


# Supporting women with learning disabilities in infant feeding decisions: UK health care professionals' experiences

Sally Dowling<sup>1,2</sup>  | Emma Douglass<sup>3</sup> | Geraldine Lucas<sup>3</sup> | Clare Johnson<sup>4</sup>

<sup>1</sup>School of Health and Social Wellbeing, Centre for Public Health and Wellbeing, University of the West of England, Glenside Campus, Bristol, UK

<sup>2</sup>Bristol Medical School, Faculty of Health Sciences, University of Bristol, Bristol, UK

<sup>3</sup>School of Health and Social Wellbeing, University of the West of England, Glenside Campus, Bristol, UK

<sup>4</sup>Faculty of Arts, Creative Industries and Education, University of the West of England, Arnolfini, Bristol, UK

## Correspondence

Sally Dowling, Bristol Medical School, Faculty of Health Sciences, University of Bristol, 69 St Michael's Hill, Bristol, BS2 8DZ, UK.  
Email: [sally.dowling@bristol.ac.uk](mailto:sally.dowling@bristol.ac.uk)

## Abstract

Women with learning disabilities are less likely to breastfeed than other women. They may find it hard to understand or learn feeding techniques or know that they have infant feeding choices. This population may be supported during their pregnancies by a range of professionals with differing priorities and responsibilities towards both the mother and the baby. This puts considerable pressure on health care professionals including, but not limited to, midwives, infant feeding specialists, health visitors and learning disability nurses. Those who support women with learning disabilities through their journey into motherhood have a responsibility to ensure the women in their care have the information they need to make decisions about a range of issues, including infant feeding. In the absence of dedicated lactation consultants, this is one of many issues to be discussed within time-limited appointments. Little is known about the experience of supporting women with learning disabilities to make infant feeding decisions from the point of view of health professionals. Using a qualitative descriptive research design, we conducted online, semistructured interviews with seven UK health professionals about their experience of supporting women with learning disabilities in infant feeding. Thematic analysis identified three themes: the importance of health professionals' having unconditional, positive regard; the need for an individualised approach to supporting women to make infant-feeding decisions; and being part of the support network. This suggests that women with learning disabilities can make and put into practice infant feeding decisions if they have access to the right support at the right time.

## KEYWORDS

breastfeeding, health professionals, infant feeding, learning disabilities, resources, support, supporting decision-making

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Maternal & Child Nutrition* published by John Wiley & Sons Ltd.

## 1 | INTRODUCTION

While the number of women with learning disabilities becoming pregnant appears anecdotally to be increasing, actual figures are unknown and this population make up a small proportion of the caseloads of health care professionals (Castell & Stenfort Kroese, 2016). The support all women receive is crucial, having long-lasting effects on maternal and infant health (Victora et al., 2016). Health care professionals in the United Kingdom have a responsibility to ensure that the women in their care have the information they need to make decisions about a range of issues, including infant feeding (Nursing and Midwifery Council, 2019). In England and Wales learning disability includes, 'a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning)' (Department of Health, 2001, p. 14). (The term 'intellectual disability' is more commonly used internationally). Women with a learning disability might, therefore, require additional support to make their own decisions. There is a legal requirement in the United Kingdom for health professionals to make reasonable adjustments in line with the Equality Act (2010) which includes making information accessible to the individual.

During the perinatal period there is a great deal of information to absorb and new skills to learn, which can be a particular challenge for mothers with learning disabilities, especially if the information provided is not 'accessible' (Homeyard et al., 2016). 'Accessible' is defined by NHS England as information that can 'be read or received and understood by the individual or group for which it is intended' (NHS England, 2017, p. 6). This includes understanding, preparing for and establishing infant feeding (including its importance for bonding) as well as health implications for mother and baby (Porter et al., 2012). Current guidance recommends exclusive breastfeeding for the first 6 months (WHO, 2003), yet women with learning disabilities are less likely to breastfeed than other women (Goldacre et al., 2015; Guay et al., 2017; Hindmarsh et al., 2015). However, in our previously published scoping review (Johnson et al., 2022) we found no specific information about why formula feeding might be understood as preferable for women with learning disabilities. It is important that this population, who face more health inequalities (NICE, 2021) and who may find it difficult to understand feeding techniques, are supported to make and fulfil infant-feeding decisions. Health Visitor and midwife training includes specific input on supporting infant feeding, usually closely aligned to the UNICEF-UK Baby Friendly Initiative (BFI) Standards (2017). Most health professionals, however, receive minimal input in relation to working with women with learning disabilities during their undergraduate courses and report feeling underprepared in supporting this population when qualified (Castell & Kroese, 2016; Daniels & Douglass, 2021).

Health visitors, through the Healthy Child Programme (Department of Health, 2009; Public Health England, 2015)—other countries in the United Kingdom have similar strategies), can offer 'targeted' or 'specialist' support to women most in need

### Key messages

- With the right support at the right time, women with learning disabilities can make infant feeding decisions and successfully feed their babies.
- Infant feeding options should be discussed early in the pregnancy, with repetition and the use of accessible resources such as videos to support decision-making.
- Breastfeeding should be considered a viable option for all women.
- Health professionals need to be flexible in their approach to supporting infant feeding decision-making, working as part of the woman's circle of support.
- Accessible resources can be helpful in supporting infant feeding decision-making, but one size does not fit all.

antenatally, as well as the 'universal offer' for the groups 0–5 and 5–19 years of age (Public Health England, 2021). The role includes using 'clinical judgement and public health expertise in identifying issues early, determining potential risk, and providing early intervention to prevent issues escalating' (Public Health England, 2021, p. 9). They specifically work towards targets in 'early years high impact areas', which include supporting the transition to parenthood, maternal and infant mental health and supporting breastfeeding (both initiation and duration).

Health care professionals clearly have a role in supporting infant-feeding decisions with women with learning disabilities, yet there is little existing data about this experience from the professionals' perspective (Johnson et al., 2022). The purpose of this research was to address this gap through undertaking qualitative interviews with a range of health professionals. Our aim was to explore how health care professionals support women with learning disabilities to make infant-feeding decisions.

This research was undertaken during the Covid-19 pandemic at a time when health professionals were under increased pressure. The interviews took place during April–May 2021 at which point perinatal health care professionals were dealing with the effects of lockdown on an already vulnerable population. Social distancing restrictions at the time resulted in women attending medical appointments alone or relying on virtual contact with health professionals (Jardine et al., 2021). It was in this context that the health professionals interviewed for this study agreed to participate.

This interview study is part of a larger piece of work, which has been discussed in an earlier paper (Johnson et al., 2022). The first phase was a scoping review exploring existing resources to support infant feeding decision-making. The second is reported here. The final stage is a focus group (held in February 2022) with women with learning disabilities (publication to follow). Our eventual recommendations for practice and future research will be informed by the perspectives of women with learning disabilities and the health care professionals who support them.

## 2 | METHODS

### 2.1 | Research design

This project took a qualitative approach, seeking to explore and increase understanding of health professionals' experiences of supporting women with learning disabilities with infant-feeding decisions. We draw on an interpretivist world view, using a social constructionist approach, which attempts to understand experiences from the participants' point of view and from within their frame of reference (Burr, 2015). A qualitative descriptive research design (Doyle et al., 2020; Sandelowski, 2010) allowed us to collect rich data relevant to our research question via semistructured one-to-one interviews, followed by a reflexive thematic analysis (Braun & Clarke, 2022). Qualitative descriptive designs are often used in nursing and health care, enabling researchers to describe experiences and perceptions. They can be good for investigating topics where knowledge is scarce as well as 'studies that do not require a deeply theoretical context and aim to stay close to and describe participants' experience' Doyle et al., 2020, p. 444).

#### 2.1.1 | Sampling, recruitment and access

We took a purposive sampling approach (Patton, 2015); wanting specifically to talk to health professionals who had experience of working with women with learning disabilities, in relation to pregnancy and early motherhood. Contact was made with a range of gatekeepers—matrons, managers, specialist midwives and area health visitor professional leads—asking them to pass on an information sheet about the study to anyone with relevant experience. Participants were additionally recruited via our networks and through contacting people known to have the relevant experience by E. D. Snowballing was also employed. We had an enthusiastic and interested response from both gatekeepers and potential participants and were able to undertake seven interviews in total. Two additional people expressed interest in participating but did not respond to further requests to arrange interviews. We are sure that pandemic-related work pressures contributed to health professionals prioritising other activities, notwithstanding their interest in our project. Conducting qualitative research during the Covid-19 pandemic has been recognised as giving rise to a range of challenges, including recruitment (Tremblay et al., 2021).

Interested participants were asked to contact S. D. They were sent a copy of the participant information sheet and allowed time to consider and ask questions. Interviewees were put in touch with one of the three interviewers (SD., E.D., and GL.)—matches were made according to availability but also to avoid interviewees being interviewed by someone who was known to them (as recruitment had used our local networks this was potentially an issue). Arrangements were made to conduct interviews via MS Teams or Zoom and consent was sought before the interview taking place. Consent forms were emailed to us from professional email addresses

and consent re-confirmed at the beginning of each interview, including consent to record the interviews via the online platform.

#### 2.1.2 | Participants

We interviewed seven health professionals working in the South-West of England—a community midwife, two infant feeding leads based in hospital maternity units, two health visitors and two learning disability nurses. All reported to have experiences of working with women with learning disabilities, ranging from working with one individual with a learning disability to several individuals over a period of years. One participant had recently supported an autistic woman. Autism is a form of cognitive diversity, which is different to learning disability, and can be disabling in a neurotypical focused world (Lord et al., 2018). Autistic people are known to communicate differently to neurotypical people. While an individual may have a diagnosis of both learning disability and autism, this is not necessarily the case. During the interview, this participant reflected on their experience of using accessible information and an individualised approach to supporting infant-feeding decision-making. The researchers felt this was relevant to the research question and therefore these data were included within analysis. Participants are identified as P1–P7 when quotations from interviews are used.

#### 2.1.3 | Interview process

All interviews took place online, due to Covid-19 restrictions on face-to-face research activity in place at our institution at the time of data collection. Despite this, we were still able to build and maintain rapport and make use of nonverbal cues; shown in the rich and interesting data we obtained. Interviews lasted between 19 and 47 min, and were audio recorded. Participants were offered a choice of online platform from those approved for use by our institution and were sent links to join at prearranged times. Interviewers used a guide, with prompts (see Table 1), to focus conversations on our topic of interest but relevant material introduced by participants was also explored. SD. facilitated four interviews, E.D. two, and G. L. one. Four people were known to one or more of the research team but, as noted above, were not interviewed by anyone they knew.

#### 2.1.4 | Analysis

All interviews were transcribed in full and imported into NVivo 12 (QSR International) for thematic analysis using Braun and Clarke's (2022) six step iterative process. E. D. undertook close reading of the transcripts, identifying 112 initial semantic codes. Two more coding sweeps were undertaken, where codes were merged, renamed or more codes were identified, before the four researchers met to review. Through discussion, codes were combined and renamed to form 105 codes, before four potential themes were identified.

**TABLE 1** Topic guide for interviews

Opening question	Can you tell us about your experiences of working with women with learning disabilities?
Introductory questions	What is your experience of discussing pregnancy and motherhood with women who have learning disabilities? What kinds of materials do you use in these discussions?
Key questions	What challenges do you face when explaining information to women with learning disabilities? Can you tell us about your experience of discussing infant feeding with women with learning disabilities (breast/bottle/combination feeding)? In your opinion, do your service users understand infant feeding choices including the benefits and challenges of breastfeeding? Do you find the current resources about pregnancy and motherhood helpful? How do your patients/clients/service users respond to these resources? Which kinds of resources make communication easier?
Ending question	Is there anything about your experiences of discussing infant feeding with women with learning disabilities that you feel is important, but that we have not yet discussed?

Further refinement of themes took place via discussion before three final themes were agreed.

## 2.2 | Ethical considerations

Ethical approval was granted by our university Research Ethics Committee on 7 October 2020 (review number HAS.20.07.205), with an amendment related to video-call interviewing granted on 20 November 2020. Consent was discussed with all participants and included permission to record, to use quotes from interviews, the removal of any identifying information and the use of pseudonyms. Participants were advised that they could withdraw all their information from the study in the 2 weeks following the interview; after this it would be included in analysis. All participants received a participant information sheet and information about data storage and security. All recordings were transferred immediately after interviews to secure cloud storage, as were the transcripts once received.

## 2.3 | Benefits of interdisciplinarity

We have written elsewhere about the importance and centrality of interdisciplinarity to our larger study (Johnson et al., 2022), of which the work reported here forms a part. All stages of the work have drawn on our professional and academic backgrounds (midwifery, learning disabilities nursing, public health and visual culture), enabling us to bring differing perspectives in relation both to knowledge of the issues and methodological expertise and traditions. We have not used visual research methods in this part of our study. However, the interviews are informed by the health care professionals' understanding of the visual resources available to them. As we have noted, (Johnson et al., 2022) our different disciplinary backgrounds encourage us in an ongoing reflexive approach when working together. We believe this both strengthens our work and—through the bringing together of clinical experience, social research methods and expertise in visual methods—gives us an opportunity to produce

novel work to contribute to supporting women with learning disabilities.

## 3 | RESULTS

Three themes were identified: health professionals having unconditional, positive regard; an individualised approach to supporting decision-making; and the health professional being part of the circle of support.

### 3.1 | Having unconditional, positive regard—'Rather than us telling you how to do it, you tell us how we can help you' (P5)

This first theme relates to the *attitude* of the health professional. All participants spoke about the importance of infant-feeding options being discussed with women with learning disabilities, advocating that with the right level of support at the right time, women with learning disabilities can successfully make, and execute decisions about how to feed their baby. Participants felt breastfeeding should always be a viable option, emphasising that infant feeding is more than providing a baby with adequate nutrition. Participants reflected on the importance of developing a trusting, therapeutic relationship as the foundation, whereby the health care professional had belief in the woman's abilities:

*Rather than us telling you how to do it, you tell us how we can help you (P5)*

However, despite these views and positive experiences, most participants felt that women with learning disabilities were 'getting a really raw deal at the moment' (P6). Participants expressed concern that there is a perception by some health professionals that breastfeeding is not for women with a learning disability:

*I do feel there is a perception that it [breastfeeding] is not for those women [women with a learning disability] and I absolutely can't see why it's not even more important (P1)*

Safeguarding was frequently cited as a reason the needs of the child were the focus, which many participants felt was at the detriment to the woman. Examples were given about formula feeding being seen as an easier option, as it was easier to document how much milk the baby was taking, potentially dismissing breastfeeding as viable:

*...the focus is on the baby (...) if mum bottle feeds then we can record how much baby is eating and you know, that can be written down when mum is feeding baby (P6)*

However, participants disagreed that formula feeding was an easier option.

Participants, especially health visitors and hospital midwives who were more likely to be involved after the baby was born, talked about the importance of infant feeding being discussed early in pregnancy. Speaking to a woman about breastfeeding after the baby had been born was considered too late. Some participants suggested that often other 'bigger' issues take focus of input/discussions in pregnancy (such as safeguarding), with infant feeding discussions potentially being missed. This was viewed as having a negative impact on offering a choice, as by the time postnatal services are involved, the woman is often already set up for formula feeding.

*I don't think mums are actually sat down and asked (...) I think quite often the choice is taken away from them (...) Often the woman had already made the decision to bottle feed and had all of the equipment ready (P5)*

The focus of this first theme is the necessity for health professionals to have unconditional positive regard, *believing* that women with learning disabilities can and should be supported to make infant-feeding decisions, with all options considered viable and explored.

### 3.2 | An individualised approach to supporting decision-making—'One size does not fit all' (P4)

This second theme focuses on the *practical* support provided to women with learning disabilities. Most participants said that supporting a woman with a learning disability to make infant feeding decisions requires a person-centred, individualised approach, which some participants felt differs from the standard maternity pathway,

*...we have got these very rigid pathways which I take quite flexibly (...) But some of my colleagues are very like, oh no, the woman is formula feeding, the baby doesn't*

*need to be weighed until day 5, she doesn't really need a face to face visit, you know, so I think its understanding that whatever, for anyone with any extra vulnerability, any, the time spent in that early stage, you know, making her realise how well she is doing whilst she is doing nice normal things with the baby (P1)*

Having a person-centred focus often required the professional to adapt their approach by spending more time getting to know the woman as an individual. This was discussed as important in ensuring infant feeding information was provided in an accessible way to meet the woman's individual needs. Consistency, and repetition, of information were frequently discussed in interviews. In addition, interviewees talked about checking what information the woman had retained and understood.

*It's having the time to have that very gentle conversation and get that feedback. So, do you know what I have explained to you, do you understand what I have said, can you tell me (P2)*

This individualised approach required additional time from the health care professional, but was considered essential in ensuring success, with participants reflecting that making information accessible was often not straight-forward,

*...unfortunately, with accessible information one size does not fit all (P4)*

Participants found it helpful to use resources when communicating infant feeding information. Some participants relied on generic information such as UNICEF Baby Friendly Initiative resources, but there were mixed opinions as to whether some of these 'generic' resources were helpful/accessible to women with learning disabilities. Instead, some participants chose to develop bespoke accessible information, which was more time-intensive, but considered by some to be more effective in supporting decision-making. All participants said that videos were particularly helpful as well as favouring practical demonstrations with props:

*...we wrote out in language that she was familiar with step by step. And then she had the video that she could then watch on a daily basis, multiple times a day if she needed (P5)*

While resources were discussed as being a useful tool in facilitating the process, what was considered equally or more important was the health professional's approach to supporting the woman to make infant feeding decisions:

*I can never really think up what physical thing would help more than just the sort of time and commitment (P1)*

This suggests that the focus needs to be on assessing which approach and resource(s) are accessible to the individual to aid communication rather than the resource being enough in itself. Discussing options with women was discussed as being a skill. Some participants felt that health professionals are skilled in this area:

*But I think, I would like to say that midwives in the community are very um, confident and skilled in regard to giving that information (P7)*

although this was not the view of all people we spoke to:

*...person needs to have the skill to be able to deliver the information in the first place ... I have worked with some brilliant, excellent midwives but actually their ability to communicate with the woman with a learning disability in front of them is actually, not great at all (P4)*

This suggests that this might potentially be an area for further training.

### 3.3 | Health professionals are part of the circle of support—'We all communicated together' (P3)

Participants discussed the importance of the woman's wider support network when considering infant feeding decision-making, recognising the importance of facilitating regular communication to ensure support.

*Well, I just think, obviously it's all about good communication from a multidisciplinary perspective for us so that we have got a good line, we know the woman is well supported, you know, outside of midwifery as well (P7)*

Due to the number of different people that are likely to be involved perinatally, consistency was highlighted as significant,

*Its, so the mum I have got at the moment, you know, one of her biggest things is too many people coming in and out of her life. So, I think consistency is very, very important (P5)*

Participants reflected that some women with learning disabilities may not be familiar with making their own decisions, recognising the influence of the wider support network. The wider support network includes other health and social care professionals, as well as the woman's family and friends. There were different opinions as to the best way to involve this support network in infant-feeding decisions. Some participants spoke of examples when they felt the support network had overridden a woman's initial decision about how she would like to feed her baby and suggested that the health professional should talk to the woman to find out their preference before involving others.

*So, I think sometimes being able to have that conversation alone with mum and getting an understanding of what it is she wants (...) it's almost as if they [woman with learning disabilities] don't feel confident enough or don't feel they are able to make those kinds of decisions because they have always been told you need help doing this and you need help doing that (P5)*

Other participants spoke about the influence of the informal network being a natural aspect of infant feeding decision-making, advocating that the health care professional should embrace this aspect, recognising that the woman was likely to be guided/influenced by those around them. Participants recognised the role of the support network in both supporting the decision about how to feed the baby, but also in supporting the woman to execute this when the baby was born, identifying a possible tension in how best to support an individual with infant-feeding:

*But I think one of the greatest things (...), I suppose underpins it, is what are the influences (...) So there is really very little point, if we are thinking about infant feeding, explaining um, the technique or the different choices or what your options might be if you are infant feeding if you don't do that with the key influencers that are around this person's life (P4)*

## 4 | DISCUSSION

### 4.1 | Competing priorities

Pregnant women with learning disabilities are likely to be supported by a range of health and social care professionals, with differing priorities. The challenges for different agencies and professionals providing integrated and 'joined up' continuous care are well-recognised (NICE, 2021; Welsh Government, 2021). Health and social care professionals need to consider the welfare of both mother and baby (Nursing and Midwifery Council, 2018, 2019), with women with learning disabilities likely to be under increased surveillance compared to other mothers. This can place considerable pressure on the professionals involved (including, but not limited to, midwives, infant feeding specialists, health visitors, social workers and learning disability nurses), for whom infant feeding is one of a range of issues to be discussed. Participants spoke about concerns for the child dominating the pregnancy. If there was a chance of the baby being removed from the mother after the birth and taken into the care of others, infant feeding discussions were seen as lower priority, and sometimes missed completely. With recognition that infant-feeding is more than providing nutrition, pivotal to bonding, communication and child development (UNICEF/BFI, 2017), participants felt that infant feeding should form part of discussions with women throughout the

pregnancy, regardless of whether safeguarding processes were involved.

Mothers with a learning disability are more likely to have safeguarding/child protection involvement (Corrigan, 2019; Lima et al., 2022; Slayter & Jenson, 2019). Earle et al. (2015) question if safeguarding procedures might have replaced the historical segregation and sterilisation of women with learning disabilities. We found that safeguarding potentially places additional pressure to 'perform' after birth, with women with learning disabilities required to demonstrate they can feed their babies appropriately. For this reason, some participants suggested formula-feeding can be viewed as an easier, or preferred option, as it is possible to assess a woman preparing a bottle and to measure how much milk the baby is having at each feed. This can overshadow the consideration of the long-term health of mum and baby, potentially further disadvantaging an already disadvantaged population of new mothers.

## 4.2 | Resources

Our participants talked about a range of resources that they had used, identifying those they had found helpful. Interestingly, overall, they found moving image/performative resources (i.e., videos and demonstrations) more useful than static ones (i.e., leaflets). There is a sense of 'live-ness' and immediacy in the former even when the resource is mediated through the screen, which problematises the distinction between live and mediated forms of culture (Auslander, 2008) and alerts us to the specific characteristics of different media forms and their modes of consumption by the target population.

The direct encounter of a live demonstration, for example, is a complex sociocultural interaction in which the proximity of the body of another, such as a health professional using props to explain a feeding technique, can be experienced as confrontational. In the context of feminist visual culture, the live confrontation with the female body has historically been understood as an intervention in the structure of visibility and an insistence on women's agency (Goldberg, 2018). Our focus group findings (paper forthcoming) suggests that women with learning disabilities have clear views about what information they find accessible, and how they would prefer information to be communicated. This resonates with the 'one size does not fit all' theme, expressed strongly by our participants, suggesting the need for a suite of resources/pathways that can enable a more flexible and individualised approach to supporting women to make infant-feeding decisions.

## 4.3 | Circle of support

Our interviewees reflected on their own position of influence over the feeding decisions made by women with learning disabilities. Most saw themselves as part of the support network, while also recognising the key role of significant others. Their position was talked about in ways that represent a conflict for health professionals—the need to

talk to a pregnant woman about infant feeding as early as possible before involving the wider support network, versus the need to involve the wider network in practical and emotional support, once the baby was born.

The finding that women with learning disabilities make infant-feeding decisions in relation to their informal support networks is in line with wider breastfeeding research. Our work suggests that—like other women—those with learning disabilities may be influenced in their decision making by what others think is the right thing to do and are guided by this. Breastfeeding decisions are related to community and family norms (Matriano et al., 2021) and the influence of key people (Hunt et al., 2022). Advice given by these people can be based on first-hand experiences and emotional reactions, rather than being evidence-based. This influence is likely to be more significant for women with learning disabilities, who may have had limited life-experience of making their own decisions (Hollomotz, 2014). This was discussed by some of our participants as an inherent challenge.

Many women cite lack of support as a reason for giving up breastfeeding early (Hoddinott et al., 2012; Schmied et al., 2010); various forms, such as breastfeeding peer support groups, are acknowledged to be helpful in establishing and maintaining breastfeeding (Thomson et al., 2015) as well as in supporting wellbeing. These are potential areas for further research to explore how accessible and helpful breastfeeding support is to women with learning disabilities.

In their qualitative study, Castell and Kroese (2016) identified the need for additional support and training for professionals in supporting women with learning disabilities through pregnancy. Staff training, in developing communication skills, was identified by some participants in our study, although there were different opinions among professionals interviewed. Due to the purposive sample, it is likely that those who chose to be interviewed were interested and had developed skills in communicating effectively with women with additional needs, yet this appears to remain an issue. The new standards for preregistration midwifery (Nursing and Midwifery Council, 2019) and nursing (Nursing and Midwifery Council, 2018) with a focus on interdisciplinary team working might have the potential to help bridge this gap for new nurses and midwives. Further consideration is required as to how best to increase awareness and develop health professionals' communication skills to meet the infant-feeding needs of women with additional needs.

## 4.4 | Cultural and historical context

Our themes resonate with the ethos of person-centred care, unconditional positive regard, and the importance of trusting therapeutic relationships, advocated by policy guidelines (Department of Health, 2001; Nursing and Midwifery Council, 2018, 2019). Health professionals are, however, also operating within specific cultural, social and historical contexts which will influence how they view and work with those in their care. In the context of infant feeding more generally there has been a call for 'strategies and

support that address personal, cultural, ideological and structural constraints of infant feeding' (Thomson et al., 2015, p. 33). Contemporary thinking about women with learning disabilities and pregnancy/motherhood intersects and is informed by historical ideas about learning disabilities and about women and their bodies. These include ideas about maternal competence (Earle et al., 2015), anxieties about the 'passing on' of disability through reproduction (Tilley et al., 2012), and the regulation of women's bodies including bodily fluids (Dowling et al., 2012), especially the bodies of women with learning disabilities (Tilley et al., 2012). Tilley and colleagues suggest a limited focus in learning disability research and policy on women's issues, such as reproductive choices.

Our research (Johnson et al., 2022) suggests that infant feeding issues for women with learning disabilities have received little attention in either research or practice, identifying a significant gap for these mothers. Our participants demonstrated significant reflexivity in thinking about their roles yet acknowledged that views among health professionals vary considerably. This aligns to contemporary thinking about our topic, for example, a potential reluctance to imagine that women with learning disabilities can successfully breastfeed—seen here as part of the context in which health professionals are working to provide support. This is a complex area requiring further consideration and research.

#### 4.5 | Strengths and limitations

The strength of this study is that, as far as we are aware, it is the only one to focus on this key area (see also: Johnson et al., 2022). Involving women with learning disabilities in an advisory/participatory role was not possible for this phase of our project. Our experience of recruitment of people with learning disabilities in research projects for the final part of this project (paper forthcoming) and the ongoing PhD study of E.D. demonstrates the importance of time and planning to ensure people are meaningfully involved. Due to this phase of the project being in the early stages of the Covid-19 pandemic, this was not possible. None of the researchers in our team has a learning disability and we are aware of the limitations this engenders. We are hoping to establish a steering group for the future phases of this project; and several women with learning disabilities have expressed an interest in being involved in this.

### 5 | CONCLUSION

The findings of our interviews with health professionals suggest that women with learning disabilities can make and put into practice infant feeding decisions if they have access to the right support at the right time. Health professionals may have a crucial role in viewing themselves as part of the woman's support network and adopting a genuine person-centred approach when providing support. The necessity to challenge cultural and historical ideas and conceptions

continues, particularly it appears with regard to breastfeeding being considered a viable option for all women. Our study suggests one challenge in discussing infant-feeding choices early in pregnancy might be due to competing priorities along with limited accessible resources. Our recommendation is to develop a suite of resources to enable a more flexible and individualised approach to supporting women to make infant-feeding decisions.

#### AUTHOR CONTRIBUTIONS

The work was jointly conceived in discussion with all authors. Interviews were carried out by Sally Dowling, Emma Douglass and Geraldine Lucas. Emma Douglass carried out thematic analysis of the interview data with themes discussed and revised by the whole team. Sally Dowling and Emma Douglass wrote the first draft of the article and edited the final version, and all contributed to subsequent reviews. All authors approved the final version of the paper.

#### ACKNOWLEDGEMENT

This work was funded by a UWE, Bristol Vice-Chancellor's Challenge Award, 2020-21.

#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

#### DATA AVAILABILITY STATEMENT

Research data are not shared.

#### ETHICS STATEMENT

Ethical approval was granted by the Faculty of Health and Applied Sciences Research Ethics Committee, UWE, Bristol on 7 October 2020 (review number HAS.20.07.205), with an amendment related to video-call interviewing granted on 20 November 2020.

#### ORCID

Sally Dowling  <http://orcid.org/0000-0002-2336-024X>

#### REFERENCES

- Auslander, P. (2008). *Liveness: Performance in a mediatized culture*. Routledge.
- Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. Sage.
- Burr, V. (2015). *Social constructionism* (3rd ed). Routledge Publications.
- Castell, E., & Kroese, B. S. (2016). Midwives experiences of caring for women with learning disabilities—A qualitative study. *Midwifery*, 36, 35–42. <https://doi.org/10.1016/j.midw.2016.02.001>
- Corrigan, A. (2019). The loaded die: Parenting with learning disabilities and the role of the midwife in Scotland. *British Journal of Midwifery*, 27(1), 49–53.
- Daniels, L., & Douglass, E. (2021). Making effective reasonable adjustments for women with learning disabilities during pregnancy. *Learning Disability Practice*, 24, 10–17. <https://doi.org/10.7748/ldp.2021.e2132>
- Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century*. [Online]. Accessed June 2022. Retrieved from <https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century>



- Department of Health. (2009). *Healthy child programme: Pregnancy and the first five years of life*. [Online]. Accessed June 2022. Retrieved from <https://www.gov.uk/government/publications/healthy-child-programme-pregnancy-and-the-first-5-years-of-life>
- Dowling, S., Naidoo, J., & Pontin, D. (2012). Breastfeeding in public: Women's bodies, women's milk. In P. Smith, B. Hausman, & M. Labbok (Eds.), *Beyond health, beyond choice: Breastfeeding constraints and realities* (pp. 249–258). Rutgers University Press.
- Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, 25, 443–455. <https://doi.org/10.1177/1744987119880234>
- Earle, S., Chapman, R., Ledger, S., Townson, L., & Walmsley, J. (2015). *Contraceptive choices for women with learning disabilities*. [Online]. Accessed June 2022. Retrieved from <https://www.open.ac.uk/health-and-social-care/research/shld/sites/www.open.ac.uk/health-and-social-care.research.shld/files/files/ecms/web-content/shld-web-content/contraceptive-choices-report-final-may-2015.pdf>
- Equality Act. (2010). Chapter 15 [2010] [Legislation.gov.uk](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf). [Online]. Accessed June 2022. Retrieved from [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)
- Goldacre, A. D., Gray, R., & Goldacre, M. J. (2015). Childbirth in women with intellectual disability: Characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *Journal of Intellectual Disability Research*, 59, 653–663. <https://doi.org/10.1111/jir.12169>
- Goldberg, R. (2018). Performance now: Live art for the 21<sup>st</sup> century. Thames and Hudson Ltd.
- Guay, A., Aunos, M., & Collin-Vezina, D. (2017). Mothering with an intellectual disability: A phenomenological exploration of making infant-feeding decisions. *Journal of Applied Research in Intellectual Disabilities*, 30, 511–520.
- Hindmarsh, G., Llewellyn, G., & Emerson, E. (2015). Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research*, 59, 541–550. <https://doi.org/10.1111/jir.12159>
- Hoddinott, P., Craig, L. C. A., Britten, J., & McInnes, R. M. (2012). A serial qualitative interview study of infant feeding experiences: Idealism meets realism. *BMJ Open*, 2, e000504.
- Hollomotz, A. (2014). Are we valuing people's choices now? Restrictions to mundane choices made by adults with learning disabilities. *British Journal of Social Work*, 44, 234–251. <https://doi.org/10.1093/bjsw/bcs119>
- Homeyard, C., Montgomery, E., Chinn, D., & Patelarou, E. (2016). Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. *Midwifery*, 32, 45–57. <https://doi.org/10.1016/j.midw.2015.10.002>
- Hunt, L., Thomson, G., Whittaker, K., & Dykes, F. (2022). Non-profit breastfeeding organisations' peer support provision in areas of socio-economic deprivation in the UK: A meta-ethnography. *Maternal and Child Nutrition*, 18, e13271. <https://doi.org/10.1111/mcn.132712022>
- Jardine, J., Relph, S., Magee, L. A., Von Dadelszen, P., Morris, E., Ross-Davie, M., Draycott, T., & Khalil, A. (2021). Maternity services in the UK, during the coronavirus disease 2019 pandemic: A national survey of modifications to standard care. *British Journal of Obstetrics and Gynaecology*, 128, 880–889. <https://doi.org/10.1111/1471-0528.16547>
- Johnson, C., Douglass, E., Lucas, G., & Dowling, S. (2022). Supporting women with learning disabilities in infant feeding decisions: a scoping review. *Maternal and Child Nutrition*, 18. <https://doi.org/10.1111/mcn.13318>
- Lima, F., O'Donnell, M., Bourke, J., Wolff, B., Gibberd, A., Llewellyn, G., & Leonard, H. (2022). Child protection involvement of children of mothers with intellectual disability. *Child Abuse and Neglect*, 126, 1–10. <https://doi.org/10.1016/j.chiabu.2022.105515>
- Lord, C., Elsabbagh, H., Baird, G., & Veenstra-Vanderweeke, J. (2018). Autism spectrum disorder. *The Lancet*, 392, 508–520.
- Matriano, M. G., Ivers, R., & Meedy, S. (2021). Factors that influence women's decision on infant feeding: An integrative review. *Women and Birth*, 18, S1871–S192. <https://doi.org/10.1016/j.wombi.2021.10.005>
- NHS England. (2017). Accessible information standard. [Online]. Accessed June 2022.
- NICE (National Institute for Health and Care Excellence). (2021). *NICE impact: People with a learning disability*. [Online]. Accessed June 2022. Retrieved from <http://www.nice.org.uk/Media/Default/About/what-we-do/Into-practice/measuring-uptake/learning-disability-impact-report/Learning%20disability%20impact%20report.pdf>
- Nursing and Midwifery Council (2018). *The Code. Professional standards of practice and behaviour for nurses, midwives and nursing associates* [Online]. Accessed June 2022. Retrieved from <https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf>
- Nursing and Midwifery Council (2019). *Standards of proficiency for midwives*. [Online]. Accessed June 2022. Retrieved from <https://nmc.org.uk/standards/standards-for-midwives/standards-of-proficiency-for-midwives/>
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). Sage.
- Porter, E., Kidd, G., Murray, N., Uytman, C., Spink, A., & Anderson, B. (2012). Developing the pregnancy support pack for people who have a learning disability. *British Journal of Learning Disabilities*, 40, 310–317. <https://doi.org/10.1111/j.1468-3156.2011.00713.x>
- Public Health England. (2015). *Healthy child programme rapid review and update evidence*. [Online]. Accessed June 2022. Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/429740/150520RapidReviewHealthyChildProg\\_UPDATE\\_poisons\\_final.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/429740/150520RapidReviewHealthyChildProg_UPDATE_poisons_final.pdf)
- Public Health England. (2021). *Best start in life and beyond improving public health outcomes for children, young people and families*. [Online]. Accessed June 2022. Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1011409/Commissioning\\_guidance\\_for\\_FNP.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1011409/Commissioning_guidance_for_FNP.pdf)
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77–84.
- Schmied, V., Beake, S., Sheehan, A., McCourt, C., & Dykes, F. (2010). Women's perceptions and experiences of breastfeeding support: A metasynthesis. *Birth*, 38, 49–60.
- Slayter, E. M., & Jenson, J. (2019). Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*, 98, 297–304. <https://doi.org/10.1016/j.childyouth.2019.01.013>
- Thomson, G., Ebisch-Burton, K., & Flacking, R. (2015). Shame if you do—Shame if you don't: Women's experiences of infant feeding. *Maternal and Child Nutrition*, 11, 33–36. <https://doi.org/10.1111/mcn.12148>
- Tilley, E., Earle, S., Walmsley, J., & Atkinson, D. (2012). 'The silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability and Society*, 27, 413–426. <https://doi.org/10.1080/09687599.2012.654991>
- Tremblay, S., Castiglione, S., Audet, L.-A., Desmarais, M., Horace, M., & Pelaez, S. (2021). Conducting qualitative research to respond to COVID-19 challenges: Reflections for the present and beyond. *International Journal of Qualitative Methods*, 20, 1–8. <https://doi.org/10.1177/16094069211009679>
- UNICEF/BFI (2017). *Guide to the baby friendly initiative standards*. [Online]. Accessed June 2022. Retrieved from <https://www.unicef.org.uk/babyfriendly/wp-content/uploads/sites/2/2014/02/Guide-to-the-Unicef-UK-Baby-Friendly-Initiative-Standards.pdf>
- Victoria, C. G., Bahl, R., Barros, A. J. D., França, G. V. A., Horton, S., Krasevec, J., Murch, S., Sankar, M. J., Walker, N., & Rollins, N. C., for the Lancet Breastfeeding Series Group. (2016). Breastfeeding in the 21st century: Epidemiology, mechanisms, and lifelong effect. *Lancet*, 387, 475–490. [https://doi.org/10.1016/S0140-6736\(15\)01024-7](https://doi.org/10.1016/S0140-6736(15)01024-7)

- Welsh Government. (2021). Learning disability improving lives programme. [Online]. Accessed July 2022. Retrieved from <https://gov.wales/sites/default/files/publications/2019-03/learning-disability-improving-lives-programme-june-2018.pdf>
- WHO (2003). *Global strategy for infant and young child feeding*. [Online]. Accessed June 2022. Retrieved from <https://www.who.int/publications/i/item/9241562218>

**How to cite this article:** Dowling, S., Douglass, E., Lucas, G., & Johnson, C. (2023). Supporting women with learning disabilities in infant feeding decisions: UK healthcare professionals' experiences. *Maternal & Child Nutrition*, 19, e13432. <https://doi.org/10.1111/mcn.13432>