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Mothers of adults with intellectual disabilities

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Mothers of Adults with Intellectual Disabilities: Experiences, Perceptions and Influences on Their Sons' and Daughters' Romantic and Sexual Lives

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Abstract

Individuals with Intellectual Disability (ID) value romantic and sexual expression, however often face barriers to developing relationships. Family caregivers play a significant role in supporting them with such matters throughout adulthood. In order to understand how to best support individuals with ID in this sphere of their lives, it is therefore essential to investigate family caregivers' perceptions, influences and experiences. This study explored the views and experiences of nine mothers of adult individuals with mild and moderate ID in relation to their children's romantic and sexual lives. Data was collected using semi-structured interviews and analyzed using Interpretative Phenomenological Analysis. Findings suggested that mothers held positive, but sometimes ambivalent, attitudes towards their children's romantic and sexual lives. They assumed the dual role of a facilitator and a protector, and although they generally expressed a commitment to supporting romantic experiences, they viewed sexual experiences with caution due to fears relating to vulnerability and risk. In the context of vulnerability, although most participants described their children's sexual knowledge as poor, they reported lack of preventative sexual or contraceptive education delivered at home. Participants hoped that their children would manage a long-term relationship, however also experienced a sense of loss related to the realization that this might not be possible. The findings of this study highlight the need to help mothers to proactively support their adult children in building sexual knowledge. This, in turn, can reduce individuals' vulnerability and improve their ability to make informed choices. Suggestions for future research are also discussed.

Keywords Sexual · Romantic · Intellectual disabilities · Mothers · Experiences · United Kingdom

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Introduction

Romantic love, intimacy and involvement in relationships represent an integral part of human experience [1]. In the mid-1980s, a number of social psychology theories explored romantic love in an attempt to better understand this complex phenomenon and its individual components. Using a questionnaire exploring love attitudes, Hendrick and Hendrick [2] proposed that couples demonstrated six different love styles: eros (i.e. passionate love), ludus (i.e. uncommitted love), storge (i.e. friendship-based love), pragma (i.e. practical and mutually beneficial love), mania (i.e. possessive or obsessive love) and agape (i.e. all-giving, unconditional love). In his Triangular Theory of Love, Sternberg [3] postulated that romantic love comprised the three components of passion, intimacy and commitment, and similarly to the theory proposed by Hendrick and Hendrick [2], he suggested that different combinations of these elements could result in six different types of love. From a different perspective and strongly inspired by Bowlby's attachment theory [4], Hazan and Shaver [5] described adult romantic relationships as involving a combination of Bowlby's evolutionary behavioural systems: attachment, sex and caregiving. They proposed that romantic attachment styles partly originate from and mirror infant attachment styles, which may account for individual differences in the way partners get involved in adult romantic relationships [5].

Despite their differences, all theories of romantic love highlight similar components, such as connectedness, physical and emotional intimacy, passion, commitment and interdependence as key. The presence or absence of these may lead to different types of romantic relationships and there is an acknowledgment that the combination of their individual elements can change as relationships evolve over time. Levinger [6] proposed that romantic relationships go through five stages: "acquaintance", where individuals experience attraction primarily based on physical characteristics; "buildup", where individuals begin to engage in self-disclosure and become increasingly interdependent; and "continuation", which involves a new level of consolidation and expressed commitment to the relationship. This stage may continue indefinitely, unless the relationship goes through the stages of deterioration and eventually termination.

Despite the large interest in the experiences of romantic love and intimacy in the typical population, the romantic and sexual expression of individuals with Intellectual Disabilities (ID) has historically been a neglected area. Contrary to the historical view of individuals with ID as non-sexual beings [7], a growing body of research has demonstrated that, similarly to their non-disabled counterparts, individuals with ID desire and value romantic relationships, and perceive these as fulfilling needs identified by classic theories of romantic love as key, such as companionship, love, support, passion, sexual intimacy, communication and commitment [8–11]. Research shows that individuals with ID generally describe their relationship experiences as going through stages similar to these observed in the typical population [6], such as selecting partners based on physical attraction and shared interests, developing interdependence, falling in love and committing to a relationship [9, 12, 13]. Furthermore, involvement in romantic relationships has been found to have similar physical and mental health benefits for individuals both in the typical population [1] and in the population of individuals with ID [14–16]. These include improved quality of life [14–16], increased confidence, happiness and independence [8, 9], and improved self-image [16].

The increasing recognition of the importance of issues relating to sexuality and relationships within the population of individuals with ID has in recent years led to a shift in

public perceptions, which is also reflected on legislative and policy developments [17–19]. Still, however, only a minority of individuals with ID report involvement in romantic or intimate relationships [11]. In line with this, research continues to show that individuals with ID experience greater barriers to romantic and sexual expression compared to their non-disabled counterparts, have fewer social opportunities and often lack the socio-sexual knowledge required to engage in relationships safely [10, 20]. As a result, individuals with ID often perceive romantic relationships as an impossible task and view their sexuality as either problematic or embarrassing [9].

When exploring the romantic and sexual lives of individuals with ID, a consideration of the role of parental influences becomes essential. As individuals with ID have fewer opportunities than their typically developing peers to obtain sexual knowledge through peer interaction [21], they tend to rely more on family caregivers for information and support [8], and therefore family caregivers may be more likely to influence their attitudes. For instance, there is some evidence to suggest that individuals with ID can internalize negative parental attitudes towards sexuality and in turn develop negative attitudes about their own sexuality [22, 23]. Additionally, as parents of individuals with ID tend to remain involved in their children's lives during adulthood [24], it is reasonable to conclude that parental influences play a significant role in individuals' ability to fulfill their romantic and sexual needs. For instance, parents may determine individuals' access to socio-sexual information as well as the level of social and sexual autonomy and freedom they may be able to achieve [25]. Although parental support and guidance can facilitate engagement in relationships, individuals with ID commonly report feeling overprotected and sometimes restricted by their caregivers [8–10, 26].

Attitudinal research in this area suggests that, although family caregivers generally express positive attitudes about their children's rights to romantic and sexual expression, they frequently report cautious attitudes towards sex education, show a preference for their child having low levels of intimacy and discuss only few topics mostly focused on safety [27, 28]. Studies have found younger parents to hold more liberal views compared to older parents [22, 27, 29] and family caregivers to hold more conservative views compared to staff [22, 27]. Such findings, however, may be confounded by age, as staff members tend to be younger than family caregivers [22]. A limitation of this line of quantitative research is that self-reported attitudes do not always translate into practice [29] and as such, they only provide limited information about parental behaviors and underlying factors influencing these.

In this context, qualitative research can be useful as it can shed light on relevant influences and underlying processes impacting on parental practices [30]. A synthesis of qualitative research conducted in 2014 [9] suggested that family caregivers expressed fear and uncertainty, as well as lack of confidence raising the issue of sexuality. In addition, although family caregivers expressed positive attitudes towards their adult children's sexual expression, they described sexuality as conditional and acceptable within certain limits. Caregivers also expressed their struggle to provide support to individuals with ID with relationships whilst protecting them and managing risk, and identified a need for more training and support from services.

More recent studies have explored the experiences of mothers in relation to supporting the sexual development of their adolescent and young adult sons with ID [31–33], as well as of family caregivers' views of the couple relationships of their adult children [34]. This research highlighted the tensions experienced by caregivers between their roles as facilitators and protectors of individuals with ID and overall suggests that parents perceive their sons' and daughters' sexuality as challenging and anxiety provoking [31–33]. Findings also highlighted that

parents felt ambivalent in relation to providing sex education [33], tended to avoid or prevent the sexual expression of their sons and daughters [32] and prioritized the protection of individuals with ID, as well as the protection of family and religious values, over the promotion of sexual autonomy [31]. Furthermore parents were found to be supportive and encouraging of their children's couple relationships, however were more likely to view them primarily as a source of physical intimacy as opposed to meeting emotional or social needs [34]. Parents additionally described that their sons and daughters had frequent difficulties within these relationships due to cognitive and social limitations, and often relied significantly on external help [34].

With the exception of one study [34], which focused on parental views on the couple relationships of adult individuals of a wider age range (i.e. 22–53 years old), the majority of recent qualitative research focusing on family caregiver experiences has suffered from two limitations. Firstly, most studies have primarily focused on parental views in relation to the sexual aspects of their children's relationships, perhaps overlooking emotional and social aspects of these, as well as the emotional meaning attached to them by individuals with ID and their families. Secondly, as most research to date [31–33, 35–38] has focused on parental perceptions of the emerging sexuality of adolescents and young adults, parental views on the sexuality of their children as they progress through adulthood remain largely unknown. It is possible to assume that parents of older individuals may face different challenges. For example, there is preliminary evidence suggesting that older individuals may be more likely to experience perceived inequality due to witnessing their siblings getting into relationships or getting married as they grow older [26].

Rationale for the Present Study

In summary, qualitative research to date has provided some valuable insights into parental experiences. It has, however, been rather limited and largely concerned with the perceptions of families of adolescents and young adults with ID in relation to sexuality, as opposed to the perceptions of families of older individuals with ID in relation to their wider romantic and sexual experiences. This study aimed to address these gaps in research, further add to the understanding of parental experiences and ultimately highlight areas of need and further support. To achieve this, it employed a qualitative design to explore mothers' experiences, perceptions and influences on their adult sons' and daughters' romantic and sexual lives. The focus on mothers was decided on the basis of research suggesting that mothers tend to be the primary care figures in the lives of individuals with ID [27] and, compared to fathers, are more likely to engage in discussions around relationships and sex [27, 39]. Evidence therefore suggests that their views and experiences might differ and as such may be worthy of exploring separately. This study aimed to recruit mothers of adults without setting an upper age limit, in order to allow for the inclusion of mothers of older individuals and facilitate the exploration of potential differences in parental experiences depending on their sons' and daughters' age.

Method

Participants

Participants were recruited from voluntary social groups run by families of individuals with ID and through snowballing techniques. Although this study used a convenience sample, during the recruitment phase services with a specific focus on providing support to individuals with ID and their families in relation to dating, sex and relationships were not approached. This was based on the assumption that the experiences and attitudes of families already accessing such services might not be typical of the population overall. Eligible participants were mothers who met the following criteria: they had a son or daughter older than 18 years old with a mild or moderate ID, they were fluent in English and they had capacity to provide informed consent.

No formal evidence of a diagnosis of ID was required, however participants' sons and daughters had a reported history of previous assessment for ID, the severity of which was established on the basis of mothers' self-reports. According to the DSM-V [40], the criteria for a diagnosis of ID include differences in intellectual functioning, impairments in adaptive functioning and onset of these impairments in the developmental period. Given that participants' sons and daughters received their diagnoses of ID in childhood, it is acknowledged that changes may have occurred to their level of ability as the result of accumulating experiences and skills over time. Despite this, we can confidently conclude that participants' children continued to meet criteria for ID in adult life. Firstly, for the majority of individuals intellectual functioning remains relatively stable over time [41]. Secondly, in this specific sample, almost all participants described their children as requiring a significant level of support with everyday tasks, such as communication, social, life and self-care skills, suggesting no significant changes in adaptive functioning. Thirdly, at the time the research took place, most participants' sons and daughters were receiving professional support from services, such as social care and respite services, access to which would require evidence of an ID. As in the United Kingdom ID is not routinely re-assessed in adulthood, the above were considered to be sufficient evidence that, at the time this study took place, participants' sons and daughters met criteria for ID.

Participants for the study were nine mothers of individuals with ID ranging from mild to moderate in severity. In order to facilitate the interpretation of the data, information regarding participants' children's characteristics (e.g. gender, age, severity of ID) was collected using a questionnaire developed by the principal researcher. Mothers' age ranged from 44 to 70 with an average age of 53. Participants' sons (n=4) and daughters (n=5) were between 18 and 41 years old, with an average age of 25 years old. A summary of additional information regarding participants' adult children collected through the questionnaire can be found in Table 1. It is worth noting that, in the present study, gender is talked about in a binary sense (e.g. sons and daughters) and gender variance and fluidity within this population are not explicitly explored. Nonetheless, during the interview process, the main researcher remained mindful of this and encouraged participants to raise any information they deemed to be important regarding their children's gender identity and sexuality. As all participants talked about their children's gender in a binary sense, the terms "sons" and "daughters" were used during the analysis of the collected material. Despite research widely suggesting that individuals with ID can be queer [42], in the present study all participants either implied or explicitly described their children as heterosexual.

Table 1 Additional information regarding participants' adult children

Characteristics	Description	N = 9
Sex	Male	4
	Female	5
Age	18–35	8
	36–55	1
Severity of ID	Mild ID	4
	Moderate ID	5
Level of support required	Requires some support, but not on day to day basis	1
	Requires a lot of support on a day to day basis	8
Residential placement	Living at family home	9
Current relationship status	Single	8
	In a relationship	1
Historical relationship status	Believed to have previously been in a romantic/ sexual relationship	5
	Not believed to have previously been in a romantic/sexual relationship	4

Although additional information regarding any co-morbid diagnoses was not collected through the questionnaire, this was informally explored with participants during the interviews. Three participants reported that their children had a comorbid diagnosis of Autism Spectrum Disorder (ASD). The decision not to exclude or treat participants' children who had a comorbid diagnosis of ASD differently was made on the basis of evidence showing that a significant proportion of individuals with ID also have co-morbid social-communication and other disorders [43]. Anecdotally, in the UK this does not exclude inclusion in the ID category as individuals presenting with both diagnoses display difficulties that are more severe and qualitatively different from higher functioning individuals with ASD.

Data Collection and Procedure

Individual interviews were conducted with participants in community settings that afforded privacy and lasted between 23 and 44 min. A semi-structured interview was used for data collection. This was developed following a review of the existing literature and discussion with the research team, and included open-ended questions aiming to obtain detailed and rich narratives. A list of questions included in the interview schedule can be found in the "Appendix". Examples of questions included *What would you say are your hopes/fears in terms of your son/ daughter's romantic life?"* and *"What kind of support have you or your son/daughter had in terms of romantic or sexual relationships?.* Prior to the interviews, the researcher explained the aims of the study to participants, sought their informed consent and made sure that they were put at ease. Interviews were digitally recorded and transcribed verbatim by the principal researcher using electronic software. During transcription all identifiable information was removed and names were replaced with pseudonyms. The first two conducted interviews were treated as a pilot of the interview schedule. As no amendments to the original interview schedule were considered necessary, this data was included in the main study.

Researcher Reflexivity

Throughout the research process, the researcher reflected on the influences of her own beliefs, expectations and experiences on the interpretation of the data through the use of a reflective diary. The researcher remained aware of her experiences of having worked with individuals with ID in a clinical capacity and the potential ways in which this might influence her interpretations of participants' accounts. The researcher was also aware that, due to the predominantly negative discourse around sexuality and ID in the research literature, during data analysis she experienced a desire to provide a more positive picture by emphasizing strengths and positive meaning in participants' accounts. The researcher remained mindful of the impact this might have on the representativeness of the produced themes and managed it by continually re-engaging with the data and comparing her analysis against participants' accounts and process of meaning-making.

Data Analysis

Transcribed data was analyzed using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative method, which is underpinned by phenomenology and hermeneutics, and is concerned with the detailed exploration of participants' personal perspective and attempts to make sense of their world [44]. IPA acknowledges and values the contribution of the researcher's own perceptions and interpretations to the analysis of participants' accounts, a process that has been described as a "two-stage interpretation" or "double hermeneutic" [45]. Following the steps suggested by Smith and his colleagues [46], each transcript was initially treated as an individual case study. After reading the transcripts several times, exploratory descriptive, linguistic and interpretative comments were made and clusters of emergent themes were drawn together. During this process the researcher continued to check her own interpretations against the participants' accounts. The above steps were repeated for each transcript, subsequently allowing for superordinate and subordinate themes that reflected the dataset as a whole to be identified.

Several steps were taken to promote the rigor of data analysis. In order to achieve coherence, the researcher developed competence and knowledge regarding the philosophical and theoretical background of IPA, and ensured compliance with the method through reflection and use of supervision. A second researcher reviewed samples of transcripts and emerging themes and, at the stage of data analysis, the principal researcher sought participants' feedback on the emerging themes. From the total of seven participants who provided their consent to be contacted at the stage of analysis, only one provided feedback, and this was incorporated into the analysis. The principal researcher also kept a reflective journal throughout the research process to guide and facilitate the analysis.

Ethical Considerations

The study was granted ethical approval by the University of Edinburgh Ethics Committee in March 2019. The potentially emotive nature of the topics covered in the interview and the protection of participants' confidentiality were amongst the ethical issues considered. Relevant permissions from voluntary organizations involved in recruitment were also sought where required.

Results

As illustrated in Table 2, four superordinate themes emerged from the data analysis, comprising twelve subordinate themes. Each subordinate theme was evidenced by data collected by at least three participants, in line with the recommendations made by Smith and colleagues [46]. During the presentation of the results, the term "children" is often used to refer to participants' sons and daughters. It should be noted that, as all participants' children were over the age of 18, the term is used to indicate their relationship to participants as opposed to their age.

Relationships and Sex: A Conflicted Discourse

Most participants talked about their sons and daughters as displaying romantic interest, expressing a desire to be involved in romantic relationships and sometimes being curious about sex. Some participants reflected on their children's previous relationships and generally described these as involving elements most commonly associated with romantic relationships. Their narratives indicated that, in some aspects, their children's romantic needs were viewed as not different to anybody else's. At the same time, however, participants' accounts suggested that they frequently questioned their adult children's romantic intent, the quality of their romantic relationships and the genuineness of their curiosity and interest in sex. This narrative, which was rather contradictory to their previous descriptions of their sons' and daughters' interest in relationships and relationship experiences, frequently echoed a discourse of what is "normal" or socially expected in the context of relationships.

Subordinate Theme 1: Involvement in Relationships: Similar but not the Same

All but one participant described that their sons and daughters had been curious about or interested in relationships and had occasionally demonstrated an awareness of various aspects of romantic relationships such as dating and kissing: "*As she was getting older you know maybe fourth year or fifth year she would come home from school saying "when can I go on a date?"" (Participant 5)*. Three participants, who were all mothers of older individuals with ID, reported that their children had expressed a desire to get married and have children in the future, and identified having witnessed other family members getting married and having children as a significant influence on their expectations from their own romantic lives.

 The majority of participants believed that their children had at some point in their lives had a boyfriend or a girlfriend. Without making an explicit distinction, participants talked about certain elements of those previous or existing relationships that differentiated them from friendships. For example, in some cases, the couple had made a conscious decision to progress a relationship from a friendship to a romantic status or to publicly share this new status: "*We had family things going on and when she had a birthday party, he was there and she introduced him to everybody "this is my boyfriend" and all the rest of it" (Participant 1)*. There was also an implication that romantic relationships involved exclusivity resulting from not dating others as well as some level of maintenance, such as going on dates regularly and talking on the phone. As opposed to other social encounters, in the context of romantic relationships individuals

Table 2 Superordinate and subordinate themes

Superordinate Themes	Relationships and sex: A conflicted discourse	Risk and Vulnerability	Facilitating and Protecting: A fine balance	Exploring personal meaning and hope
Subordinate Themes	Involvement in relationships: Similar but not the same	Vulnerability and on-going concerns	Mothers as facilitators	Exploring the meaning of relationships
	Interest in sex: Acknowledging and questioning	Risk in relation to gender	Protection and measures	Hopes for the future
	Barriers to relationships	Managing emotional challenges	Getting help when necessary	Accepting it may never happen

also experienced an additional level of independence and privacy: *"They go out and have a wee date and go to the pictures and they go for dinner and then he tends to walk her home and make sure she's safe" (Participant 6).*

Despite acknowledging their children's interest in relationships and previous relationship experiences, several participants explicitly or implicitly questioned whether the romantic intent their children expressed necessarily translated into a genuine desire to be involved in a romantic relationship. For example, the following participant described her daughter's intention to be involved in a romantic relationship as driven by a need for social acceptance and inclusion, indicating that the expressed desire was guided by societal expectations as opposed to a need for connection: *"She just thought that that's what she should be doing rather than what she wanted to do (…). Probably peer, not peer pressure, but what her peers were doing as well. And obviously she sees things in television and on the Internet and she very much wants to be a normal girl" (Participant 3).*

Other participants talked about their children as not displaying a proactive attitude with regard to pursuing relationships or making it a priority. Interestingly, although this "passive" attitude was often described as a result of individuals' cognitive limitations and poor social skills, it was frequently interpreted as evidence that their interest in relationships might not be genuine. In their narratives, mothers sometimes also described the relationships their sons and daughters had been able to develop as "childish" or resembling friendships. Their accounts often echoed an implicit view that these relationships lacked certain elements that would qualify them as being "romantic", such as involvement in shared activities, reciprocity and physical intimacy beyond hand holding and kissing: *"I believe it was more like a friendship. I do think they did kiss and I know they did use to hold hands because she made him" (Participant 1).*

Subordinate Theme 2: Interest in Sex: Acknowledging and Questioning

Although none of the participants believed that their sons and daughters had been sexually active, in the majority, they described that their children had, at some point in their lives, expressed curiosity about sex either by asking questions or making statements about sex: *"We were in the car one day, I looked in the mirror and she says "Mum, when can I start sleeping with Stewart?"" (Participant 2).* All participants stated that sexual education had been provided at school and there was a shared view that this had in some cases triggered more curiosity about sex, which many of them reacted to with surprise. This would suggest that in most cases, this was perhaps the first time the topic of sex was being talked about at home: *"They did a bit at school, some sexual education and the first time he said something about a penis, I was like "what?" (with emphasis), "where did you get that from?" (Participant 7).* Other participants acknowledged that their sons and daughters experienced sexual desire, most often expressed through experimentation with masturbation. Interestingly, however, in some cases participants reflected that their sons and daughters had not successfully mastered the skill of masturbation. Although some limited discussions regarding this had taken place at home, usually initiated by the fathers, no further action had been taken to ensure masturbation was possible, indicating that it was perhaps not viewed as a topic they could comfortably explore.

Despite acknowledging that their adult children showed curiosity or made statements about sex, almost all participants reflected that in reality they had very limited understanding of the concept of sex. Although all participants reported that their children had received sexual education at school, the general consensus was that this had only had a

limited impact on their understanding, which remained relatively poor: "*You know she has come home and said so and so and so were kissing you know how in school they tried to talk about sex education (…) and she would come home and say "oh we had that today" and I would say "all right, what were they talking about?" and she'd be like "I don't know". It goes over her head"(Participant 5)*. This narrative of individuals with ID as not able to process or understand sexual concepts, often led to participants interpreting their sons' and daughters' statements or questions as attempts to elicit a reaction rather than communicate a need, meaning that these were perhaps not perceived as worth following up on: "*He did mention the word vagina once so he did know the words, but I think he knew that he was getting a reaction when he was saying them. Because we all looked at him when he said them and we knew that he must have been getting sexual education*" (Participant 7).

Of note is that, despite the identified gap in their children's understanding of issues surrounding sex, only two participants described having had additional, detailed discussions about sex at home. There was an acknowledgment that this was due to their children not actively trying to find out more about sex or initiate such conversations. This expectation that the individuals with ID would initiate such conversations suggested that participants often felt that it was better to avoid this topic unless guidance was actively sought by their children. As illustrated in the following extract, this might also reflect a worry around creating more curiosity or creating further problems if such topics are raised before the individual with ID is considered to be ready: "*Because if she doesn't ask the question, I just always think she's not thinking about it. So there's no point going there if that hasn't gone into her mind yet*" (Participant 5).

Subordinate Theme 3: Barriers to Relationships

Participants spoke about several barriers that could compromise their sons' and daughters' ability to get involved in and maintain relationships. Some reflected on their children's limited understanding of the social rules that typically govern relationships, such as monogamy and reciprocity. Interestingly, this was a concern predominantly expressed by the participants whose children had a confirmed or suspected diagnosis of ASD in addition to ID, potentially due to the social limitations often present in individuals with ASD. In some cases, participants expressed a concern that, due to these limitations, their children might accidentally hurt others, for example by going out with two people at the same time. As illustrated in the following excerpt, others expressed a concern that their children might not be able to find someone who would "tolerate" them: "*A relationship with a person is a two way thing and she is not going to give anything, she's going to keep everything to herself (laughs). You would need to find someone who could do that and he (her previous boyfriend) had years of it and I'm not joking, he wasn't even given time to say hello on the phone*" (Participant 2).

Across participants' accounts there was also a general sense that a potential partner would need to be able to handle certain aspects of their children's needs arising from their ID and/or ASD, such as performing personal care or being able to handle challenging behaviour in public. As illustrated in the following extract, for some participants, this narrative led to a realisation that finding a partner who would be able to fulfil the role they themselves previously occupied would be hard, and might in fact be impossible: "*But saying that, who's going to change her bum? Clean her? Do all the things? Shower her?*

I've tried it for so many years to teach her to wash, toilet herself and she still can't do it" (Participant 8).

Risk and Vulnerability

There was a real sense of fear across participants' accounts about the possibility of their sons or daughters being taken advantage of by others emotionally, physically and sexually. Participants frequently discussed their children's own experiences of harassment or shared stories of abuse that had recently been shown in the news, suggesting that they remained continually vigilant to potential risks. Participants described their sons and daughters as vulnerable on multiple levels and across their accounts there was a sense that the nature and level of risk was partly dependent on the individual's gender.

Subordinate Theme 1: Vulnerability and On-going Concerns

Participants talked about their sons and daughters as vulnerable due to their limited understanding of sex, consent and personal space. Almost all participants expressed a fear that their adult children might become victims of exploitation and abuse, and described several behaviors they engaged in, such as taking their clothes off when others were present or being overfamiliar with strangers, which could place them at risk. Participants generally shared the view that their sons and daughters were most often oblivious to their vulnerability or risks: "*Obviously because she can't, well at this moment in time she can't stand up for herself, she doesn't realize how vulnerable she is and doesn't realize the impact that vulnerability has on her life, does that make sense?" (Participant 5).*

Some participants reflected that, due to their sons' and daughters' limited ability to identify risks, they often felt unsure about whether they would be able to alert their families if something was wrong: "*I suppose a worry is that she gets involved with somebody and she doesn't feel that she's happy with them and then maybe not know how to get out of a relationship. You know, she might just keep it all to herself and you know, let it all build up" (Participant 3).* This narrative suggested that, although most participants' sons and daughters had received some education about risk and protection, they were generally not viewed as capable of protecting themselves and safeguarding was viewed as the responsibility of their families. Three participants reported previous incidents where their sons or daughters had been sexually harassed. These often involved other individuals with ID and in some cases, peers without ID. There was a general sense that, although such incidents had, to some extent, been unsettling for the individuals with ID themselves, due to them being of a young age or being unaware of the risks involved, it was predominantly their families that had to live with their emotional implications: "*She didn't know how severe it was, but for me… it was for me. I was really hurt and felt invaded but no, she didn't care" (Participant 2).*

Subordinate Theme 2: Risk in Relation to Gender

The predominant theme discussed in the context of gender was that of sexual relationships, possibly due to the more complicated nature of consent involved in such scenarios. Participants' accounts often revealed stereotypical views on gendered sexual behaviors echoing a discourse that portrayed females as potential victims and males as potential perpetrators.

The following participant refers to "rape" as her greatest concern, implying that if both parts involved in the sexual relationship had limited understanding of consent, the male partner would be more likely to be held accountable: "*If (you had a girl) you would still be concerned that they would be forced upon (…) but obviously I have the boy so my concern is the other side of it. That she wasn't maybe quite understanding, basically rape. You know, that would be my fear. And that's not in his nature whatsoever but you are just not sure how other people would misread that*" (Participant 6).

Females were also described as facing greater risks by three participants, who directly expressed a belief that having a daughter with an ID created more concern due to the possibility of a pregnancy, which would then be perceived as the responsibility of her family. Despite being the mother of a male, the following participant describes the often reluctant and fearful attitude held by other mothers, whose daughters have been involved with her son, as understandable and reflects that she herself would not be as open-minded if she had a daughter with ID: "*I think this girl/boy thing is very different. I think it is. I think if I had a girl what I would be worried about is a baby. That's what my fear would be. I don't think that's the same if you have a guy because that would then not be so much our problem, that would be the girl's problem and I think that's why the mums have been the way they have with him*" (Participant 1).

Subordinate Theme 3: Managing Emotional Challenges

Participants talked about the emotional implications rejection and relationship breakdown had on their sons and daughters. There was an acknowledgement that involvement in romantic relationships exposed individuals to emotional risks, such as being rejected, that they had never encountered before. There was also a sense that, for their child to be involved in a romantic relationship, participants had to give up some of the control they had over their emotional lives up until that point, meaning that the individual with ID, perhaps for the first time, had to process and cope with difficult emotions independently: "*Unfortunately one day she came home and she said that he didn't want to be her boyfriend anymore because he didn't have time and she was absolutely devastated. It was probably a form of rejection to her and she's never been rejected by anybody in her life because she's always been in a very safe environment with family and friends (…) it was a very difficult time in that you felt so helpless because you couldn't make it right, whereas in her life anything else that happened we could always make it right*" (Participant 9).

Participants also indicated that their adult children often found it hard to navigate more complex or emotionally challenging aspects of relationships, such as not having their romantic interest reciprocated or realising that their partners had met someone new and wanted to end the relationship, and this was often expressed through sadness and upset: "*But the downside to that is that when it ends, he can get really down. And that side of that, "why am I not good enough, what did I do wrong" (…) you try to explain to him that they've, not everybody feels the same. It's difficult to explain to him how everybody doesn't feel the same way, that maybe they met somebody else, so it can be a bit of a mine field*" (Participant 6).

Facilitating and Protecting: A Fine Balance

Participants reflected on their role in supporting their sons' and daughters' romantic lives, which was often described as necessary for the maintenance of their relationships.

Participants also reflected on possible limitations to their role and the need to find other support when necessary. Although their narratives generally revealed positive attitudes towards the romantic lives of their sons and daughters, there was a general sense that certain aspects of these relationships, especially when it came to their potential to become sexual, were perhaps less easy to accept or support.

Subordinate Theme 1: Mothers as Facilitators

All participants reflected on the fact that, if their son or daughter wished to pursue a romantic relationship, they and the rest of their family would most definitely support them. Several participants described arranging and setting up dates for their sons or daughters as a key element of their role, and this most often involved liaising with their partner's family. Some participants expressed negative feelings about this level of involvement, for example by reflecting on having to be present during dates, which felt intrusive and uncomfortable. As illustrated in the following extract, for others this level of involvement was a difficult reminder of their sons' or daughters' limitations: "*I have to do the dates, I have to arrange the dates, I have to keep it going. I have to arrange with the mum, because she is not able to arrange with that person. Every time it will be me and the other mum making the arrangements. You know what I mean, it wouldn't be her, she's not able to do that. And that's the sad thing about it that she is not able to do that*" (Participant 2).

Participants frequently described their involvement in their sons' and daughters' relationships as not being limited to practically facilitating dates, but also extending to providing ongoing social and emotional coaching. This often involved encouraging them to go out and socialize or, as illustrated in the following extract, advising them on the social rules attached to meeting potential partners and dating: "*And you know what I've tried to say to her is "if you're in a club or if you are somewhere else and someone asks you if you have a boyfriend, tell them no". And if they want to be your boyfriend and you like them, then you say yes and then they ask you to go on a date*" (Participant 5).

Subordinate Theme 2: Protection and Measures

The majority of participants were their children's nominated Legal Guardians, and their narratives echoed the conflict of supporting healthy relationships whilst providing protection. Most of these discussions were held in the context of the perceived sexual risks involved in sexual interactions and relationships. Despite expressing liberal views regarding the possibility of a relationship becoming sexual, this was widely described as conditional upon certain factors, such as meeting the "right" person and being in a "secure" relationship. For most participants, there was a lack of clarity as to who would make the judgment about whether these conditions were met. As illustrated in the following extract, for Participant 3 this would be someone of a similar level of ability who her daughter felt safe and happy with: "*Yeah, we would all encourage it as long as it was the right person (…) someone who cared for her and wouldn't take advantage of her basically. And who she thought, you know, that she wanted to be with. So yeah, I wouldn't rule anything out. As long as she was happy with who it was. Obviously you wouldn't want someone who is maybe quite you know, highly intelligent. You would be, you would wonder what their motives were, you know to be with a young girl with learning disabilities*" (Participant 3).

Only one participant spoke about sex as being definitely discouraged, by ensuring that her daughter was never alone for sexual activity to take place. Other participants spoke

about practical measures that might need to be put in place such as making sure that any interactions with the potential to be sexual were only taking place at the girl's home: "*If there was any canoodling it would be in my house. I'd rather have it in my house. It wouldn't be in anybody else's home, it would in mine where she would feel safe and secure" (Participant 8)*. Of note is that only one participant raised the issue of contraception as important when considering sexuality, by stating that she would seek contraceptive advice to eliminate the possibility of a pregnancy should her daughter get involved in a relationship. The absence of the issue of contraception from participants' accounts would indicate that unless individuals with ID were in a relationship with a potential to be sexual, contraception was not considered as an essential preventative measure that needed to be explored.

Subordinate Theme 3: Getting Help When Necessary

Participants spoke about certain limitations to their role and reported having to seek support in relation to sex and relationships. Three participants reflected on having found the input of social workers, nurses and psychologists valuable. This, however, was largely described in the context of the person with ID having encountered difficulties in their relationships rather than as a preventative measure, suggesting that the day-to-day management of issues surrounding sex and relationships came primarily from the family: "*We also had a learning disability nurse. She did a bit of work with him as well roundabout when this wee girl was mucking with his head, really something terrible" (Participant 1).*

Two participants reflected on the key role support workers played in their sons' and daughters' lives in terms of supporting them to go out on dates, providing information about relationships and on one occasion supporting the individual with ID with their sexual education. These participants also reflected on the normalising effect of employing support workers of a similar age to their sons and daughters, as this allowed for a more "normal" dating experience by setting up double dates and, as illustrated below, offered the individual with ID an opportunity to learn from a more able peer when navigating romantic relationships: "*I've got one (carer) who is exactly the same age as her and it almost looks like a friend. So I believe that now they are talking about boyfriends and stuff like that (laughs), which is very good" (Participant 2).*

Even those who had not utilized any external supports for relationships or sex specifically, stated that they felt confident that support would be available if it was required: "*I probably would discuss it with his social worker. He's got an excellent social worker, she's very very good. And perhaps ask her if she knows of any groups that we could perhaps go along to and discuss it with" (Participant 4).*

Exploring Personal Meaning and Hope

Participants reflected on the personal meaning relationships held for them and the several meanings they attached to their children involvement in relationships. Participants shared their hopes from their sons' and daughters' romantic lives, however at the same time acknowledged that they might need to come to terms with the fact that their hopes might be realistically unachievable and might therefore never materialize.

Subordinate Theme 1: Exploring the Meaning of Relationships

All participants talked about their personal views on relationships and the value of relationships in life. Their narratives implied that relationships were viewed as a natural part of life and the way we are "meant to be", suggesting that they were essential for happiness: "*I think it's important to have relationships. I think that's the key to everything and even being happy. Because you know that's how we are meant to live is being in relationships with people*" *(Participant 1).*

Participants' accounts also suggested that they attached several different meanings to their sons or daughters being involved in a romantic relationship. For some participants this related to the personal meaning of knowing that their child could do what is "normal" or expected at their age: "*Just to be the same as everybody else, to make a choice "would I like to go out with that boy? Would I enjoy going out with him?"* *(Participant 8).* This view of involvement in romantic relationships as being the norm is perhaps unsurprising given that throughout their narratives, participants often expressed feelings of loss and disappointment in what their children might not be able to achieve. For others, relationships were viewed as an opportunity for social interaction and company. Some participants reflected on the fact that a romantic partner could take up a caring role and continue to provide care and company when they are no longer here: "*I would hope really that she would have somebody to share her life with because I'm not going to be here forever and I would like her not to be lonely*" *(Participant 3).*

Subordinate Theme 2: Hopes for the Future

Participants spoke about their hope that their sons and daughters would in the future be able to have a fulfilling relationship and live with a partner. Most of them, however, viewed this as a romantic but limited to non-sexual relationship, and attributed this to their perception of their sons and daughters as either not having an interest in a sexual relationship or not being cognitively able to comprehend what this would entail: "*I would like her to meet a nice guy just like her, a genuinely nice person that's kind and would take care of her in so far as, maybe not sexually, I don't know if she could cope with that, but just a nice friendship. A good friend, more of a friend than a boyfriend. I don't actually ever see her in a sexual relationship to be fair. I don't think she has the understanding. I don't see it*" *(Participant 9).*

Participants frequently spoke about their hope that a long-term partner would be of a similar level of ability and that as partners they would be able to enjoy a friendship and perhaps live together semi-independently and look after each other. For several participants, a long-term friendship was viewed as an appropriate alternative to a romantic relationship. Their narratives often reflected concerns about their children growing older alone and perhaps unsurprisingly, this was a theme predominantly raised by those participants whose sons and daughters were in the older age group. Some participants expressed a hope that their sons and daughters might be able to get married. There was, however, a general sense that having children was not viewed as a plausible outcome. Although only one participant stated this explicitly, most participants generally made no reference to pregnancy and parenthood unless this was in the context of the female's vulnerability.

Subordinate Theme 3: Accepting it May Never Happen

Participants' accounts revealed feelings of sadness arising from the realization that their sons and daughters might never be able to be in a long-term relationship. Some participants talked about the need to prepare themselves for this reality. Understandably, for many participants this was a very emotive topic and one that they found so difficult to discuss openly, that they often avoided thinking about: "*We watched that dating thing, I don't know if you know it, the "Undateables". So we've watched that and I don't think that it could happen for her. That's the sad thing and I've got to be prepared that that's going to be the way it is*" (Participant 2).

Across some participants' accounts there seemed to be an emerging theme of questioning if involvement in relationships was more of a priority for them than it might be for their sons and daughters. As illustrated in the following extract, these participants reflected on their own hopes and expectations of how a life should be lived or what represents a fulfilling life, and in some cases expressed a hope that their children might be able to experience what they had experienced from their own relationships. This naturally led to a realization that their sons and daughters might not necessarily share this view: "*And that's the part I'm sorry about because… I don't mean you're not complete if you've not had a romantic relationship… but she feels complete in her life, her life is totally, she doesn't seem to want anything else because everything she wants she gets (…) Yeah. It's something that I miss for her, that she's never missed*" (Participant 8). For some participants, this seemed to lead to an acknowledgement of the fact that they would need to let go of that expectation and focus on what really matters to their sons and daughters, regardless of whether that is a relationship or not: "*And I think maybe I do push and I do want that to be going on but I still would want him to be happy, you know and I think if that's what he wants that's fine*" (Participant 1).

Discussion

One of the key findings of the present study was the ambivalent and often conflicted discourse participants engaged in when discussing their children's romantic lives. Consistently with previous research [9, 47, 48], participants acknowledged their children's rights to a romantic life and took an active role in supporting and facilitating relationships by providing ongoing emotional and practical support. Although participants described the role of support staff as useful [34], they generally viewed their frequent involvement in their children's romantic lives as an integral part of the maternal role. At the same time, however, participants appeared to frequently question their children's romantic intent and wondered if their relationships were truly "romantic" in nature. This narrative seemed to arise from a perception that these relationships did not follow certain social norms, for example in relation to physical intimacy, reciprocity and understanding of monogamy. Similarly, curiosity about sex and communication of sexual interest were often not perceived as a meaningful expression of sexuality, leading to remarks about sex or attempts to experiment with sexuality, for example through masturbation, not being further explored or proactively supported.

The theme of questioning the true nature of individuals' romantic and sexual experiences is in contrast with findings from research that has given voice to individuals with ID. These suggest that, consistently with observations in the typical population and classic

theories of romantic love, individuals with ID perceive romantic relationships as meeting a range of physical as well as emotional and social needs, such as companionship, support, love and care [8–11], and experience sexual desire and satisfaction even if that is not necessarily expressed through sexual intercourse but through lower levels of sexual intimacy [11]. The Philosophy of Normalization, which was introduced in the 1970s to promote equal rights, provides an interesting viewpoint from which to understand societal expectations regarding the sexual expression of individuals with ID. Brown [7] argued that, despite the positive implications of the Philosophy of Normalization for inclusion, its application to issues of sexuality remained problematic. This was due to an expectation that individuals with ID would adopt a "normative" sexual identity and a failure to acknowledge alternative routes to sexuality as well as the impact of structural and social inequalities on public perceptions of sexuality. Such reflections may still be valuable when considering how the social construct of normative sexuality may be influencing parental expectations of what represents a "true" romantic or sexual experience and how these may subsequently impact on parental practices in this sphere of their children's lives.

In the population of individuals with ID, vulnerability and autonomy are often viewed as conflicting concepts, with protection from harm having the potential to lead to practices that undermine individuals' right to self-determination [49]. References to vulnerability and safeguarding were present across participants' accounts and, consistently with previous research [9, 32, 33], in this study participants perceived their children as lacking sexual knowledge and sufficient understanding of consent, and therefore felt torn between promoting their independence and protecting them from risk. Although participants fully supported their children's involvement in romantic relationships and recognized their rights to sexual expression, their narratives revealed a much more complex picture, with sex being described as conditional upon certain factors, such as only in the context of an established relationship with the "right" person [34, 50]. Similarly to previous findings [31], participants often highlighted that if a relationship became sexual beyond lower levels of intimacy, this would require a degree of monitoring, suggesting that families themselves identified a fine line beyond which supervision or intervention would be required. In this study, gender specific factors influenced perceptions of risk, possibly grounded on stereotypical perceptions of males with ID as more sexually impulsive [51, 52] and of women as innocent, naïve and driven by a need for emotional connection [52]. With such gendered messages often communicated to individuals with ID [22], it is reasonable to conclude that misconceptions regarding gendered roles are likely to influence the way they experience their own sexuality and approach relationships.

With an understanding of vulnerability not as inherent to individuals but rather as created within social contexts [53], placing the focus on enabling and disabling factors within these contexts is of immense value when exploring dilemmas around safeguarding and self-determination. One such enabling factor is access to sexual knowledge and education, which is not only essential in terms of individuals' ability to make safe choices, but also key in determining their ability to consent to sexual relationships [23]. In the present study, despite acknowledging their children's poor understanding of sexual concepts, most participants reported having had limited in-depth conversations about sexuality at home. This was often a result of participants not viewing their sons and daughters as interested or able to understand the topic [28], an implicit view that this might have been a role for professionals, as well as a belief that sexual education was not necessary unless the individual was involved in a sexual relationship. Such findings are of high importance as they suggest that avoiding or postponing more in depth conversations about sex has the potential to further exacerbate individuals' vulnerability, as they enter relationships without the knowledge of

family carers and therefore lacking sufficient sexual information [25, 54]. This ultimately perpetuates their limited autonomy, reduces their capacity to make informed choices and increases their potential exposure to risk.

Participants in this study expressed a sense of investment in their children's ability to find a long-term partner and a commitment to helping them achieve this, and on several occasions expressed feelings of sadness and loss arising from the realization that this might not be possible. Although this was not the focus of the present study, the topic of pregnancy and the future possibility of parenthood were remarkably absent from participants' accounts unless discussed as a prospect that needed to be avoided [31] or in the context of female vulnerability [55]. Neuman [34] similarly concluded that parents did not consider parenthood as a right or a possibility from their children's lives. Such findings may suggest that, although some progress has been made in relation to rights to relationships and sexuality, the topic of parenthood remains highly controversial and difficult to explore.

As the sample of this study was small and no formal comparisons on the basis of participant characteristics were made, it is not possible to draw conclusions regarding their potential interaction with this study's findings. Nevertheless, certain trends were observed within the data set. For example, mothers of individuals with ID and ASD tended to make reference to greater barriers with regard to reciprocity in relationships, which are likely to be related to the specific difficulties in social reciprocity and communication that characterize ASD [56]. Mothers of older individuals were more likely to report that their children expressed a desire to live independently, get married and, in some cases, have a family, which, consistently with previous research findings [26], was attributed to witnessing relatives of a similar age achieving those milestones. Mothers of older individuals were also more likely to report negative emotions associated with the possibility of their children never managing a long-term romantic relationship. As those participants were also older in age compared to the rest of the sample, this trend was perhaps reflective of their wider concerns regarding the care and well-being of their children when they would no longer be able to look after them, which is a commonly reported worry by ageing family carers [57].

Study Limitations

Although this study did not recruit from services focusing on dating and relationships in an attempt to mitigate the risk of systematic bias, a degree of self-selection bias could have impacted on the findings. For example, it is possible that mothers who felt comfortable about participating in the study were those who recognized and valued the need for promoting the rights of individuals with ID to relationships and sexuality. Nonetheless, there was a wide spectrum of conservative and liberal viewpoints represented in the sample, suggesting a degree of diversity amongst participants. Furthermore, opportunities for triangulation while conducting this study were limited. More specifically, although respondent validation was sought by asking participants' consent to be contacted at the stage of analysis in order to check the accuracy of the first draft of results and interpretative comments, only one out of the seven participants who provided consent offered feedback on the findings. Nevertheless, quality was continually monitored through ongoing reflection and the review of samples of transcripts and emerging themes by a second researcher during data analysis.

Value and Implications for Research and Practice

The present study provides some valuable evidence in relation to the way mothers of individuals with ID perceive and experience the romantic and sexual lives of adults with ID. In contrast with the majority of previous studies, the inclusion of mothers of both younger and older individuals and the focus on sexual, as well as emotional and social aspects of relationships, allowed for the exploration of issues related to the parental role in the longer-term management of individuals' romantic experiences, the ongoing challenges in relation to autonomy and protection, and maternal perceptions and hopes regarding the future potential of individuals' relationships. Some of the themes raised by this study, such as the distinction often made by participants between the romantic and sexual nature of relationships, with the latter being viewed as more difficult to support, and the role of gender in relation to parental perceptions of vulnerability have not been commonly reported by previous research. Considering the potential impact of such views on sexual education provision as well as on how supported and validated individuals may feel by their families to pursue romantic relationships, these issues are certainly worth exploring further by future research.

As the present study focused only on the experiences and perceptions of mothers, the role of fathers was not captured. There were indications across participants' accounts that fathers may hold more conservative views towards their children's romantic and sexual lives or get involved with specific aspects of their socio-sexual education, such as teaching their sons about masturbation. The role of fathers specifically remains largely unexplored by research and it may therefore be worth investigating further in order to allow for their own contributions to the romantic and sexual lives of individuals with ID to be highlighted. Furthermore, although the issue of parenthood was not explored in any depth by this study, the present findings suggest that it continues to remain a taboo topic that families avoid discussing openly. Existing research with staff [58] and parents [34] has provided some preliminary evidence showing that the reproductive rights of individuals with ID continue to be under-recognized. Given the reported frequency and intensity of parental involvement in the romantic and sexual lives of adults with ID, further research into how reproductive rights and parenthood are perceived and managed by family carers is essential.

Perhaps the most important finding of the present study, with the most significant implications for practice, was the general lack of sexual education reported by participants. Findings suggest that sexual education provided within the school environment was generally not viewed as sufficient, and most participants lacked the confidence to proactively support their children to develop more in depth sexual knowledge. The implication of this is that individuals with ID remain likely to enter relationships ill prepared and with poor socio-sexual knowledge [25], which can limit their ability to make decisions about their romantic and sexual lives autonomously and can expose them to further risks. Such findings therefore highlight the necessity of reconsidering the role parents could play in their children's sexual education and the practice implications this has on supporting them to develop skills and assume a key role in sexual education implementation. With universal sexual education being widely implemented across schools in the United Kingdom, parental involvement can be valuable in terms of adapting the content of sexual education according to their cultural background and family conditions, as well as to the unique needs and demands of their children. Finally, based on this study's findings, sexual education provided at home as well as at school is likely to be more meaningful if it emphasizes

both protection from risk as well as positive sexual behaviors, and is delivered in a manner that is mindful of potential stereotyped gendered messages.

Appendix: Interview Schedule

Q1 How would you describe your views on romantic/ intimate relationships in general? (How would you describe your views on co-habiting/ sexual relationships before marriage? Have your views changed at all over time? What are they currently and what were they when your child/ children were younger? What has influenced these beliefs?).

Q2 Can you tell me about relationships your child has had? (What has good or bad about them? Are they or have they been different to these of others e.g. sibling? Are there any barriers/ facilitating factors?).

Q3 Do you think that you or other family members influenced your child's opportunities for relationships? How involved do you feel? Has your role changed at all over the years?

Q4 What do you think your child feels about the relationships they've had/ are in/ haven't been able to get? Do you think their views would be similar or different to yours or those of other family members?

Q5 What would you say are your biggest fears in terms of your child's romantic life? What might be a worry when thinking about your child being in a relationship?

Q6 What would you say are your hopes in terms of your child's romantic life? What would be the ideal scenario when thinking about your child's romantic life?

Q7 What kind of support have you or your child had in terms of relationships? What has helped you to cope with challenges? Is there anything you have found unhelpful?

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval Granted.

Consent to participate Written informed consent obtained.

Consent for publication Consent for publication has been received by all participants and involved authors.

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