, we worked collaboratively with women with learning disabilities to undertake a rapid scoping review of the literature alongside a stakeholder consultation. This paper reports our findings, setting out co-produced priorities for future research on menstruation for women and girls with learning disabilities across the life course.

2 | METHODS

Our scoping exercise comprised two distinct components, each contributing to the co-production of research priorities:

- Part 1: a rapid scoping review of the literature between 1980 and 2022.
- Part 2: a stakeholder consultation.

The rapid scoping review of the UK literature was originally run in January 2021 and updated in January 2023 (resulting in the inclusion of one further paper). In November 2023, we piloted a review of the international literature to scope the breadth of relevant material and to explore potential synergies/divergences with the UK literature. The stakeholder consultation exercise ran in parallel during 2021–22. Ethical approval was not required for this consultation stage as it did not reach the threshold for research and the intention was to support the co-identification of research priorities.

2.1 | Rapid scoping review of the UK literature

Scoping reviews can provide a descriptive account of the existing literature when time and resources are scarce, helping identify gaps for further study which can be easily summarised and shared (Arksey & O'Malley, 2005; Levac et al., 2010). Researchers have previously combined rapid reviews of the existing evidence with explorations of stakeholder experience to provide additional insight (Arksey & O'Malley, 2005; Jacobs et al., 2016; Ledger et al., 2022; Roberts et al., 2018). This is the approach we took for the purposes of our review. In line with Arksey and O'Malley's (2005) framework, we followed the five steps of identifying the research question, identifying relevant studies, study selection, charting the data and collating, summarising and reporting the results (Arksey & O'Malley, 2005). Our review aimed to address the following questions:

- What issues do women and girls with learning disabilities, and their carers, face around menstruation?
- Has there been any evaluation of interventions/services/resources to support girls and women with learning disabilities around menstruation?
- Are there any obvious gaps in the existing academic literature?

2.1.1 | Search strategy & identifying relevant studies

An inclusive team worked together to select inclusion/exclusion criteria and search terms for the scoping review of the literature (see Supporting Information: Tables S1 and S2). The search terms were determined using the framework of population, concept and context (Peters et al., 2020) and refined through an initial limited search of Academic Search Complete. The literature review aimed to find papers that described research which added to our understanding of menstruation for people with learning disabilities and their carers across the life course, published in the United Kingdom between 1980 and December 2022. The start point of 1980 was chosen to capture increased attention on the topic in the latter decades of 20th century due to heightened public awareness about premenstrual syndrome, toxic shock syndrome and increased academic and lay interest in the cultural aspects of menstruation.

Search terms were designed to cover variations on the terms 'learning disability' and 'menstruation' recognising that these terms would change over time. Due to the potentially limited amount of research on the specific topic of learning disabilities and menstruation, we included papers in our UK-based search which addressed the topic of learning disabilities and menstruation as part of a wider project; for example, papers that described sex education programmes which included coverage of menstruation.

Databases were chosen based on their availability and relevance to this interdisciplinary topic. The search strategy was piloted and adapted after initial searches returned many irrelevant papers. The search strategy was adapted for each database including the use of available filters relevant to the inclusion/exclusion criteria. Reference lists of selected existing literature were also checked but did not identify new results. A full search of citations and a search of the grey literature was not completed due to time constraints. Details of the searched databases, study selection and screening processes can be found in the PRISMA diagram (Supporting Information Material). In total, 32 UK papers were included, details of which can be found in Supporting Information: Table S3, Included Study Characteristics (Supporting Information Material).

2.1.2 | Collating, summarising and reporting results for the UK review

Included papers were collated in a summary table and organised into narrative themes in line with the aims of a scoping review (Arksey & O'Malley, 2005). The research team met to discuss these and agree on key findings, questions to follow up, gaps in the research and their relevance to the stakeholder consultation. An accessible presentation was developed for stakeholder feedback and verification of the relevance of key findings.

2.2 | Pilot scoping review of the international literature

The limited UK literature found during the scoping review indicated a need to scan the international literature. Time and resource constraints prevented the research team from undertaking a review of the international literature with the same depth of analysis as the UK literature review. However, a pilot search of the international literature was run to build a wider understanding of the scope and focus of existing research and to identify broad thematic areas and synergies between the United Kingdom and international literature.

The international review sought research conducted outside of the United Kingdom. The search strategy mirrored the UK review described above except that due to the high number of hits found when searching titles and abstracts, the search was limited to publication titles. The inclusion/exclusion criteria matched the UK search with one exception. Due to the large number of returns in the international review, papers were excluded during screening if menstruation was not the primary focus. These decisions reflect that this was a pilot scoping review that aimed to provide context to the UK review rather than present a comprehensive and systematic review of the international literature.

The search of the international literature returned 1409 hits. Following the removal of duplicates and UK research, 625 titles were screened for relevance and 260 full-text articles were included for full-text screening, of which 37 met the inclusion criteria. Following the screening process, papers were read to determine fit with the five narrative themes previously identified in the UK literature described below in Section 3.1 and to identify additional themes. In this paper, we only reference international papers relevant to the wider findings and discussion.

2.3 | Stakeholder consultation methods

Part two of our scoping exercise, co-designed with women with learning disabilities, aimed to increase understanding of how menstruation is experienced across the life course by people with learning disabilities and the carers and practitioners involved in their support. Previous research demonstrates the critical importance of listening to lived experience as a way of shedding light on areas where gaps exist between policy and practice, in addition to turning a spotlight on examples of good practice (Ledger, 2019; Wiseman & Ferrie, 2020).

2.3.1 | Preparation of stakeholder consultation documents

Women with learning disabilities on our team championed the importance of understanding menstruation across a lifetime,

leading to the selection of images² that would most effectively prompt and support stakeholders to share their experiences of each life course stage.

These images were incorporated into the development of two stakeholder consultation documents:

- A pictorial life course prompt sheet titled 'Periods (menstruation) across a lifetime - what's working well and where are the gaps?' (see Figure 1).
- A list of questions with images titled 'Information and support with periods for people with learning disabilities' (see Figure 2). This was the main consultation document used to invite feedback from stakeholders.

The same list of questions with images was used for all participants accompanied by the pictorial life course prompt sheet.

Stakeholder documents were trialled with members of a self-advocacy group for feedback and further refinement, including the vocabulary that would be most accessible to girls and women with learning disabilities. After careful consideration of the word 'menstruation', including the advantage of people with learning disabilities getting to know words that are complex but important (Leonard et al., 2022) women with learning disabilities advised that the term 'period' rather than 'menstruation' remained the one that was most commonly used and understood. Below are quotes from two self-advocates we spoke to:

Menstruation, well it's not really a word you hear much. People talk about periods and period pain.

It [term menstruation] might put them off saying something. They might think it's nothing to do with them.

Reflecting this, our stakeholder consultation was publicised as 'The Open University Period Project'.

2.3.2 | Stakeholder consultation

Invitations to take part in our stakeholder consultation were circulated through social media and the Supported Loving Network and sent via email to groups and organisations including self-advocacy groups and RSE trainers and resource-writers, learning disability charities, menstrual health charities and/or education providers. Many people then forwarded invitations to others, enabling further 'snowball sampling' within networks.

People were offered the opportunity to take part online as an individual or as part of a group or to respond to questions by

²Images were selected from Photosymbols and other online open-access sources.

Periods across a lifetime – what's working well and where are the gaps?

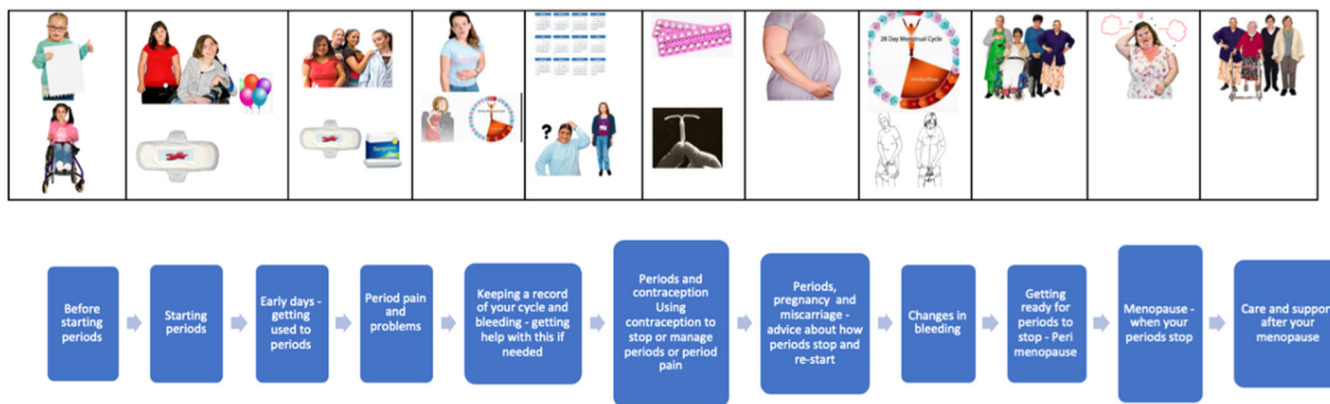


FIGURE 1 Extract from pictorial life course prompt sheet used during stakeholder consultation.

phone, online platforms, email or post. For telephone or online platform participation, researchers gained verbal consent at the outset of the call confirming that the information reported would be fully anonymised. All participants were also sent a written scoping project information sheet explaining that any information shared would be fully anonymised before reporting.

A list of questions with images accompanied by a pictorial prompt sheet was used to ask participants about their experiences of periods across seven broad life course stages:

- Before starting periods.
- Starting periods.
- Early days—getting used to periods.
- Having periods.
- Getting ready for your periods stopping: peri-menopause.
- When periods stop: menopause.
- After periods stop: post-menopause care.

For each life course stage, stakeholders were invited to share their experience of periods including:

- Any use of information or resources (as part of the consultation stakeholders were invited to share any documents, videos or links to resources they had found helpful).
- Any access to local or national support groups or services.
- Any big gaps in access to information or support.

Stage 4, 'Having Periods', contained five further prompts exploring particular aspects of menstruation (e.g., cycle tracking; pregnancy and miscarriage).

At the close of our consultation, all stakeholder responses were collated in a spreadsheet with an entry for each participant or group containing anonymised key messages and quotes. Manual thematic analysis was undertaken using index cards and post-it notes to identify and report key themes.

3 | FINDINGS

In this section, we present the findings of the rapid scoping review of the literature followed by the findings from our stakeholder consultation.

3.1 | Rapid scoping review of the literature

The majority of included papers from the UK were published between 2000 and 2009 (n20). The earliest included paper was published in 1992 and the most recent paper was published in 2020. International papers that met the inclusion criteria for the pilot review were published between 1983 and 2022 and the majority were conducted in the United States (×13) and Taiwan (×5). Our analysis of the UK-based literature identified five narrative themes, presented below in order of highest to lowest frequency: (1) concerns relating to menopause (2) limited knowledge and understanding of menstruation (3) problematic menstruation (4) contraception and sterilisation (5) menstruation differences specific to women and girls with learning disabilities.

The pilot review of international literature demonstrated that there is wide-ranging interest in learning disabilities and menstruation. In addition to discussing the five narrative themes found in the UK literature, the international literature had a particular focus on the piloting and evaluation of interventions to prepare young people and/or carers for menarche (Altundağ & Çalbayram, 2016; Ersoy et al., 2009; Fei et al., 2021) and on examining menstruation related differences/concerns for people with learning disabilities and genetic syndromes (Kaskowitz et al., 2016; Wandresen et al., 2019).

3.1.1 | Concerns relating to the menopause

The most frequently raised concern in the menopause literature was that women with learning disabilities lack understanding of the menopause (McCarthy, 2002a; McCarthy & Millard, 2003;

FIGURE 2 Extract from the main consultation document (questions with images) used to explore information and support with periods (menstruation) for people with learning disabilities across the life course.

<p>Periods over a life time</p> 	<p>Information you have used</p> 	<p>Support groups or services in your area</p> 	<p>Any big gaps you have found in support?</p> 
			
<p>Before starting periods</p> 			
<p>Starting periods</p> 			
			
<p>Early days - getting used to having periods</p> 			

Willis, 2008; Willis et al., 2011) and do not have access to accessible information and training on the topic (McCarthy & Millard, 2003; Willis et al., 2010, 2011). A recurrent theme was that women with learning disabilities and their carers face problems relating to menopause and that there is a concerning lack of interventions and resources on the topic. Eight papers that focused on the experience of menstruation more broadly also discussed or reported concerns relating to menopause (Ditchfield & Burns, 2004; Ledger, et al., 2016; Mason & Cunningham, 2008; McCarthy, 2009a, 2009b; O'Dwyer & Friedman, 1995; Rodgers, 2001; Rodgers & Lipscombe, 2005). A further eight papers focused specifically on the topic of menopause for women with learning disabilities and/or those who support them (Carr & Hollins, 1995; Martin, et al., 2003; McCarthy, 2002a, 2002b; McCarthy & Millard, 2003; Willis, 2008; Willis et al., 2011).

In common with the general population, women with learning disabilities tend to confuse signs of ageing with menopause symptoms and report that doctors tend to dismiss their symptoms (McCarthy, 2002a; McCarthy & Millard, 2003). Two papers found women with learning disabilities described the experience of menopause in a different way to women without learning disabilities including a focus on physical symptoms with lesser consideration of psychological, social and emotional impact (Martin et al., 2003; McCarthy, 2002a; McCarthy & Millard, 2003). Willis (2008) argues that their findings challenge this idea. Women with learning disabilities may experience similar physical and psychological impacts of menopause but need support to understand and communicate their symptoms (Martin et al., 2003).

The literature reported a need for specific education and training for staff who support women with learning disabilities through menopause (McCarthy & Millard, 2003; Willis et al., 2010, 2011). Post-menopause support, communicating concerns about symptoms to GPs, awareness of the risk of diagnostic overshadowing and early menopause, explaining physiological changes, HRT and treatment options were emphasised (Willis et al., 2010, 2011). A paper from Taiwan similarly noted a lack of preparation for menopause in people with learning disabilities and reported that how their carers perceived the level of menopausal symptoms in their relatives with learning disabilities was affected by factors such as carer age, education and own experience of menopause (Chou et al., 2013).

3.1.2 | Limited knowledge and understanding of menstruation

Eleven papers reported that women with learning disabilities often did not have a good understanding of menstruation (McCarthy, 2002a; McCarthy & Millard, 2003; Rodgers, 2001; Willis, 2008; Willis et al., 2011), including gaps in knowledge, misunderstandings and confusion about menstruation such as being unaware of common terms like 'pre-menstrual tension', 'menopause' and 'change of life', confusion about the process of menstruation (what happens), not knowing the reproductive significance of menstruation and that periods will one day stop, and being unable to identify the symptoms of menopause (Ditchfield & Burns, 2004; McCarthy, 2002a; McCarthy & Millard, 2003; Willis, 2008).

Additionally, three papers describe a lack of knowledge and understanding about the management of their own menstruation including being unaware of the purpose and consequences of interventions being used to manage their menstruation and difficulty recognising problems that might require support (McCarthy, 2009b; Rodgers et al., 2006; Walmsley et al., 2016). The international literature included a particular focus on improving knowledge and understanding of menstruation through interventions aimed at preparing young people with learning disabilities for menarche (Altundağ & Çalbayram, 2016; Ersoy et al., 2009; Fei et al., 2021).

3.1.3 | Problematic menstruation

Six papers focused on the topic of problematic menstruation including pre-menstrual syndrome (PMS), difficulty managing menstrual care, high frequency of pain/pain management and prolonged bleeding (Cooper et al., 2019; Kennedy et al., 2014; Mason & Cunningham, 2009; Obaydi & Puri, 2008; Pillai et al., 2010; Rodgers et al., 2006). This issue was also raised in six additional papers exploring other aspects of menstruation (Cummins et al., 2020; Ditchfield & Burns, 2004; Ferguson et al., 2002; Ledger et al., 2016; Rodgers, 2001; Walmsley et al., 2016). The most commonly raised problem was PMS. Cooper et al. (2019) reported that all papers in their review demonstrated higher rates of PMS in women with learning disabilities compared with the general adult population and that there were no standardised symptom criteria for diagnosis of PMS in women with learning disabilities (Cooper et al., 2019).

Two studies examined the prevalence and nature of menstrual problems (Obaydi & Puri, 2008; Rodgers et al., 2006). Rodgers et al. (2006) conclude that menstrual problems may be experienced differently and more negatively and may not always be recognised appropriately for women with learning disabilities and that those with a severe/profound learning disability were more likely to have marked or severe period problems at some stage (Rodgers et al., 2006).

Three papers reported on or evaluated interventions for problematic menstruation (Kennedy et al., 2014; Mason & Cunningham, 2009; Pillai et al., 2010). Mason and Cunningham (2009) reported on the adaption and evaluation of a daily diary, used to diagnose PMS in the general population for women with Down's syndrome and/or their carers (Mason & Cunningham, 2009). The authors conclude that the diary is a user-friendly way of assessing PMS. Kennedy et al. (2014) report on the development of a small non-randomised controlled pilot study to evaluate elements from an existing Cognitive Behavioural Therapy programme as an intervention for menstrual pain management for young women with mild to moderate learning disabilities. The paper reports on how the evaluation was conducted but does not report on the findings of the evaluation. A paper by Pillai et al. (2010) which reports on experience with the levonorgestrel intrauterine system (LNG IUS) for the treatment of menstrual problems in adolescents included three participants described as having a severe learning disability (Pillai et al., 2010). Overall, the authors conclude that the LNG IUS provided good therapeutic benefits to a high proportion of adolescents. For all three participants

with learning disabilities, the outcome was given as 'Amenorrhoea' but in the long-term families requested removal rather than replacement of the device. The reasons for this are unclear.

Four papers describe barriers to accessing support with problematic menstruation (McCarthy, 2002b; McCarthy & Millard, 2003a, 2003b; Willis et al., 2011). Women who spoke to someone such as staff, family or healthcare professionals about menopause symptoms were not always satisfied with the outcome (Willis et al., 2011). GPs have reported that during appointments, family and staff carers can be a hindrance, for example, deciding the person is attention-seeking (McCarthy, 2002b).

3.1.4 | Contraception and sterilisation

Five papers contribute to our knowledge of the use of contraception and sterilisation to manage menstruation for girls and women with learning disabilities. Three studies focused on the experience of women with learning disabilities themselves (McCarthy, 2009b, 2009a; Walmsley et al., 2016), one on the experiences of those who support them (learning disability nurses, paid care/support workers and family) (Ledger et al., 2016) and one on the experience of GPs (McCarthy, 2011). Six papers reported the use of contraception or sterilisation to manage/regulate menstruation or as a response to problematic menstruation for women with learning disabilities including for those not sexually active (Ledger et al., 2016; McCarthy, 2009a, 2009b, 2011; Stansfield et al., 2007; Walmsley et al., 2016). All of the studies which interviewed women with learning disabilities on the topic found that they had limited knowledge and understanding of contraception including the purpose of contraception (McCarthy, 2009a, 2009b, Walmsley et al., 2016). All of these papers also reported that women with learning disabilities had limited/constrained or no involvement in the decision-making around their contraception use (McCarthy, 2009a, 2009b; Walmsley et al., 2016).

Two papers focus on forced sterilisation (sterilisation without consent) and offer a historical review of the literature (Tilley, et al., 2012) and a retrospective case note study (Stansfield et al., 2007). These draw specific attention to the wide-ranging reasons that have underpinned decisions taken by practitioners and families to sterilise women with learning disabilities without their knowledge or consent through secrecy, coercion or compulsory programmes. Such decisions have in some historical and geographical contexts been sanctioned by state legislation; in other cases, such procedures were undertaken without the authority of the relevant legal body. These papers highlight the implications of forced sterilisation for women's human rights making a clear distinction between involuntary sterilisation and the use of sterilisation as an informed contraceptive choice.

The use of contraception and sterilisation to manage menstruation for people with learning disabilities was also a theme in the international literature (Dizon et al., 2005; Retznik et al., 2023; Wandresen et al., 2019).

3.1.5 | Menstruation differences specific to women and girls with learning disabilities

The literature highlights physiological differences in menstruation experiences linked to specific genetic syndromes relating to menopause (as described above) and during other stages of the life course (Butler et al., 2002). This theme was also reflected in the international literature (Ejskjaer et al., 2006; Ibralic et al., 2010; Schupf et al., 1997; Seltzer et al., 2001). Four papers describe differences in the onset of menopause, menarche or frequency of menstruation (Butler et al., 2002; Carr & Hollins, 1995; Martin et al., 2003; Rodgers & Lipscombe, 2005). In contrast, Mason and Cunningham (2008) report that the age and pattern of menses in their population of women with Down's Syndrome was similar to that of the general population (Mason & Cunningham, 2008).

Six papers discuss the different contexts in which women with learning disabilities experience menstruation across the life course as complicating factors (McCarthy & Millard, 2003). These include the lack of privacy that comes with group living, the role of family/paid carers, tensions between independence and control and taboos and social attitudes around reproductive health (Mason & Cunningham, 2008; McCarthy, 2002a, 2002b; McCarthy & Millard, 2003; Rodgers, 2001; Rodgers & Lipscombe, 2005; Tilley et al., 2012; Willis, 2008).

3.2 | Stakeholder consultation findings

This section presents findings from our stakeholder consultation. In doing so, it highlights recurrent themes in relation to support with menstruation across the life course, and at specific life stages.

A total of 70 individuals, groups and organisations living and/or working in the United Kingdom contributed to our stakeholder consultation. Some participants elected to take part via telephone (22) with a number then emailing additional information (10); some people chose to contribute via online platforms (5); and others emailed (29) or posted (1) their completed responses to our list of questions. The team facilitated two some people chose to contribute via online group stakeholder sessions, the first attended by adults with learning disabilities (12), the second by carers, trainers, teaching staff, health and social care practitioners including specialists in the development of RSE (Relationships, Sex and Education) policy and practice for people with learning disabilities (19).

Methods resulted in engagement with a wide cross-section of stakeholders (see Supporting Information: Table S4) generating primary and secondary accounts of menstruation support across the life course.

Analysis of stakeholder responses resulted in the identification of five key themes:

- (1) Access to information and support.
- (2) Access to local or national support groups or services.
- (3) Examples of what is working well.
- (4) Period Pain, problematic periods and use of long-term contraception.
- (5) Gaps in current support.

3.3 | Access to information and resources

During the stakeholder consultation exercise, the team were sent a range of examples of information and resources used by stakeholders to support people with learning disabilities with menstruation across the life course. This included accessible publications, videos, training materials, books, online toolkits and websites, in addition to brief descriptions of resources developed in individual classroom or adult settings. Responding to our prompt questions, stakeholders identified the life course stage where they primarily used the resource (with some resources described as relevant to more than one stage). Other resources, notably the Supported Loving online toolkit, were listed as very helpful across the life course.

Women with learning disabilities, advocacy groups and trainers/authors emphasised the importance of including the perspective of people with learning disabilities in the development of future menstruation resources and delivery of training. Stakeholders currently engaged in delivering training reported the value of co-presenting RSE training, including teaching about menstruation. One school for people with complex learning and physical disabilities described having successfully involved former pupils in presenting information for a session on managing periods and reported this had been very well received by pupils.

Despite the existence of these resources, a significant number of stakeholders (including front-line staff, non-specialist nurses and GPs), reported being unfamiliar with any accessible resources relating to menstruation or menopause, suggesting a need for more effective signposting to what is already available.

Three groups of women with learning disabilities reported their members had been unprepared for periods and menopause, with no previous access to information to support their understanding, as exemplified in this quote from one advocacy group facilitator:

I spoke to a small group of women with learning disabilities regarding your questions. It was really sad, as they answered that they hadn't had any help in any of the areas and couldn't think of resources that supported their understanding [...] They also felt that they hadn't been given sufficient information about period products, with an assumption that they would just use pads or sanitary towels.

Echoing this, many front-line workers said they felt unprepared to introduce people with learning disabilities to a range of menstrual products. Stakeholders reported that although they could see the potential benefit of reusable period pants for many of the people they were supporting, they were unsure if the organisation they worked for supported this or the use of internal products such as cups, sponges or tampons.

Funding was frequently mentioned as a barrier in access to more expensive resources to support learning about menstruation such as anatomically correct dolls and menopause training packs. After stakeholder consultation ended the research team received 25 follow-

up requests from care providers and advocacy groups for details of resources shared, further underlining the lack of access to menstruation information adapted to the needs of people with learning disabilities.

Stakeholders consistently identified period pain, heavy bleeding, changes in bleeding and what they might mean, peri-menopause, menopause and post-menopause care as gaps in accessible information. Women with learning disabilities felt there was a need for clearer information about links between periods and pregnancy. Two organisations, two trainers and one author explained that they had prepared new resources about menopause in response to an identified gap.

Several stakeholders drew attention to the need for improved resources to support people with complex learning and physical disabilities where the use of wheelchairs, incontinence pads and prosthetics can make it even harder for young people to see/touch and understand their own bodies.

3.4 | Access to local or national support groups or services

Stakeholders pointed us to a number of support groups that were relevant to menstruation for people with learning disabilities. Most of these were local and often sought in response to individual needs. Stakeholders with learning disabilities repeatedly drew attention to the importance of opportunities for peer support in managing their health and wellbeing, including periods and period pain:

What is important to us is coming together as a group to support each other.

Respondents referred to four strands of existing work where menstruation support has begun to be embedded at the national level. These were Positive Behavioural Support where cycle tracking is being incorporated to reduce the risk of diagnostic overshadowing, work to support older people with a learning disability where menopause training and support are included, work in special schools to support mandatory RSE education that included support for families, including menstruation support and health action planning - where some NHS regions have introduced specific questions about menstrual health and changes in bleeding.

All stakeholders from mainstream and national organisations promoting menstrual health (10) and helping women with problematic menstruation (2) and menopause (1) identified a significant gap in support for women with learning disabilities in that none were currently providing any form of direct support or accessible information to this population.

We don't currently have any resources for women with learning difficulties sadly [...] which certainly speaks to a clear gap here.

Some stakeholders reflected on a gap between available information and resources and their actual use with women with

learning disabilities in everyday practice. However, across education settings, many teachers reported that the introduction of compulsory RSE teaching for children and young people with learning disabilities in the United Kingdom in 2021 has increased the engagement of special school staff with the RSE curriculum and how to adapt it:

This has resulted in our staff team initiating work to deliver improved RSE including better support with menstruation for children and parents.

This raises questions about effective drivers for national improvement in terms of support for women with learning disabilities, including partnership work currently in progress between Supported Loving and regulatory bodies such as CQC and the national training agency Skills for Care.³

3.5 | What is working well: Stakeholder examples

Stakeholders were asked to share examples of what is currently working well. Responses included rapid access to skilled advice from a GP, Paediatrician or community learning disability nurse that helps with period pain and concerns regarding heavy bleeding, including consideration of alternatives to the use of long-term contraception. Respondents also highlighted the use of pre-Health Action Plan documents that specifically ask about 'changes in periods/painful periods/and menopause symptoms'. Peer support—facilitated by special schools either face-to-face or online—was identified as providing opportunities for people with learning disabilities to come together to share information about menstruation and help and learn from each other.

For people with more complex needs, the use of social stories to accompany work with anatomically correct dolls (including an explanation of the use of internal products such as tampons) was identified as working well, as were the use of reusable and washable 'Period pants' to help people with learning disabilities and their carers manage bleeding, often especially helpful to wheelchair users.

Respondents also pointed to the importance of menstruation/menopause training for family carers and staff in education, health and adult social care settings and the benefits of apps and paper-based diary sheets to record and monitor menstruation cycles. Finally, the use of massage and movement sessions was highlighted as good practice in schools to alleviate experiences of period pain.

3.6 | Period pain, problematic periods and use of long-term contraception

Improved understanding, management and treatment of pain, heavy bleeding and problematic periods was the gap in support most

frequently identified by women with learning disabilities and across all stakeholders. Examples were shared from across the life course. A head teacher of a large special school explained how addressing pain was frequently part of a classroom teacher's role in her school:

Taking time to respond on an individual basis if a child in pain. Some children can just cry and cry with period pain and this has to be responded to before they can learn.

One woman with learning disabilities in her 30s explained how she suffered extreme pains for 6 years before endometriosis was diagnosed following an emergency hospital admission.

Many teachers of young people with complex needs and communication specialists identified a need for additional images or communication symbols to enable young people who communicate non-verbally to explain they are in pain and to indicate their preferred pain management options.

Advocacy group co-ordinators, front-line staff and service managers highlighted concerns about whether women with learning disabilities are at higher risk of premature ovarian insufficiency (POI). One women's group leader said that in her experience, women with learning disabilities are finishing periods five years earlier but there is very little information about how to support peri-menopause and menopause—and if people need additional support with HRT if they are stopping periods early. For other women, prescribed long-term contraception for menopause can be concealed as the medication has already suppressed their bleeding. An RSE specialist working in further education said that it was common for young people aged between 16 and 25 not to have periods as they have been prescribed contraception from a young age and wanted to carry on taking it as they are worried about period pain, highlighting a need for understanding of alternative forms of pain management.

3.7 | Stakeholder identification of 'big gaps' in current menstruation support

Stakeholders were asked to share their views on any 'big gaps' they had encountered in current menstruation support. There was notable consistency across stakeholder responses. For example, nearly half of respondents flagged the need for improved treatment of pain, heavy bleeding and problematic periods including clear pathways for effective support if the person is in severe pain or there is concern about their menstrual health. Over a third of respondents identified the lack of training and resources to support people with menopause and post-menopausal care including prescribing of HRT. For people with learning disabilities of all ages, respondents highlighted a lack of opportunity to connect with each other directly to discuss periods/menopause and support each other by sharing information and experiences.

Respondents also identified that mainstream menstruation (and problematic menstruation) support organisations and helplines are generally not accessed by or accessible to people with learning

³<https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Supporting-personal-relationships/Supporting-personal-relationships.aspx>

disabilities. This is accompanied by a lack of opportunity for people to touch and try different types of menstrual products, hampered further by staff often not feeling confident in supporting this and uncertain about the legal framework concerning the use of internal products.

Over a third of respondents highlighted the need for an improved understanding of the use of long-term contraception to manage periods and period pain. Many people with learning disabilities do not understand the implications of this. GPs were identified as needing more advice on how to support people with learning disabilities and their families/carers with period pain. Children, young people and adults with complex needs require a lot more support with learning about and managing menstruation. This includes improved understanding and confidence in applying the legislative framework. Finally, respondents pointed to a lack of understanding of the intersection between culture and menstruation/use of menstrual products and the need for more positive messages about menstruation to people with learning disabilities—framing periods as a sign of growing up, not a problem or risk.

4 | DISCUSSION AND CONCLUSION

The purpose of our scoping exercise was to identify what is currently known about menstruation for girls and women with learning disabilities and their carers across the life course, identify existing interventions/resources and highlight where there are gaps. In our stakeholder consultation, we included the viewpoints of women with learning disabilities to ensure their full inclusion in prioritising future research direction. Overall, the scoping exercise identified that there are important gaps in, and demand for, knowledge, training and resources on menstruation covering all stages of the life course aimed at people with learning disabilities and those who support them.

Key themes arising include problematic or painful menstruation and the use of contraception to manage menstruation, both of which may be more common in women with learning disabilities. We noted a limited understanding of menstruation, particularly regarding the link between menstruation and pregnancy and knowledge of period product options. Furthermore, the literature highlights that girls and women with learning disabilities may face specific challenges linked to the distinct physiological and social contexts in which they experience menstruation across the life course, contributing to reproductive healthcare inequalities (Butler et al., 2002; Carr & Hollins, 1995; McCarthy, 2002a).

Both the literature and our stakeholder consultation raised numerous concerns including whether women's needs relating to menopause symptoms and problematic menstruation are being recognised and met (Willis, 2008). Barriers that may contribute to inequalities in access to knowledge and support to date have not been followed up in research or policy in sustained ways. The voices of women with learning disabilities have been largely absent from the broader societal conversations about menstrual health that have

gained momentum in recent years (McAteer, 2022; Wiseman & Ferrie, 2020), speaking to wider healthcare inequalities for this population (Emerson et al., 2016).

The existing literature and our stakeholder engagement exercise identified that some menstruation resources have been developed that are aimed at people with learning disabilities and their carers (McCarthy & Millard, 2003). The stakeholder consultation also indicated some ongoing work and further plans in this area. However, there was an overwhelming emphasis on the lack of support and access to appropriate resources (McAteer, 2022; Willis, 2008). Barriers include a lack of awareness about available resources, cost and mainstream menstruation support organisations not being accessible to people with learning disabilities.

Our scoping review identified a particular gap in knowledge about the experience of people with profound and multiple learning disabilities, with some studies focusing on the carer perspective (Ferguson et al., 2002) and others specifically excluding this population due to concerns about their ability to take part in interviews (Willis, 2008). Likewise, studies that consider menstruation for autistic people with learning disabilities do not focus on the experience of the individuals themselves but on those who support them (Cummins et al., 2020; Ferguson et al., 2002). The voices of people from ethnic minority communities are largely missing from the literature, with only one paper briefly addressing this (McCarthy & Millard, 2003).

The scoping review of the literature found that attention to the topic of menstruation and learning disability has fallen over the last two decades with only two of the included UK-based papers being published within the last five years. The lack of recent empirical studies on menstruation and learning disability may be related in part to significant barriers in recruitment practices, as documented by Langer-Shapland et al. (2023); detailed further in a follow-up paper for *In Response* (Millar et al., 2023). This implies that the most recent generation of women with learning disabilities is not sufficiently included in the evidence base, which is a notable concern. Differences in the experience of menstruation for this population are often related to the context of their experience including living arrangements that lack privacy, tensions around independence and choice in their lives and social attitudes towards sexual relationships and reproduction (McCarthy & Millard, 2003; Rodgers, 1999). The experiences, expectations and perceptions of people with learning disabilities may have changed since this earlier research was conducted, especially in terms of living arrangements from institutional to community settings. Similarly, it has been over a decade since the literature reviewed the availability of accessible resources on menstruation (Willis, 2008), since when, as indicated by our stakeholder consultation, further resources have been developed.

Existing studies also tend to focus on specific stages of menstruation such as menopause rather than taking a life course approach to the topic. The experiences of different phases are potentially related as a lack of knowledge about the menstrual cycle could impact later confusion and experience of menopause (Langer-Shapland et al., 2023; Moore et al., 2023). McCarthy (2002a)

questions whether the distinct phases of the lifecycle are meaningful/experienced in the same way by women with learning disabilities. This may make attempts to separate experiences into different stages problematic. To address the ongoing and systematic reproductive healthcare inequities facing women and girls with learning disabilities, there is an urgent need for contemporary empirical research that encompasses and evaluates recent developments in resources and accounts for the changing life circumstances of people with learning disabilities across the life course. This includes co-producing research and resources with people with learning disabilities themselves.

This inclusive scoping exercise points to a number of directions for future research, including the impacts on menstrual wellbeing for women experiencing different support and living arrangements; the specificities of menstrual support for women and girls with profound and multiple learning disabilities and/or complex healthcare needs; the experiences of menstruation amongst women with learning disabilities from minority ethnic communities; support for painful or problematic periods; and further research to explore the impact of a life course approach to menstrual support across health, education and social care services. Most notably our scoping exercise has identified the urgent need for research on menstruation that foregrounds the voices, experiences and perspectives of women and girls with learning disabilities.

4.1 | Limitations

Since this was a research prioritisation scoping exercise, designed to inform the ongoing co-production of research, we limited the rapid scoping review to academic papers that were published in the English language, and we did not subject them to a quality assessment. Time and resource constraints as well as the specific goals of this scoping review meant that a pilot review only was undertaken to begin to explore the international literature. The pilot search of the international literature indicates that this is a rich topic for a more comprehensive and systematic review. It is noteworthy that although they did not meet the inclusion criteria for the brief review reported here, the international literature often attends to the topic of menstruation within papers that focus on RSE/sex education for this population suggesting this may also be a fruitful area of future research.

In the stakeholder consultation, we only engaged with those living and/or working in the United Kingdom. Undertaking a systematic thematic analysis of stakeholder consultation responses would not have been appropriate as this was a scoping exercise with the aim of listening to people's experiences of menstruation support rather than a systematic collection and analysis of research data. While we received 70 responses to our stakeholder consultation, the results are still only representative of the individuals who responded to our consultation. When we present examples shared through consultation, we are aware this is only a small snapshot and cannot represent the views of women with learning disabilities across the UK more widely.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the contribution of self-advocates Pat Charlesworth and Beth Lewis in this scoping exercise, particularly their valued input into the stakeholder consultation exercise.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

ORCID

Sarah Earle  <https://orcid.org/0000-0003-2810-5659>

Susan Ledger  <https://orcid.org/0000-0002-5927-6963>

Victoria Newton  <https://orcid.org/0000-0003-4622-6286>

Lorna Rouse  <https://orcid.org/0000-0002-0278-9952>

Elizabeth Tilley  <https://orcid.org/0000-0003-4665-394X>

REFERENCES

- All-Wales Menopause Task and Finish Group. (2023). *All-Wales Menopause Task and Finish Group, Final Report, January 2023*. <https://www.gov.wales/all-wales-menopause-task-and-finish-group-final-report-january-2023-html>
- Altundağ, S., & Çalbayram, N. Ç. (2016). Teaching menstrual care skills to intellectually disabled female students. *Journal of Clinical Nursing*, 25(13–14), 1962–1968. <https://doi.org/10.1111/jocn.13215>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Barrington, J. D., Robinson, H. J., Wilson, E., & Hennegan, J. (2021). Experiences of menstruation in high income countries: A systematic review, qualitative evidence synthesis and comparison to low- and middle-income countries. *PLoS one*, 16(7), e0255001. <https://doi.org/10.1371/journal.pone.0255001>
- Butler, J. V., Whittington, J. E., Holland, A. J., Boer, H., Clarke, D., & Webb, T. (2002). Prevalence of, and risk factors for, physical ill-health in people with Prader-Willi syndrome: A population-based study. *Developmental Medicine and Child Neurology*, 44(4), 248–255. <https://doi.org/10.1017/S001216220100202X>
- Carr, J., & Hollins, S. (1995). Menopause in women with learning disabilities. *Journal of Intellectual Disability Research*, 39(2), 137–139. <https://doi.org/10.1111/j.1365-2788.1995.tb00481.x>
- Chou, Y. C., Jane Lu, Z. Y., & Pu, C. Y. (2013). Menopause experiences and attitudes in women with intellectual disability and in their family carers. *Journal of Intellectual & Developmental Disability*, 38(2), 114–123. <https://doi.org/10.3109/13668250.2013.768763>
- Cooper, N. C., Balachandran Nair, D., Egan, S., Barrie, A., & Perera, B. (2019). Current evidence for the identification and management of premenstrual syndrome in women with intellectual disabilities: A systematic review. *Advances in Mental Health and Intellectual Disabilities*, 13(6), 268–283. <https://doi.org/10.1108/AMHID-05-2019-0015>
- Cummins, C., Pellicano, E., & Crane, L. (2020). Supporting minimally verbal autistic girls with intellectual disabilities through puberty: Perspectives of parents and educators. *Journal of Autism and Developmental Disorders*, 50(7), 2439–2448. <https://doi.org/10.1007/s10803-018-3782-8>
- Department of Health and Social Care. (2022a). Results of the 'Women's Health—Let's talk about it' survey. Retrieved 6 March 2023, from

- Consultation Outcome. <https://www.gov.uk/government/consultations/womens-health-strategy-call-for-evidence/outcome/results-of-the-womens-health-lets-talk-about-it-survey>
- Department of Health and Social Care. (2022b). *Women's health strategy for England*. Gov.uk. <https://www.gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england#menopause>
- Ditchfield, H., & Burns, J. (2004). Understanding our bodies, understanding ourselves: The menstrual cycle, mental health and women with learning disabilities. *Tizard Learning Disability Review*, 9(4), 24–32. <https://doi.org/10.1108/13595474200400035>
- Dizon, C. D., Allen, L. M., & Ornstein, M. P. (2005). Menstrual and contraceptive issues among young women with developmental delay: A retrospective review of cases at the Hospital for Sick Children, Toronto. *Journal of Pediatric and Adolescent Gynecology*, 18(3), 157–162. <https://doi.org/10.1016/j.jpag.2005.03.002>
- Ejskjaer, K., Uldbjerg, N., & Goldstein, H. (2006). Menstrual profile and early menopause in women with Down syndrome aged 26–40 years. *Journal of Intellectual & Developmental Disability*, 31(3), 166–171.
- Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: Cross-sectional study. *International Journal for Equity in Health*, 15(1), 11. <https://doi.org/10.1186/s12939-016-0296-x>
- Ersoy, G., Tekin-Iftar, E., & Kircaali-Iftar, G. (2009). Effects of antecedent prompt and test procedure on teaching simulated menstrual care skills to females with developmental disabilities. *Education and Training in Developmental Disabilities*, 44(1), 54–66.
- Fei, Y. F., Ernst, S. D., Dendrinis, M. L., & Quint, E. H. (2021). Preparing for puberty in girls with special needs: A cohort study of caregiver concerns and patient outcomes. *Journal of Pediatric and Adolescent Gynecology*, 34(4), 471–476. <https://doi.org/10.1016/j.jpag.2021.03.008>
- Ferguson, A. P., McKinlay, I. A., & Hunt, A. (2002). Care of adolescents with severe learning disability from tuberous sclerosis. *Developmental Medicine & Child Neurology*, 44(4), 256–262. <https://doi.org/10.1017/s0012162201002031>
- Glover, G., Williams, R., Heslop, P., Oyinlola, J., & Grey, J. (2017). Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, 61(1), 62–74. <https://doi.org/10.1111/jir.12314>
- Ibralic, I., Sinanovic, O., & Memisevic, H. (2010). Age at menarche and premenstrual syndrome in adolescent girls with intellectual disability in Bosnia and Herzegovina. *Research in Developmental Disabilities*, 31(3), 800–803. <https://doi.org/10.1016/j.ridd.2010.02.004>
- Jacobs, M., Downie, H., Kidd, G., Fitzsimmons, L., Gibbs, S., & Melville, C. (2016). Mental health services for children and adolescents with learning disabilities: A review of research on experiences of service users and providers. *British Journal of Learning Disabilities*, 44(3), 225–232. <https://doi.org/10.1111/bld.12141>
- Kaskowitz, A. P., Dendrinis, M., Murray, P. J., Quint, E. H., & Ernst, S. (2016). The effect of menstrual issues on young women with Angelman Syndrome. *Journal of Pediatric and Adolescent Gynecology*, 29(4), 348–352. <https://doi.org/10.1016/j.jpag.2015.12.004>
- Kennedy, S., O'Higgins, S., Sarma, K., Willig, C., & McGuire, B. E. (2014). Evaluation of a group-based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: Protocol for a mixed methods controlled clinical trial. *BMC Women's Health*, 14(1), 107. <https://doi.org/10.1186/1472-6874-14-107>
- Langer-Shapland, K., Minton, S. J., & Richards, N. (2023). 'It should be more outspoken and not hushed away, not like put in a dark box' an interpretative phenomenological analysis of experiences of menopause voiced by women with learning disabilities. *British Journal of Learning Disabilities*, 51(4), 509–521. <https://doi.org/10.1111/bld.12527>
- Ledger, S. (2019). *Stories show the way to stay home*. Community Living (CL Initiatives).
- Ledger, S., Earle, S., Tilley, E., & Walmsley, J. (2016). Contraceptive decision-making and women with learning disabilities. *Sexualities*, 19(5–6), 698–724. <https://doi.org/10.1177/1363460715620576>
- Ledger, S., McCormack, N., Walmsley, J., Tilley, E., & Davies, I. (2022). "Everyone has a story to tell": A review of life stories in learning disability research and practice. *British Journal of Learning Disabilities*, 50(4), 484–493. <https://doi.org/10.1111/bld.12388>
- Leonard, E., McMeel, K., O'Regan, H., Burke, C., & Maxell, N. (2022). 'In response to "Being part of history, being part of activism: Exploring the lives and experiences of Black people with learning disabilities"'. *British Journal of Learning Disabilities*, 50(2), 252–257. <https://doi.org/10.1111/bld.12475>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(69), 1–9. <https://doi.org/10.1186/1748-5908-5-69>
- Martin, D. M., Kakumani, S., Martin, M. S., & Cassidy, G. (2003). Learning disabilities and the menopause. *The Journal of the British Menopause Society*, 9(1), 22–26. <https://doi.org/10.1258/136218003100322107>
- Mason, L., & Cunningham, C. (2008). An exploration of issues around menstruation for women with Down syndrome and their carers. *Journal of Applied Research in Intellectual Disabilities*, 21(3), 257–267. <https://doi.org/10.1111/j.1468-3148.2007.00406.x>
- Mason, L., & Cunningham, C. (2009). Pre-menstrual syndrome in women with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 22(3), 287–297. <https://doi.org/10.1111/j.1468-3148.2008.00461.x>
- McAteer, M. (2022). Women's health strategy: What about support for learning disabilities? *Learning Disability Practice*, 25(6), 16–17. <https://doi.org/10.7748/ldp.25.6.16.s10>
- McCarthy, M. (2002a). Going through the menopause: Perceptions and experiences of women with intellectual disability. *Journal of Intellectual and Developmental Disability*, 27(4), 281–295. <https://doi.org/10.1080/1366825021000055817>
- McCarthy, M. (2002b). Responses to women with learning disabilities as they go through the menopause. *Tizard Learning Disability Review*, 7(1), 4–12. <https://doi.org/10.1108/13595474200200002>
- McCarthy, M. (2009a). Contraception and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(4), 363–369. <https://doi.org/10.1111/j.1468-3148.2008.00464.x>
- McCarthy, M. (2009b). 'I have the job so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum*, 32(3), 198–208. <https://doi.org/10.1016/j.wsif.2009.05.003>
- McCarthy, M. (2011). Prescribing contraception to women with intellectual disabilities: General practitioners' attitudes and practices. *Sexuality and Disability*, 29(4), 339–349. <https://doi.org/10.1007/s11195-011-9216-6>
- McCarthy, M., & Millard, L. (2003a). *Supporting women with learning disabilities through the menopause: A resource pack* (2nd ed.). Pavilion. <https://www.pavpub.com/supporting-women-with-learning-disabilities-through-the-menopause-2nd-edition-2>
- McCarthy, M., & Millard, L. (2003b). Discussing the menopause with women with learning disabilities. *British Journal of Learning Disabilities*, 31(1), 9–17. <https://doi.org/10.1046/j.1468-3156.2003.00182.x>
- McKinlay, I., Ferguson, A., & Jolly, C. (1996). Ability and dependency in adolescents with severe learning disabilities. *Developmental Medicine and Child Neurology*, 38(1), 48–58.
- Millar, A., Slattery, J., & Johnson, K. (2023). In response to: "It should be more outspoken and not hushed away, not like put in a dark box": An interpretative phenomenological analysis of experiences of menopause voiced by women with learning disabilities (Katie Langer-Shapland, Stephen J. Minton, Nel Richards). *British Journal of Learning Disabilities*, 51, 613–616. <https://doi.org/10.1111/bld.12557>
- Moore, K., Reidy, M., & Foran, S. (2023). Understanding the menopausal experiences of women with intellectual disabilities: A scoping

- review. *Journal of Intellectual Disabilities*, Online First, 1744629 5231182246. <https://doi.org/10.1177/17446295231182246>
- National Institute of Health and Care Excellence (NICE). (2019). Premenstrual syndrome. Retrieved 6 March 2023, from <https://cks.nice.org.uk/topics/premenstrual-syndrome/>
- O'Dwyer, J. M., & Friedman, T. (1995). Menstruation and aggression in a population of women with learning disabilities. *British Journal of Learning Disabilities*, 23(2), 51–55. <https://doi.org/10.1111/j.1468-3156.1995.tb00163.x>
- Obaydi, H., & Puri, B. (2008). Prevalence of premenstrual syndrome in autism: A prospective observer-rated study. *Journal of International Medical Research*, 36(2), 268–272. <https://doi.org/10.1177/147323000803600208>
- Office for Health Improvement and Disparities. (2023a). Health inequalities: Menopause. Retrieved 6 March 2023, from Public Health Profiles. <https://fingertips.phe.org.uk/profile/learning-disabilities>
- Office for Health Improvement and Disparities. (2023b). Health inequalities: Menstrual issues. Retrieved 6 March 2023, from Public Health Profiles. <https://fingertips.phe.org.uk/profile/learning-disabilities>
- Office for National Statistics. (2020). Estimates of the population for the UK, England, Wales, Scotland and Northern Ireland. Retrieved 6 March 2023, from Dataset. <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>
- Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2021). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Implementation*, 19(1), 3–10. <https://doi.org/10.1097/XEB.0000000000000277>
- Pillai, M., O'Brien, K., & Hill, E. (2010). The levonorgestrel intrauterine system (Mirena) for the treatment of menstrual problems in adolescents with medical disorders, or physical or learning disabilities. *BJOG*, 117(2), 216–221. <https://doi.org/10.1111/j.1471-0528.2009.02372.x>
- Retznik, L., Wienholz, S., Höltermann, A., Conrad, I., & Riedel-Heller, S. G. (2023). "It gives me, as her caregiver, a sense of security." Young people with intellectual disability and their experiences with sexuality, menstruation, gynecological treatment and contraception: A follow-up analysis of parents' and caregivers' perspectives. *Sexuality and Disability*, 41(1), 97–116. <https://doi.org/10.1007/s11195-022-09770-y>
- Roberts, H., Ingold, A., Liabo, K., Manzotti, G., Reeves, D., & Bradby, H. (2018). Moving on: Transitions out of care for young people with learning disabilities in England and Sweden. *British Journal of Learning Disabilities*, 46(1), 54–63. <https://doi.org/10.1111/bld.12211>
- Rodgers, J. (1999). Learning Disabilities: Helping women manage menstruation. *Nursing Times*, 95(15), 52–53. <https://doi.org/10.1111/j.1536-7150.1978.tb02790.x>
- Rodgers, J. (2001). Pain, shame, blood, and doctors. *Women's Studies International Forum*, 24(5), 523–539. [https://doi.org/10.1016/S0277-5395\(01\)00195-9](https://doi.org/10.1016/S0277-5395(01)00195-9)
- Rodgers, J., & Lipscombe, J. (2005). The nature and extent of help given to women with intellectual disabilities to manage menstruation. *Journal of Intellectual & Developmental Disability*, 30(1), 45–52. <https://doi.org/10.1080/13668250500033094>
- Rodgers, J., Lipscombe, J., & Santer, M. (2006). Menstrual problems experienced by women with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(4), 364–373. <https://doi.org/10.1111/j.1468-3148.2006.00298.x>
- Schupf, N., Zigman, W., Kapell, D., Lee, J. H., Kline, J., & Levin, B. (1997). Early menopause in women with Down's syndrome. *Journal of Intellectual Disability Research*, 41(3), 264–267. <https://doi.org/10.1111/j.1365-2788.1997.tb00706.x>
- Seltzer, G. B., Schupf, N., & Wu, H. S. (2001). A prospective study of menopause in women with Down's syndrome. *Journal of Intellectual Disability Research*, 45(1), 1–7. <https://doi.org/10.1046/j.1365-2788.2001.00286.x>
- Stansfield, A. J., Holland, A. J., & Clare, I. C. H. (2007). The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999. *Journal of Intellectual Disability Research*, 51(8), 569–579. <https://doi.org/10.1111/j.1365-2788.2006.00920.x>
- Steele, L., & Goldblatt, B. (2020). The human rights of women and girls with disabilities: Sterilization and other coercive responses to menstruation. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. A. Kissling, Roberts, & Tomi-Ann (Eds.), *The palgrave handbook of critical menstruation studies* (pp. 77–91). <https://doi.org/10.1007/978-981-15-0614-7>
- The Scottish Parliament. (2023). Period Products (Free Provision) (Scotland) Bill. Retrieved 2 March 2023, from <https://www.parliament.scot/bills-and-laws/bills/period-products-free-provision-scotland-bill>
- Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. (2012). 'The silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, 27(3), 413–426. <https://doi.org/10.1080/09687599.2012.654991>
- Walmsley, J., Earle, S., Tilley, E., Ledger, S., Chapman, R., & Townson, L. (2016). The experiences of women with learning disabilities on contraception choice. *Primary Health Care*, 26(9), 28–32. <https://doi.org/10.7748/phc.2016.e1139>
- Wandresen, G., Sgarbi, F., & Nisihara, R. (2019). Management of contraceptives and menstrual complaints in patients with Down syndrome. *Gynecological Endocrinology*, 35(2), 103–108. <https://doi.org/10.1080/09513590.2018.1501017>
- Wilbur, J., Torondel, B., Hameed, S., Mahon, T., & Kuper, H. (2019). Systematic review of menstrual hygiene management requirements, its barriers and strategies for disabled people. *PLoS one*, 14(2), e0210974. <https://doi.org/10.1371/journal.pone.0210974>
- Willis, D. S. (2008). A decade on: What have we learnt about supporting women with intellectual disabilities through the menopause?. *Journal of Intellectual Disabilities*, 12(1), 9–23. <https://doi.org/10.1177/1744629507086604>
- Willis, D. S., Wishart, J. G., & Muir, W. J. (2010). Carer knowledge and experiences with menopause in women with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 42–48. <https://doi.org/10.1111/j.1741-1130.2010.00246.x>
- Willis, D. S., Wishart, J. G., & Muir, W. J. (2011). Menopausal experiences of women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24(1), 74–85. <https://doi.org/10.1111/j.1468-3148.2010.00566.x>
- Wiseman, P., & Ferrie, J. (2020). Reproductive (In)Justice and inequality in the lives of women with intellectual disabilities in Scotland. *Scandinavian Journal of Disability Research*, 22(1), 318–329. <https://doi.org/10.16993/sjdr.677>
- Wishart, K., Hart, R., & Outen, P. (1998). A patient with learning disability and menorrhagia. *The Practitioner*, 242, 9–15. <https://doi.org/10.1111/j.1536-7150.1978.tb02790.x>
- World Health Organisation. (2022). WHO statement on menstrual health and rights. Retrieved 1 March 2023, from statement. <https://www.who.int/news/item/22-06-2022-who-statement-on-menstrual-health-and-rights>

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Earle, S., Ledger, S., Newton, V., Rouse, L., & Tilley, E. (2024). Menstruation and learning disability across the life course: Using a two-part scoping exercise to co-produce research priorities. *British Journal of Learning Disabilities*, 52, 524–537. <https://doi.org/10.1111/bld.12592>