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ORIGINAL ARTICLE

Motherhood and intellectual disability in Spain: Experienced difficulties and shared desires for change

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Abstract

Backgroud: Despite the advancements in the rights of persons with disabilities in Western countries, the motherhood of women with intellectual disabilities remains scarcely visible. The approval of the Convention on the Rights of Persons with Disabilities (2006) and its subsequent ratification by the Spanish Government (2008) recalls the obligation to fulfil the rights of persons with disabilities to found a family (art. 23) and to choose who they want to live with (art. 19). While the importance of this legislation is undeniable, the personal experiences of women with intellectual disabilities still demand effective changes.

Methods: This article reports the results of a study entitled *Subjectivities and motherhood in women with intellectual disabilities. Reflections in dialogue through an inclusive research project*. In this study, we delved into the stories of 13 women, aged between 24 and 72, to learn about their motherhood experiences (before, during and after making the decision of being mothers) and to identify the barriers and supports encountered. Methods for data collection included individual semi-structured interviews, discussion groups and other narrative and visual resources (images and biograms).

Findings: This study explores in depth the obstacles identified by the participating mothers, which have been organised around six themes: (1) information and guidance on sexuality and family planning, (2) assistance of health services, (3) employment and housing situation, (4) child custody, (5) raising children, and (6) informal support. The participants encountered difficulties in all the above fields related to contextual factors. In other words, these barriers do not derive from individual issues centred on their disability, but from factors that often do not depend on mothers with intellectual disabilities, such as deprivation of socio-educational opportunities.

Conclusions: Our results show the nuanced ways in which these mothers were immersed in a social system that questions them as 'good mothers' and violates their rights. As we discussed, the participants' desires and decisions to engage and/or continue with motherhood constitute an exercise of resistance to this system.

KEYWORDS
barriers, motherhood, supports, women with intellectual disabilities

Accessible Summary

- People with intellectual disabilities have the right to start a family and to choose who they want to live with.
- These rights need the support of society and institutions to be effective.
- This paper deals with interviews and discussion groups with thirteen women with intellectual disabilities.
- Women with intellectual disabilities shared their experiences of motherhood.
- The participating women and academic researchers found some of the barriers mothers with intellectual disabilities encountered.
- Women with intellectual disabilities defend their desire and ability to become mothers.

1 | INTRODUCTION

The rights of persons with disabilities to decide the number of children they want to have, to be respected in the exercise of parenting, and to not be discriminated against in the decision to found a family were enshrined in Article 23 of the International Convention on the Rights of Persons with Disabilities (United Nations—Office of the High Commissioner for Human Rights [OHCHR], 2006). This Article includes persons with intellectual disabilities. The ratification of this Convention by the Spanish Government 2 years later allowed some issues to be radically addressed, including the amendment of the Spanish Penal Code by the Organic Law 2/2020 that eradicates forced or nonconsensual sterilisation of persons with disabilities. However, other important issues covered by the Spanish law, such as reproductive care and support during and after pregnancy, are scarcely visible and addressed concerning people with intellectual disabilities. As the consortium of organisations of the European project *Parents with Intellectual Disabilities* (2013) has warned, Nongovernmental Organisations are replacing the role that public administrations should have in this issue, both in policy formulation and in the actual support they need, by participating in the provision of public services such as health and social care, counselling, housing and financial assistance (Parents with Intellectual Disabilities, 2013). Likewise, the lack of research in the Spanish context that makes the experiences of mothers with intellectual disabilities visible is a further obstacle to achieve their fundamental rights.

The data reported in this article draw from a broader research project entitled *Subjectivities and motherhood in women with intellectual disabilities. Reflections in dialogue through an inclusive research project* whose aim is to explore the construct of motherhood (assumptions, beliefs or implicit norms) of a group of women with intellectual disabilities in Spain and make the structural changes that they consider necessary visible. Specifically, this article focuses on the barriers identified by the participants from the moment they expressed their decision of becoming mothers and continuing with their pregnancies.

1.1 | Literature review

Women with intellectual disabilities often express their desire to start a family like many other women (Conder et al., 2011; Rojas-Pernia et al., 2016; Theodore et al., 2018). Some studies emphasise that only a few mothers with intellectual disabilities had considered the implications of becoming mothers before pregnancy and that many of the pregnancies were unplanned (Conder et al., 2011; Jamieson et al., 2016). These unplanned pregnancies increase the feelings of uncertainty among women with intellectual disabilities and generate some fears, such as the removal of custody or the lack of parenting support (Sigurjónsdóttir & Rice, 2018). However, successive international studies have reported high rates, in the range of 40–60%, of children being removed from their parents with intellectual disability (McConnell & Llewellyn, 2002). In the United Kingdom, for example, this rate was at 48% (Emerson et al., 2005). More recent international data have pointed out that around 20% of all children who are removed by Child Protective Services are from parents with intellectual disabilities (Lightfoot & DeZelar, 2020; Pacheco et al., 2022). The risk of losing the custody of their children is much higher in mothers with intellectual disabilities and the fear that they have of this happening has been consistently underlined by studies in the field (Bachrach, 2023; Lightfoot & DeZelar, 2020; Slayter & Jensen, 2019). This fear has been identified as one of the variables explaining women's delay in asking for help, telling others about the pregnancy, and engaging with the support offered to them (Jamieson et al., 2016). The above studies with different focus and in different geographical contexts seem to report that the percentage of children who are separated from their mothers has been reduced by half in the last decade.

Some studies have also highlighted that mothers with intellectual disabilities have a lower support network than other people without disabilities: mothers with intellectual disabilities 'reported fewer social supports, were less likely to have other parents to talk to and someone to share feelings with' (Hindmarsh et al., 2015, p. 548). Family and social support seem to be key to accompanied decision-making during pregnancy and in the positive construction of the childbearing experience (Darbyshire & Stenfert Kroese, 2012; Jamieson et al., 2016). As outlined by Conder et al. (2011), 'family response to the news of a pregnancy was pivotal to the future success of many of the parents in this study. Family and social support have been identified elsewhere as markers for successful parenting' (p. 110). Independent of the quantity of support available, women appreciate the quality of relationships that are established from nearby contexts and how these fit their needs (Starke, 2022). This result evidence that women with intellectual disabilities understand the social nature of motherhood, foreseeing that they will need support from close or trusted people to accompany them in making some decisions related to the baby's care, thus looking for people in their environment to provide it and being actively engaged in decisions regarding the upbringing of their children (Mayes et al., 2006).

Despite being varied across countries, there is a general lack of research on the functioning of public or private services that support mothers with intellectual disabilities (Gudkova et al., 2019; Lightfoot & DeZelar, 2020), formal supports that assist women as mothers seem to be limited and focused on training personal caregiving skills rather than on encouraging contextual or community support. In the words of Lightfoot and DeZelar (2020), programmes that increase parenting skills are important for anyone, but it is critical to emphasise 'the role developing or enlisting broader family and community support to assist parents with disabilities in their parenting' (p. 1).

The aforementioned demands a reconsideration of the focus of the analysis and actions related to motherhood and intellectual disabilities. It is necessary to draw attention to the inaction of public institutions, the lack of support for women who decide to become mothers, and the social stigma that mothers with intellectual disabilities suffer (Booth & Booth, 2005). Mothers with intellectual disabilities receive messages that consider themselves incapable of taking care of themselves and their children (Olavarrieta et al., 2013), questioning their ability to care for and raise their children, even when taking their custody and raising them (Theodore et al., 2018). Likewise, making visible the stories in which mothers with disabilities successfully raise their children helps other mothers and their families to trust them and learn about the role that formal and informal support plays in the process (Conder et al., 2011). The right of any person to found a family and the rise of people with intellectual disabilities who decide to become parents (Jamieson et al., 2016; Lightfoot & DeZelar, 2020) require continuing working alongside mothers with intellectual disabilities, to listen to what difficulties they encounter and to make society aware of their needs and demands.

2 | METHOD

This study explores, in collaboration with the participants, the motherhood experiences of a group of 13 women with intellectual disabilities. The study adopted a participatory and inclusive approach that allowed us to identify connections among the mothers' experiences. According to Nind (2016), inclusive research is itself a learning opportunity and complex issues are addressed in complex ways. Unlike more extractive research models that sustain and nurture unequal forms of relationship with people with intellectual disabilities within and outside the research (Milner & Frawley, 2019), the inclusive research model recognises the wisdom of the experience of the women with intellectual disabilities and the need for more democratic forms of research. This approach deepened our understanding of the issues mothers with intellectual disabilities perceived as important and facilitated the formulation of proposals. Their collaborative analysis of common experiences became an opportunity to weave a support network between them. Regardless of the level of involvement each woman wanted or was able to take on, the joint work environment created a space where life experiences could be discussed. In this sense, the researchers try to accompany and empower these women constantly and to recognise the value of their experiences.

2.1 | Recruitment

Access to the participants was made through professionals in the associative sector who develop programmes aimed at people with intellectual disabilities. The first contact was made in person or by telephone and some of the professionals acted as liaisons with other organisations. Forty-one entities from different Spanish regions were informed. Eleven out of the 41 entities replied to our calls: two indicated that none of the women attending their services were mothers and the others had a varied number of mothers involved, which ranged from 1 to 18 women (see Table 1).

To present the research to the potential participants, a video call was made with them and the professionals from the associations to support with them technical issues. The second phase involved the organisation of individual and group sessions with potential participants who expressed interest in the research. Some of these meetings were organised online due to the travel restrictions imposed by the pandemic. The purpose of both face-to-face and online meetings was to provide a more in-depth understanding of the research objectives, the collaborative enquiry process and the ethical aspects of the research. Finally, out of the 35 potential participants, 13 women with intellectual disabilities expressed interest in being involved in the research.

TABLE 1 Entities contacted and their responses.

Entities reported	Response	Mothers using any service or programme
41	11	None
		None
		1
		1
		1
		2
		3
		4
		5
		18

2.2 | Participants

Thirteen mothers with intellectual disabilities, aged between 24 and 72 participated in the research. When the data collection process began, the work, family and housing circumstances of the participants were very diverse (see Table 2). As can be observed in Table 2, nine of the participants (Alicia, Lourdes, Emma, Rocío, Sol, Andrea, Remedios, Fátima and Camino) had their children before the ratification of the CRPD in 2008. Four of the mothers (Remedios, Sol, Marina and Emma) had their children in foster care after a few months of parenting, although they didn't lose contact with their children. The rest of the 13 mothers, including Remedios' second pregnancy, kept custody of their children. One of the participants (Fátima), however, temporarily ceded custody of her child to her sister after divorce.

In terms of the relationship status of the mothers, only four participants had a partner: two were married to the fathers of their children (Andrea and Lourdes) and the other two (Sandra and Remedios) had other relationships, although one of them was defined as not stable (Sandra's relationship). The other nine participants were single at the time of the interviews.

Regarding the housing situation of the participants, two of the mothers were living in residential settings, five in sheltered accommodation (alone or with other housemates), and the rest were living independently, with or without family support. In addition, most of the mothers (eight of the participants) were in occupational centres, with temporary jobs or without an employment contract.

2.3 | Procedure

The research process with the participants consisted of two stages. In the first stage, all the meetings were face-to-face. Twelve out of 13 interviews were individual (researcher-mother) and just in one of the interviews the professional was present. These interviews were in depth and asked them questions about their experiences related to pregnancy and the upbringing of their children. During the interviews, the participants were also asked to recreate their home with the support of a template of a possible dwelling or through a free drawing. As an eliciting resource (Mannay, 2017), the drawing helped the women to talk about how they use the spaces, with whom they share these spaces and what is important for them in the process of raising and caring for their children. Six themes were identified as the most frequently recurring barriers encountered by mothers with intellectual disabilities in the development of their motherhood: (1) the lack of guidance and information on sexuality and family planning, (2) the lack of follow-up during pregnancy and the lack of confidence in the mothers' judgement by doctors, (3) the precariousness of employment and access to adequate housing, (4) the possibility of separation from their children, (5) the fear of making mistakes and not knowing how to do something during parenting, and (6) the lack of support from family, partner or friends.

The second stage began with the sharing and discussion with the participants of the results from the previous stage, for which a series of worksheets were drawn up with anonymised fragments of their stories. Due to the diversity of profiles within the group of women (their age, their educational background, and difficulties with reading and writing), it was decided to opt for a content presentation that would be accessible to all, so the easy-read format was used 'as a more effective way of presenting information for people with intellectual disabilities than standard formats' (Sutherland & Isherwood, 2016, p. 12). Several meetings were organised to ensure that all mothers were able to attend. Four working groups were carried out with 3–4 participants and a duration of about 2 h. At the beginning of the focus groups, the researcher introduced the participants without mentioning anything personal about them and reminded them about some basic instructions to ensure that the ethical and confidentiality principles of this work were respected. Thus, the importance and sensitivity of the information discussed in the focus groups and the purpose of the research is emphasised, and participants are asked to be cautious about using this information. Additionally, participants are reminded not to share anything they do not want others to know and to feel comfortable and free to not respond or to cease participation at any time during the research.

These meetings allowed the women involved to get to know each other, to find out what the other participants had said and to exchange impressions and experiences. To analyse the fragments extracted from the interviews, the situation was first given context without naming the protagonist, then the experience was read aloud and, finally, the researcher raised the debate through questions in a script: *What do you think? Has any of these experiences happened to you? Do you think it needs to be changed? Why? How does it occur to you? What is needed to change it? Who has to do it?* Through these questions, a dialogic process is provoked among the participants, involving them in the analysis of the content of the previous interviews, re-signifying the shared experiences of others and engaging them in making decisions about the relevant issues they wanted to address. Lastly, these gatherings also allowed them to think about the type of feedback or final production (audiences,

TABLE 2 Summary of participant data.

Pseudonym	Age range in 2021	No. of children and children status	Year of children's birth	Relationship status	Housing situation	Employment status
Carol	20–40	One daughter (2 years old). Currently: stays with her mother.	2019	Single	Lives in a supervised flat with her daughter	Student and Occupational Centre
Sandra	20–40	One son (6 years old)Currently: stays with her mother	2015	Partner (not stable), father of her child	Lives in a flat with his son	Factory employment
Lidia	41–60	One daughter (3 years old). Currently: stays with her mother.	2018	Single	Shares a flat with her daughter, brother and father	Occupational centre
Camino	41–60	One daughter (20 years old, dies in 2022). Past: stayed with mother.	2001	Single	Lives at home with her parents	Occupational centre
Fátima	41–60	One son (30 years old). Past: For some years under the guardianship of his aunt. Currently: Stays with mother.	1991	Married (second husband, nonparent)	Family home with her mother, husband and son	Employment without contract
Remedios	41–60	Two daughters of two couples (23 and 30 years old). Past: The older one was with her in the foster home for the first months and then in foster care. The younger one stayed with her. Currently: The older one she does not know anything about. The younger one is independent.	1998 and 1991	With partner (nonparent)	Lives in a supervised flat with a female companion	Occupational centre
Andrea	41–60	Two daughters and 1 son (30 and 28 years old). Past: stay with their mother. Currently: live in the family home with their father and grandmother.	1991 and 1993	Married with the father of her children (outside the community dwelling)	Shared housing with other people with intellectual disabilities	Unemployed
Sol	41–60	Two children (1 son aged 37 missing and 1 daughter who would have been 32, died at age 24). Past: in foster care (until she passed away).	1984 and 1989	Single (had a boyfriend after both fathers of her children, but he passed away)	Shared housing with other people with intellectual disabilities	Unemployed
Rocío	41–60	One son and 1 daughter with her first husband (35 and 32 years old) and another (24 years old) with another partner. Past: remain with their motherCurrently: All independent from the family home.	1986, 1989 and 1997	Single	Lives in a supervised flat with two female companions	Occupational centre
Marina	41–60	One son (13 years old)Past: stays with her for the first few months. Currently: residential care.	2008	Single (Her partner and father of her child died 5 months after the birthing)	Lives alone in a supervised flat	Occupational centre
Emma	61–80	One son (20 years old). Past: stays with her for a year and a half, then goes into foster care with her paternal aunt. Currently: Lives with her paternal aunt.	2001	Single	Lives in a shared supervised flat	Casual labour

(Continues)

TABLE 2 (Continued)

Pseudonym	Age range in 2021	No. of children and children status	Year of children's birth	Relationship status	Housing situation	Employment status
Lourdes	61–80	Two children (41 years old and the youngest, who would have been 38, died at the age of 30). Past: stay with mother. Currently: Independent from family home.	1980 and 1983	Married with the father of her children	Lives in a flat with her husband and father of her two children	Retired
Alicia	61–80	One son (47 years old). Past: stays with mother. Currently: independent family home.	1974	Single	Lives in a flat with her aunt	Retired

format or dissemination), since at the end of the discussion of each thematic block, the participants were asked to elaborate proposals for improvement for these situations and possible ways to disseminate these proposals, including scientific articles, letters and audiovisual products. According to some authors (Fudge Schormans et al., 2019; Holt et al., 2019; Nind, 2014), the research activities need to acknowledge the experience of the mothers with intellectual disabilities and to be meaningful and understandable to participants.

Both the individual interviews and the meetings were audio-recorded with the signed consent of the participants and subsequently transcribed. Data analysis was based on a systematic thematic coding process (Gibbs, 2012). The catalogue of categories, subcategories and codes was developed on the basis of deductive-inductive analysis processes, meaning processes of going back and forth from the theoretical framework of the research to the narratives constructed by the participants. Lastly, 11 categories were established, then differentiated into two time periods (before and after pregnancy) and into barriers and support encountered (see example in Table 3 below). NVivo software was used to analyse the data. Some fragments were coded by several researchers to ensure that they accurately represented the codes and categories indicated.

2.4 | Ethical considerations

All participants were informed of the aims of the research and the conditions for its development. At the first face-to-face meeting, the mothers with intellectual disabilities were given a written document that was read and reviewed together with the researcher. It included the nature of the study, the form of participation, the rights and duties involved, as well as issues related to data processing and data protection. All participants took the document with them to share its contents with people they trusted and, lastly, they agreed to take part in the research and were assured of anonymity. Therefore, the names of persons and locations have been changed or deleted. Ethical approval was granted by the Research Ethics Committee of the University of Cantabria on the 21st of January 2021.

3 | FINDINGS

This section explores the experiences of motherhood of the 13 women with intellectual disabilities involved in the research, focusing on the barriers identified by the participants from the moment they express the desire to go ahead with their pregnancies.

(1) ***The precarious employment situation and, hence, the precarious housing situation.***

At the time of the interviews, only one of the mothers had a job with a contract outside an occupational centre. All of the participants reported a lack of training and labour opportunities and guidance as well as experiences of precarious and unstable employment. Some of the mothers had worked in the family

TABLE 3 Example category family relationships.

Family relations	Before pregnancy	Descriptive	Information about the situation with her nuclear family before pregnancy: who she talked to, what they said to her, what they did when they were together…
		Supports	Statements about relationships with their nuclear family that facilitated participants' autonomy, well-being and/or childbearing development before pregnancy.
		Barriers	Statements about relationships with their nuclear family that limited participants' autonomy, well-being and/or childbearing development before pregnancy.

business or in jobs that other family members had found for them (as caregivers, cleaners, street sellers or in local shops), but as Lourdes said, it was not easy to find jobs outside these informal support networks:

> I've been searching and searching and searching, and nothing. On the phone, they told me, 'well, come and see us, blah, blah, blah'. As they saw that I had a little problem with my nerves, that I was handicapped and so on, they closed the doors, 'we'll call you back', but no. In another case, I went with my deceased mother, my mother met her and everything, she said, 'we'll call you', but she didn't (Lourdes).

The social isolation resulting from the lack of support experienced by some of the women forced them to live in flats in uninhabitable conditions (without electricity or hot water), even living in squats and on the street. The situation of many of the mothers did not improve until they received the support from professionals.

(2) ***Scarce information and counselling on sexuality and family planning.***

As the participants reported, the information they received about sexuality and family planning before their first pregnancy conditioned their decisions and experience. All 13 participants indicated that this information is relevant, but no one provided it to them. Neither their support network, nor the professionals (in the health or education system), with whom the participants were in contact before pregnancy, provided them with information about sexuality or family planning. When talking about their first pregnancy, the majority of the participants (10 out of 13) recognized that it was not planned and said that when they found out that they were pregnant, they had to deal with the situation and make the decision to go ahead or have an abortion with little information on the matter.

> At the beginning, that is, when I became pregnant, I had doubts because as a mother with a disability, at first I had doubts about whether my child would turn out like me and I didn't want him to. (…) It seemed difficult to me to think that if my child would turn out, if he would turn out with a disability… (Sandra).

(3) ***Inadequate assistance from health services.***

Some of the women attended health services at a very late stage of their pregnancy or went to the doctor occasionally during pregnancy. In particular, seven of them went after the seventh month of pregnancy, or did so on an ad hoc basis: '*No, I didn't [go to the doctor], no. I knew I was pregnant, well, I went a few times, two, three or four times, but then no more*' (Remedios).

All the participants identified two significant obstacles. First, the lack of information about their rights and about the support they are entitled to raise their children. Second, the mistrust towards the health system, as it questioned them as potential mothers. Some mothers with intellectual disabilities were reluctant to attend the health services due to the negative attitudes from certain health professionals that judged them during the appointments.

> [The doctor] said to me 'but are you sure you're pregnant?'. I said, 'I'm sure because I haven't had my period and I always have it, but I want to take the pregnancy test (…) I don't come here for fun and pleasure, I come here because I want to get rid of this doubt'. (…) And he says, 'alright, alright, we are going to do it, but I don't think you are in doubt', (…) and in the end he did it, but he did it reluctantly (Lidia).

According to the participants, the health staff not only questioned the ability of mothers with intellectual disabilities to perceive their own pregnancy, but also to raise their children in the future, expressing these prejudices through advice geared towards that vision. One of the focus groups (Group 2), when asked what a doctor had said to one of the mothers, generated a subversive response of rejection and anger:

> Ana: [The doctor] asked me if I wanted to give him up [for adoption] or if I wanted an abortion (…) The gynaecologist who looked at me [wanted me to have an abortion]. And I told her, 'no, this child is going to go ahead, with all the problems it may have, but it's going to go ahead'. [He wanted me to have an abortion] so that I wouldn't have him. (…) I don't know, maybe he thought I wasn't capable of raising the child (Extract from Marina's interview).

> Marina: That doctor should have been denounced for saying the wrong thing to a person.
>
> Remedios: The three of us are disabled, retarded or whatever we are, but we raise our children no matter what, even with bread and water, but we get our children ahead.
>
> Lidia: Exactly. I'll give you an example. It's like if I tell you that you're not good for work, and I treat you like an old piece of furniture, there, on the side, and I don't value you.
>
> Remedios: That's right. We have to evaluate you, see what you do, what you don't do…
>
> Marina: That's it, if you haven't seen what she can do, don't talk about it, don't give your opinion, don't interfere…

(4) ***Fear of losing custody of children.***

The prejudices mentioned above heightened the fear of the participants of not being 'good mothers' and being deprived of the custody of their children. Nine out of the 13 participants always had their children with them, although on some occasions they had to find an alternative way to keep their children close to them by, for example, giving custody to other relatives. However, four out of them, even though they had expressed the wish to raise their children themselves, were not allowed to keep custody of their children:

> Having your child and then having her taken away from you and given up for adoption, that's really hard. (…) It's very hard. It's very hard because, I'm telling you, until I was able to see my daughter, it was hard for me, it was hard for me. It was hard because I had to keep fighting, talking to the social worker, telling her, please, that I wanted to see my daughter, that I couldn't be here. Every now and then I was depressed, I didn't sleep, I didn't eat…. (Sol).

Another mother recounted her memory of the fear of losing custody of her daughter on the day she gave birth. While at the hospital, she was afraid that she would not leave the medical centre with her daughter in her arms:

> With everything I've been through and the happiest day of my life arrives and I don't know if they're going to take her from me or not, because of the disability, because of this, because I have nothing… Sure, it's still a baby at risk, it's understandable (…) But, of course, she's the only thing you have, what you've fought for and the most important thing, how are you going to feel? But, of course, you have a slight constant fear that they're going to…. (Carol).

(5) ***Fears around parenting.***

The fear of making mistakes or not knowing how to do something during parenting and that this may affect the child was a common theme among the interviewees. Most of the mothers explained that the associations they are members to and/or their families supported them in this process, especially during the first days after birth. However, some mothers experienced different situations and stated that they did not know how to deal with certain care tasks, such as cradling, feeding, changing nappies or bathing the babies. This insecurity increased the fear of being labelled as 'bad mothers' and being separated from their children:

> I live in fear that I will make a mistake and so on and they will take her away, but I endure it, I know that…, every little thing, I ask every little thing…, I don't know, I need something and I ask about it. (…) A single mother is judged for being alone, because of this, because of how I do something, what I give to her, if that milk is good, how I hold her up…. That's bad enough, imagine with my 'burden' (Carol).

Other participants highlighted how difficult it was to 'get it right' when raising children, even when done with love and good intentions:

> I have protected him too much and maybe by protecting him too much, things can also go wrong. So… You can't be so protective either, so protective, because maybe later you think they turn out well and they turn out badly (Marina).

(6) ***Negative attitudes of informal supporters.***

The participants also expressed mistrust towards other people in their surroundings (family and friends). As they reported in the interviews, some friends and relatives questioned the ability of mothers with intellectual disabilities to care for their children and to learn how to do so. This prejudice becomes an emotional burden for women who feel the need to continually prove they can care for their children, and they perceive a lack of support from these people:

> I keep proving it, still to this day I have to… Even my friends, all day long judging. 'But do you know…? But do you know…? But do you know…?'. 'No, I'm stupid'. Just because I have a disability doesn't mean I'm stupid (Carol).

Despite this, all the mothers who kept their children with them were aware that this was partially possible because of the support they had from their family, with the exception of Carol,

> whose support was only provided by professionals from associations and the Social Services.

Another negative experience for most of the mothers was the break-up with their partners, who often did not support them during pregnancy and upbringing. In two of the 13 cases, the partners died (one within a few months and another when the child turned five), three separated after a few years (although the mothers explained that they never exercised responsible parenting) and five disappeared from their lives when the pregnancy was reported:

> I could feel that I wasn't going to have my boyfriend's support, because I didn't see him as capable, because I saw him as very scared (…) Of course, I felt like… 'now I have to do it on my own', because I could see that he was distancing himself from me (Lidia).

Most mothers mentioned that at some point they felt a lack of support or that the partner was an additional obstacle. Likewise, the women who had this support temporarily or permanently value the importance that this support had in their upbringing by providing financial support and facilitating the care of the baby.

This lack of informal (and sometimes formal) support, the constant questioning of their ability to raise their children, and other barriers already mentioned, are some of the reasons why the mothers with disabilities have pointed out the need to make their experiences visible, to show (and demonstrate) their ability to raise their children. This is how Working Group 1 explained its proposal:

> Sandra: People think that because you have a disability, you can't take care of anyone, that you can't even take care of yourself, so you can't take care of anyone. That's what people think, they're out of their minds.
>
> Sol: That's what my brother said to me, that because I had a disability, I couldn't take care of my daughter. And I said, 'I can look after my daughter, and well'.
>
> Sandra: That's it, that's it!
>
> Ana: So, do you think that the lack of information, rather than your…?
>
> Sandra: It's theirs! Totally, yes, because there are people without any disability and they don't know how to look after their children.
>
> Ana: And how could we change that perception?
>
> Sandra: I can think of many ideas: going on a TV programme, or to the radio (…) It's better to go on TV, which is what reaches the people most, because you can tell the politicians, but they don't care. (…) We have to tell people what is happening to women with disabilities and to explain that things are not the way they think.
>
> Sol: Yes, that's it, to tell people about it.

4 | DISCUSSION

The barriers reported by the 13 mothers suggest the need for structural changes, especially in the public systems and resources (health, social and educational) that are made available to them with the intention of providing wellbeing and autonomy in their motherhood. Statistics often suggest that these resources are insufficient, for instance, in a study conducted in Spain, they show that the employment rate of women with intellectual disabilities is 17.2% compared to 66.3% for people without disabilities (Observatorio sobre Discapacidad y Mercado de Trabajo en España [ODISMET], 2023), and this gap is even wider if we focus on education, where 0% of women with intellectual disabilities achieve higher education (compared to 38.1% of people without disabilities) and the majority of them, 60.6%, only completed primary studies in contrast to 6.1% of the population without disabilities (ODISMET, 2023).

Among the reflections of the participating mothers, there is a central theme that crosses their experiences in the different spheres included in the results of this research (family, medical, social, work, and housing), which is social stigma, as other studies have also pointed out (Booth & Booth, 2005; Potvin et al., 2019; Wos & Baczała, 2021). This stigma results in them being forced to delegate decisions about their motherhood to others (Earle et al., 2015; Sheerin et al., 2013) and justifies interventionist discourses and practices over their bodies (Hamilton, 2012; Heifetz et al., 2019). These discourses frame the difficulties they face as an issue of individual deficit that renders them unable to be 'good mothers' rather than a matter of systemic lack of support in the development of full and satisfying motherhood. One of the needs that this situation reveals has to do with the access and information that women with disabilities have about sexuality and family planning. There is a lack in this respect, which, while it should be addressed by public policies and services, it is the entities and nongovernmental organisations that offer programmes that try to guarantee this right to women with disabilities (Fundación CERMI Mujeres, 2023). This is not only the case in the Spanish context, but other authors report the same shortcomings and barriers in the results of their studies (Conder et al., 2011; Jamieson et al., 2016; Wos & Baczała, 2021). Although some of them show positive experiences in the accompaniment of these women during family planning decision-making by state agencies (Sigurjónsdóttir & Rice, 2018) and organisational alternatives that guarantee this support (Lightfoot & DeZelar, 2020).

As participants underlined, the most illustrative example of this can be found in some of the discouraging comments made by their relatives, friends and, particularly, the staff from the health services.

According to Starke (2022), trust is crucial for mothers to accept and receive support from professionals, and mistrust leads to greater isolation and less access to information and possible resources (Lightfoot et al., 2018; Ransohoff et al., 2022). The mothers' distrust towards professionals left them in a precarious situation which contributed to confirm the gutted impression of some professionals that these mothers with intellectual disabilities 'are not capable of being good mothers' (Mayes et al., 2006; Strnadová et al., 2016). And this dynamic operated as a self-fulfilling prophecy.

The way a problem is framed largely conditions the type of solutions given. In this case, framing the precarious situation faced by mothers and mothers-to-be with intellectual disabilities as an individual problem related to a lack of skills or ability has led to reductionist evaluations and interventionist practices. The best example of this is the implicit consideration of the children of mothers with intellectual disabilities as 'children at risk' (Perkins et al., 2002), which leads to the deprivation of custody as a response (Albert et al., 2022). Some studies already point to a decrease in the removal of custody in the last few years (Bachrach, 2023; Jamieson et al., 2016; Lightfoot & DeZelar, 2020; Slayter & Jensen, 2019), which could be explained as a consequence of effective changes in the guidelines followed by the assessment processes of the needs of mothers with intellectual disabilities and their children and as a result of legislative advances and social movements in pro of the rights of people with disabilities. The responses, however, would be much different if the context of these mothers and the possible support to be offered for the development of their children's upbringing were analysed. These responses would require a focus on the needs of mothers with intellectual disabilities and a public commitment to respect their rights and they should be based on the principles and rights enshrined in the CRPD (OHCHR, 2006).

The assessment of the support necessary for the development of motherhood of the participants was, however, often limited to aspects of basic care, hygiene, economic resources, housing, and so on, which reflects a confusion between 'needs' and 'situations of risk' or vulnerability (Tarleton et al., 2006; Vandenbeld Giles, 2012). This assessment restricted the decision-making of these mothers and their possibilities to upbring their children. As other researchers have pointed out, the challenges experienced by mothers with intellectual disabilities are not only shaped by complex needs related to being poor, socially isolated or unemployed, having housing problems, poor health and high levels of stress (Baum & Burns, 2007; Hindmarsh et al., 2015), but also by needing supports (Feldman et al., 2002; Gudkova et al., 2019).

The diagnosis based on individual deficit neglects the social responsibility towards mothers with intellectual disabilities and their right to found a family, in breach of the agreements contained in the CRPD (OHCHR, 2006). It is unethical not to provide these women with the support they need, often linked to an emotional and social sphere, considering the deprivation of socialisation spaces to which they have been historically subjected beyond the family and the compulsory school (not always inclusive) (Harrison et al., 2021). This isolation limits their network and hinders and impoverishes the support mothers with intellectual disabilities receive (Conder et al., 2011; Hindmarsh et al., 2015; Jamieson et al., 2016; Starke, 2022). This isolation is also evidence of the lack of public services that respond to their needs (Parents with Intellectual Disabilities, 2013) and the dependence of these women on associations or entities that are not in the structure of the public system itself, often becoming the only ones to facilitate social support programmes for these women, designing programmes which are not focused on behavioural aspects to develop basic parenting care tasks but on different social issues that help them to build their own support network (Fundación CERMI Mujeres, 2023; Lightfoot & DeZelar, 2020; Mayes et al., 2006; Starke, 2022).

In the different studies cited above (Jamieson et al., 2016; Starke, 2022; Wos & Baczała, 2021), there are similarities in terms of barriers encountered by mothers with intellectual disabilities in developing and enjoying motherhood, which highlights the need to make visible and disseminate the success stories of mothers with intellectual disabilities who have raised their children (Conder et al., 2011). In fact, during the working groups developed in our research, the participating mothers with intellectual disabilities pointed out the need to make their own stories visible, verbalising the proposal to make an audiovisual product to be sent to different groups (professionals and society in general). Through this audiovisual product they intend to show their reality, to refute those preconceptions that other people have about them and to show their motherhood as the natural experience that it is for them. Through this audiovisual product they intend to show their reality, to refute those preconceptions that other people have about them and to show their motherhood as the natural experience that it is for them. In this way, the perception that mothers with intellectual disabilities have about the audiovisual resource coincides with what some authors point out about how the visual can contribute to broadening the understanding of the ways in which social inequalities are imagined, constituted and reinforced (Mannay, 2017) and how these visual resources configure "affordable, high-impact material such as video and disseminate it via the internet" (Nind, 2014, p. 18).

5 | CONCLUSION

The lack of research on the experiences of mothers with intellectual disabilities in the Spanish context reflects a dearth of interest in the topic, becoming another obstacle for those women who wish and decide to become mothers. This absence is unlikely to be explained by a potential equality in support and access to resources between mothers with intellectual disabilities and mothers without intellectual disabilities. As this study and international research shows, mothers with intellectual disabilities face barriers in several spheres (social, economic, housing and employment) and from the professionals who are supposed to care for them, limiting their access to planning services or to parenting support programmes.

Not considering the circumstances in which many of these women find themselves, reinforces a deficient view of women with intellectual disabilities to be able to be 'good mothers'. In addition, the actions derived from this vision become arbitrary and insufficient and do not take into account other aspects of these women's realities: their decisions, interests, potential, context, networks. But, most importantly, their rights.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES

Albert, S. M., Powell, R. M., & Rubinstein, J. (2022). Barriers and solutions to passing state legislation to protect the rights of parents with disabilities: Lessons from interviews with advocates, attorneys, and legislators. *Journal of Disability Policy Studies*, *33*(1), 15–24. https://doi.org/10.1177/10442073211006394

Bachrach, T. (2023). Reflections of adult children of mothers with intellectual disability. *Journal of Intellectual Disabilities*, *27*(3), 671–688. https://doi.org/10.1177/17446295221096930

Baum, S., & Burns, J. (2007). Mothers with learning disabilities: Experiences and meanings of losing custody of their children. *Tizard Learning Disability Review*, *12*(3), 3–14. https://doi.org/10.1108/13595474200700018

Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system; experiences and perspectives. *Journal of Intellectual Disabilities*, *9*(2), 109–129. https://doi.org/10.1177/1744629505053922

Conder, J., Mirfin-Veitch, B., Sanders, J., & Munford, R. (2011). Planned pregnancy, planned parenting: Enabling choice for adults with a learning disability. *British Journal of Learning Disabilities*, *39*(2), 105–112. https://doi.org/10.1111/j.1468-3156.2010.00625.x

Darbyshire, L. V., & Stenfert Kroese, B. (2012). Psychological well-being and social support for parents with intellectual disabilities: Risk factors and interventions. *Journal of Policy and Practice in Intellectual Disabilities*, *9*, 40–52. https://doi.org/10.1111/j.1741-1130.2012.00326.x

Earle, S., Chapman, R., Ledger, S., Townson, L., & Walmsley, J. (2015). *Contraceptive choices for women with learning disabilities*. The Open University.

Emerson, E., Malam, S., Davies, I., & Spencer, K. (2005). *Adults with learning disabilities in England 2003/4*. Health and Social Care Information Centre.

Feldman, M. A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *15*, 314–323. https://doi.org/10.1046/j.1468-3148.2002.00132.x

Fudge Schormans, A., Wilton, R., & Marquis, N. (2019). Building collaboration in the co-production of knowledge with people with intellectual disabilities about their everyday use of city space. *Area*, *51*(3), 415–422. https://doi.org/10.1111/area.12492

Fundación CERMI Mujeres. (2023). *Informe España 2022. Derechos Humanos de las Mujeres y Niñas con Discapacidad*. https://cermi.es/novedad/informe-espana-2022-derechos-humanos-de-las-mujeres-y-ninas-con-discapacidad

Gibbs, G. R. (2012). Different approaches to coding. *Sociological Methodology*, *42*(1), 82–84. https://doi.org/10.1177/0081175012460853

Gudkova, T., Hedlund, M., & Midjo, T. (2019). Supporting children of parents with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *32*(4), 737–749. https://doi.org/10.1111/jar.12573

Hamilton, C. (2012). Sterilisation and intellectually disabled people in New Zealand - still on the agenda? *Kōtuitui: New Zealand Journal of Social Sciences Online*, *7*(2), 61–71. https://doi.org/10.1080/1177083X.2012.724693

Harrison, R. A., Bradshaw, J., Forrester-Jones, R., McCarthy, M., & Smith, S. (2021). Social networks and people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *34*(4), 973–992. https://doi.org/10.1111/jar.12878

Heifetz, M., Brown, H. K., Chacra, M. A., Tint, A., Vigod, S., Bluestein, D., & Lunsky, Y. (2019). Mental health challenges and resilience among mothers with intellectual and developmental disabilities. *Disability and Health Journal*, *12*, 602–607. https://doi.org/10.1016/j.dhjo.2019.06.006

Hindmarsh, G., Llewellyn, G., & Emerson, E. (2015). Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research*, *59*(6), 541–550. https://doi.org/10.1111/jir.12159

Holt, L., Jeffries, J., Hall, E., & Power, A. (2019). Geographies of co-production: Learning from inclusive research approaches at the margins. *Area*, *51*(3), 390–395. https://doi.org/10.1111/area.12532

Jamieson, R., Theodore, K., & Raczka, R. (2016). Becoming a mother: Supported decision-making in context. *Journal of Intellectual Disabilities*, *20*(4), 313–328. https://doi.org/10.1177/1744629515604552

Lightfoot, E., & DeZelar, S. (2020). Parent centered planning: A new model for working with parents with intellectual and developmental disabilities. *Children and Youth Services Review*, *114*, 105047. https://doi.org/10.1016/j.childyouth.2020.105047

Lightfoot, E., LaLiberte, T., & Cho, M. (2018). Parental supports for parents with disabilities: The role of informal supports. *Child Welfare*, *96*(4), 89–110. https://www.jstor.org/stable/48625524

Mannay, D. (2017). *Métodos visuales, narrativos y creativos en investigación cualitativa*. Narcea.

Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research*, *8*(2–3), 120–131. https://doi.org/10.1080/15017410600774178

McConnell, D., & Llewellyn, G. (2002). Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law*, *24*(3), 297–317. https://doi.org/10.1080/09649060210161294

Milner, P., & Frawley, P. (2019). From 'on' to 'with' to 'by': People with a learning disability creating a space for the third wave of inclusive research. *Qualitative Research*, *19*(4), 382–398. https://doi.org/10.1177/1468794118781385

Nind, M. (2014). *What is inclusive research?* Bloomsbury.

Nind, M. (2016). Inclusive research as a site for lifelong learning: Participation in learning communities. *Studies in the Education of Adults*, *48*, 23–37. https://doi.org/10.1080/02660830.2016.1155847

ODISMET. Observatorio sobre Discapacidad y Mercado de Trabajo en España. (2023). *Informe 8 del Observatorio sobre Discapacidad y Mercado de Trabajo de la Fundación ONCE*. Fundación Once. https://www.odismet.es/sites/default/files/2023-05/INFORME%208.v2_0.pdf

Office of the High Commissioner for Human Rights (OHCHR). (2006). *Convention on the rights of persons with disabilities*.

Olavarrieta, S., Darín, L. A. D., Suárez, P., Tur, N., Besteiro, B., & Gómez-Jarabo, G. (2013). Actitudes hacia la sexualidad, esterilización, maternidad/paternidad y habilidades de crianza de personas con discapacidad intelectual: Un estudio preliminar. *Siglo Cero*, *44*(4), 55–69.

Pacheco, L., Aunos, M., Feldman, M., & McConnell, D. (2022). Reasonable efforts? Child maltreatment investigations and service referrals of parents with ascribed cognitive impairments in Canada. *Child Maltreatment*, *27*(3), 501–510. https://doi.org/10.1177/10775595211001109

Perkins, T. S., Holburn, S., Deaux, K., Flory, M. J., & Vietze, P. M. (2002). Children of mothers with intellectual disability: Stigma, mother-child relationship and self-esteem. *Journal of Applied Research in Intellectual Disabilities*, *15*, 297–313. https://doi.org/10.1046/j.1468-3148.2002.00140.x

Parents with Intellectual Disabilities (PID). (2013). *European family set*. Project number: 518380-LLP-1-2011-1-AT-GRUNDTVIG-GMP.

Potvin, L. A., Barnett, B. M., Brown, H. K., & Cobigo, V. (2019). "I didn't need people's negative thoughts": Women with intellectual and developmental disabilities reporting attitudes toward their pregnancy. *Canadian Journal of Nursing Research*, *51*(3), 154–167. https://doi.org/10.1177/0844562118819924

Ransohoff, J. I., Sujin Kumar, P., Flynn, D., & Rubenstein, E. (2022). Reproductive and pregnancy health care for women with intellectual and developmental disabilities: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *35*(3), 655–674. https://doi.org/10.1111/jar.12977

Rojas, S., Haya, I., & Lázaro-Visa, S. (2016). 'My great hope in life is to have a house, a family and a daughter': Relationships and sexuality in intellectually disabled people. *British Journal of Learning Disabilities*, *44*(1), 56–62. https://doi.org/10.1111/bld.12110

Sheerin, F. K., Keenan, P. M., & Lawler, D. (2013). Mothers with intellectual disabilities: Interactions with children and family services in Ireland. *British Journal of Learning Disabilities*, *41*, 189–196. https://doi.org/10.1111/bld.12034

Sigurjónsdóttir, H. B., & Rice, J. G. (2018). 'Evidence' of neglect as a form of structural violence: Parents with intellectual disabilities and custody deprivation. *Social Inclusion*, *6*(2), 66–73. https://doi.org/10.17645/si.v6i2.1344

Slayter, E. M., & Jensen, 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

Starke, M. (2022). Parents with intellectual disability and their reflections about relationships and support. *Journal of Social Work*, *22*(5), 1276–1295. https://doi.org/10.1177/14680173221092703

Strnadová, I., Bernoldová, J., Adamčíková, Z., & Klusáček, J. (2016). Good enough support? Exploring the attitudes, knowledge and experiences of practitioners in social services and child welfare working with mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *30*(3), 563–572. https://doi.org/10.1111/jar.12307

Sutherland, R. J., & Isherwood, T. (2016). The evidence for easy-read for people with intellectual disabilities: A systematic literature review. *Journal of Policy and Practice in Intellectual Disabilities*, *13*(4), 297–310. https://doi.org/10.1111/jppi.12201

Tarleton, B., Ward, L., & Howarth, J. (2006). *Finding the right support? A review of Issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation. https://baringfoundation.org.uk/wp-content/uploads/2014/10/Findingrightsupport.pdf

Theodore, K., Foulds, D., Wilshaw, P., Colborne, A., Lee, J. N. Y., Mallaghan, L., Cooper, M., & Skelton, J. (2018). 'We want to be parents like everybody else': Stories of parents with learning disabilities. *International Journal of Developmental Disabilities*, *64*, 184–194. https://doi.org/10.1080/20473869.2018.1448233

Vandenbeld Giles, M. (2012). From "need" to "risk": The neoliberal construction of the "bad" mother. *Journal of the Motherhood Initiative for Research and Community Involvement*, *3*(1), 112–133. https://jarm.journals.yorku.ca/index.php/jarm/article/view/35342

Wos, K., & Baczała, D. (2021). Parenting by mothers with intellectual disabilities in Poland: A photovoice study. *Journal of Applied Research in Intellectual Disabilities*, *34*(6), 1452–1462. https://doi.org/10.1111/jar.12887

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