

People with intellectual disabilities' sexuality from three different perspectives: Parents, professionals, and themselves

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Funding information

Ministerio de Ciencia e Innovación; ERDF A way of making Europe

Abstract

Background: A positive conception of sexuality among people with intellectual disabilities is crucial and relies on several social and interpersonal contexts. The goal of this study is to analyse the interaction and impact of three different contextual groups: individuals with intellectual disabilities, their parents, and professionals working with them.

Methods: Survey data were collected from 330 people with intellectual disabilities attending occupational centres in eastern Spain, 330 parents, and 100 professionals.

Results: Correlation and variance analyses of dyad-level data show significant differences among the three groups in all variables. Professionals perceived people with intellectual disabilities to have higher knowledge of socio-sexual norms than people with intellectual disabilities actually appear to be, but they are also more concerned about aspects related to this area of people with intellectual disabilities. Compared to people with intellectual disabilities and professionals, parents perceived people with intellectual disabilities to have lower sexual knowledge.

Conclusions: Our study demonstrates inconsistent perceived knowledge of people with intellectual disabilities' socio-sexual norms and sexual knowledge among the three groups, leading to disparate levels of concern regarding people with intellectual disabilities sexuality. Thus, the need to collect information from different perspectives for more accurate reporting and the critical need for sex education programs that involve the target population, but also parents and professionals who frequently interact with people with intellectual disabilities are highlighted.

KEYWORDS

cross-sectional design, parents, people with intellectual disability, professionals, sexuality, Spain

1 | INTRODUCTION

Sexuality of people with intellectual disabilities continues to be overlooked, avoided, and dismissed due to long standing stigma, myths, stereotypes, and false beliefs (Gil-Llario et al., 2018).

The inattention to this matter and its implications for people with intellectual disabilities increases the likelihood of experiencing sexual risk behaviours and sexual abuse (Gil-Llario et al., 2020); approximately people with intellectual disabilities are between 4 and 10 times more likely to experience sexual abuse than those without intellectual

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disabilities (Gil-Llario, Morell-Mengual, et al., 2019; Reiter et al., 2007). The difficulty in identifying high-risk situations and the lack of self-protection skills are possible explanations for sexual risk behaviours among this population (Gil-Llario, Morell-Mengual, et al., 2022).

In order to develop effective and tailored intervention programs, it is necessary to know the people with intellectual disabilities skills and knowledge (i.e., sexual practices, knowledge of social norms related to privacy, and concerns regarding sexuality) (McCann et al., 2019). The Biographical-Professional Model (López, 2005) is considered to be one of the most appropriate and inclusive theoretical approaches to evaluate sexuality among people with intellectual disabilities (Escalera & Iniesta, 2004; Rodríguez-Mayoral et al., 2006). It is based on a positive conception of sexuality, as a dimension that directly impacts people's well-being and quality of life. It recognises the ability and the autonomy of people with intellectual disabilities to make decisions about their sexual and affective life, considering their limitations and granting great importance to the two important interpersonal groups interacting with people with intellectual disabilities, parents and professionals. According to the Biographical-Professional Model, it is necessary to analyse the information provided by the three groups: the people with intellectual disabilities themselves, the professionals who work with them, and their parents (Gil-Llario, Elipe-Miravet, et al., 2019; Pownall et al., 2012; Stein et al., 2018). Therefore, data triangulation will increase objectivity, as well as document and contrast information of the same phenomenon from different points of view (Rodríguez et al., 2006).

It is known that people with intellectual disabilities often have difficulties expressing their needs, and they can experience difficulties when completing self-informed instruments due to their reduced verbal ability to express desires and experiences (Gil-Llario et al., 2021). To respond to these reliability problems, their parents and professional caretakers could provide objective information on certain aspects that concern them most, such as compliance with social norms and knowledge about privacy (Gil-Llario, Morell-Mengual, et al., 2022). Parents can share their perspectives on aspects related to people with intellectual disabilities' sexual development, as they can provide private information about situations that occurred in the most intimate family environment (Pownall et al., 2012; Stein et al., 2018). Professionals also have information regarding people with intellectual disabilities' behaviour in the occupational centre context, such as their ability to differentiate between socially appropriate public and private sexual behaviours. Studies have shown that people with intellectual disabilities do have difficulties in determining what behaviours are to be performed in private (Medina-Rico et al., 2018). A lack of understanding of appropriate behaviours in the private versus public setting may create heightened sexual-risk situations with others, therefore, this topic becomes an essential aspect of their sexual education. The perspective about people with intellectual disabilities' sexuality provided by professionals has been found to be different from that of parents (Gil-Llario, Morell-Mengual, et al., 2022), and they are generally more tolerant towards the people with intellectual disabilities' sexual manifestations. However,

professionals have great variability regarding their attitudes towards people with intellectual disabilities' sexuality (Charitou et al., 2021).

Although parents and professionals can provide more objective information, only a low percentage of them have received specific training on people with intellectual disabilities' sexuality (Brown et al., 2020; Löfgren-Mårtenson, 2012). Therefore, they unknowingly could provide misleading information because of the uncertainty, anxiety, and lack of confidence regarding sexual behaviour acceptance among people with intellectual disabilities (Pownall et al., 2012; Tamas et al., 2019).

There is a need for information from these three interpersonal contexts. Even though there are studies that separately collect and analyse people with intellectual disabilities' attitudes and knowledge reported by themselves, their parents, and professionals (Gur & Stein, 2020; Manor-Binyamini & Schreiber-Divon, 2019; Mattila et al., 2017), no studies have been found that consider the information reported by the three groups simultaneously or analyse the concordance among them. Moreover, in those studies in which the perspective of more than one group is presented simultaneously (East & Orchard, 2014; Morales et al., 2011), there is not a dyad evaluation.

The goal of this study is to present and compare the information provided by the three interpersonal contexts indicated (people with intellectual disabilities, their parents, and their professionals) regarding the people with intellectual disabilities' sexuality. The study focuses on three aspects of people with intellectual disabilities' sexuality, that is: (1) sexuality basics (*Sexual Knowledge*); (2) social norms about private and public sexual behaviours (*Socio-Sexual Norms*); and (3) perception stigma as their concerns on how others and themselves perceived their possibilities to have romantic and/or sexual interactions (*Stigma/Concerns*). This study specifically aims to justify the need to bring together these three sources of information (triangular evaluation model) by analysing the similarities and discrepancies between the assessments made by each of the sources regarding these three sexuality aspects mentioned above.

2 | METHODS

The present observational study is a cross-sectional design. Outcome variables of the study were sexual knowledge, socio-sexual norms, and stigma/concerns of the participants. These variables were selected according to the aspects that parents, professionals, and people with intellectual disabilities themselves consider most relevant and, therefore, most in need of providing comparative information. Of course, the assessment of sexual knowledge is essential to evaluate how informed people with intellectual disabilities really are. Parents and professionals sometimes prohibit them from making decisions or carrying out activities in the belief that they do not have sufficient knowledge to do so, which is also of concern to people with intellectual disabilities as they are affected by this perception (Caballero-Gascón et al., 2018). The lack of socio-sexual norms is one of the main arguments often given for not providing information on sexuality to this group and one of the main concerns of people close to people

with intellectual disabilities. People with intellectual disabilities are aware of the stigma attached to their intellectual disability (Beart et al., 2005) and are very concerned about it (Whittle & Butler, 2018). The people around them tend to adopt a negative and protective perspective towards their sexuality, as they are concerned about the conformity of their sexual behaviour with socially accepted norms (Swango-Wilson, 2008). Finally, knowing whether the concerns of people with intellectual disabilities and their caregivers coincide is essential to know where to direct future actions.

2.1 | Variables and measures

1. **Sexual Knowledge:** This construct examined the people with intellectual disabilities' knowledge on topics related to sexuality, such as sexual hygiene, contraceptive methods, sexually transmitted diseases, and the human reproductive process. This variable was measured among professionals using the factor 'KNOW-SEX' (e.g., 'Does the user understand the human reproduction process?') from ABSKID (Gil-Llario, Morell-Mengual, et al., 2022); among parents using 'KNOW-SEX' (e.g., "Does your child understand the human reproductive process?") from ASBID-PA (Gil-Llario, Elipe-Miravet, et al., 2019); and among people with intellectual disabilities using 'KNOW-CONDOM USE' (e.g., 'Do you have to "make love" to have a child?') from SEBECOMID-S (Gil-Llario, Flores-Buils, et al., 2022). In all cases the number of items is six, and the reliability measured by Cronbach's alpha in the self-informed version was $r = .76$; in the parents' version $r = .77$ and in the professional's version $r = .70$.
2. **Socio-Sexual Norms:** It evaluates people with intellectual disabilities' socio-sexual norms and it is measured among professionals using factor 'PRIV-NOR' (e.g., 'Does the user know the social norms about not letting others touch one's private body parts?') from ABSKID (Gil-Llario, Morell-Mengual, et al., 2022); among parents using factor 'PRIV-NOR' (e.g., 'Does your child know the social norms about not letting others touch intimate areas of their body?') from ASBID-PA (Gil-Llario, Elipe-Miravet, et al., 2019); and among people with intellectual disabilities using factor SEX-BEHAV (e.g., 'Would you allow other people to touch your penis/vulva?') from SEBECOMID-S (Gil-Llario, Flores-Buils, et al., 2022). The number of items is eight in all cases, and the Cronbach's alpha in the self-informed version was $r = .67$, in the professional's version $r = .74$, and in the parents' version $r = .73$.
3. **Stigma/Concerns:** To measure this construct among professionals the factor 'CONCERN' (e.g., 'Are you concerned that the user's sexual behaviour will be misinterpreted?') from ABSKID (Gil-Llario, Morell-Mengual, et al., 2022) was used; among parents factor 'CONCERN' (e.g., 'Are you concerned that your child's sexual behavior may be misinterpreted?') from ASBID-PA (Gil-Llario, Elipe-Miravet, et al., 2019); and among people with intellectual disabilities the factor STIGMA (e.g., 'Do you worry that people you like will look at you funny or misunderstand you when you show that you like them?') from SEBECOMID-S (Gil-Llario, Flores-Buils,

et al., 2022). In all cases, the number of items is three and the reliability measured by Cronbach's alpha for the self-informed version was $r = .64$, for the professional's version $r = .59$, and for the parents' version $r = .68$.

Regarding the assessment instruments used in this study, the score for each subscale is obtained by adding the scores obtained in each of the items that, according to the validation of these instruments in the Spanish context, belong to that subscale.

2.2 | Participants and procedure

Twenty-three occupational centres (OCs) in Comunidad Valenciana, Spain, were recruited for our study. The OCs are centres aimed at providing disabled people of working age with therapeutic occupation for their personal adjustment, professional techniques for their labour integration, and convivial activities for their social integration (Generalitat Valenciana, n.d.). These centres were selected using a stratified random sampling procedure, in order to take into account, the population density (Lohr, 2010), which made it possible to obtain a representative sample of people with intellectual disabilities. During selection, we prioritised centres located in urban areas with a medium population density, and then we included centres located in areas with high and low population densities. Our final participant sample included 22% participants from cities with a population density > 500,000, 65% from cities with a population density between 10,000 and 500,000, and 13% from cities with <10,000.

First, the two entities that manage most of the OCs in eastern Spain were contacted to present the project and obtain their authorization. After this, the principal investigator (PI) met with the centres management team to explain the study and invite them to participate. In those centres that agreed to do so, it was the centres own management team who transmitted all the information (in an adapted form) to the people with intellectual disabilities, their parents and the professionals, separately, inviting them to a meeting at their centre, where two members of the research group and a member of the centres management team explained the purpose of the research. Professionals, parents, and people with intellectual disabilities interested in participating in the study individually filled out an informed consent form. For this purpose, the informed consent form was adapted to an easy language for people with intellectual disabilities and was explained to them in detail, giving them time to assess whether they agreed. Parents and professionals were given the informed consent form and were given time to read it carefully, having at their disposal the PI's contact so that they could ask any questions at any time they wished. In the case of people with intellectual disabilities, whose guardianship is in the hand of their parents, parental approval was also required for inclusion in the study. All participants were informed of the confidentiality of their responses, the purpose of data collection, and their right to leave the study at any time. Participants did not receive any remuneration for participating in the study, nor was there any consequence for not doing so.

The eligibility requirements to participate in the study included: (1) people with intellectual disabilities had to be of legal age (2) people with intellectual disabilities had to have sufficient communication and reading skills (3) people with intellectual disabilities had to meet DSM-5 criteria for mild intellectual disabilities. Participants' reading skills were assessed before the study by consulting their educational supervisors at the support service. The eligibility requirements for professionals including (1) active communication with clients (2) rapport with the client, (3) at least 2 years of work experience at an OC.

Assessments were conducted by a member of the research team who had extensive experience in treating people with intellectual disabilities. Each participant was assessed individually in a separate room of their OC. Participants were given instructions on how to complete the SEBECOMID-5 questionnaire and were provided support while completing the assessment (e.g., explaining the meaning of words or expressions, rewording items when participants were confused about the meaning of a question, etc.). Parents and professionals were provided with ASBID-PA and ABSKID questionnaires, respectively, and were given a week to fill it out and return it to the OC. Parents and professionals were allowed to contact one of the researchers for clarifications on questionnaires. Both parents and professionals filled out the questionnaire, reflecting upon the characteristics of their child and their client, respectively. Three reports were obtained for each participant, one from themselves, one from their parents, and one from their professional. A total of 17 OCs were recruited for this study. Specifically, 330 adults with mild intellectual disabilities along with their parents (mothers or fathers) ($N = 330$) and 100 professionals working in the OC they attend participated in the study.

People with intellectual disabilities were between the ages of 19 and 67 years old ($M = 31.21$; $SD = 18.74$) and 57.57% ($n = 190$) were men and 42.43% ($n = 140$) were women. Among parents, 55.15% ($n = 182$) were men and 44.85% ($n = 148$) were women between the ages of 52 and 76 years old ($M = 62.34$; $SD = 14.35$). Among professionals, 41% ($n = 41$) were men and 59% ($n = 59$) were women between the ages of 36 and 51 years old ($M = 48.63$; $SD = 16.89$).

The study complies with the ethical principles of the Declaration of Helsinki and was approved by the Ethics Committee of the University of Valencia.

2.3 | Data analysis

First, descriptive analyses were conducted to explore the characteristics of the participants. Assumptions of normality were tested using Kolmogorov–Smirnov test and homogeneity of variances using the Levene test. Pearson correlations were conducted to test the

relationship between the different variables and the dyad following Cohen's (1988) classification for their interpretation. Analysis of variance (ANOVA) and post hoc tests with Bonferroni adjustment were run to evaluate the main differences among groups in each of the variables measured. Significant values were considered when $p < .05$. The data were analysed using SPSS software version 26.0.

3 | RESULTS

First, the information reported by each of the informants (people with intellectual disabilities, parents, and professionals) is presented separately, analysing possible correlations between the different variables evaluated according to who provided the information. Second, possible differences between the information reported by people with intellectual disabilities, parents, and professionals with respect to each of the variables evaluated are analysed.

3.1 | Analysis of information reported by people with intellectual disabilities, parents, and professionals separately

Sexual knowledge and social-sexual norms are positive and significantly correlated with a small effect when they are reported by people with intellectual disabilities ($r = .12$, $p = .039$, Table 1).

Regarding the information reported by parents (Table 2), a positive, medium effect and statistically significant relationship exists between the parents' estimation of their children's sexual knowledge and their children's knowledge about socio-sexual norms ($r = .22$, $p = .029$).

Data collected among professionals (Table 3), indicated how their concern regarding the social perception of their clients' sexuality and romantic interactions a positive and statistically significant small correlation with the professionals' estimation of their clients' sexual knowledge ($r = .14$, $p = .041$). The professionals' estimation of their clients' socio-sexual norms knowledge shows a positive, high, and statistically significant correlation with their estimation of the clients' sexual knowledge ($r = .44$, $p < .001$).

3.2 | Comparison between the perception of parents, professionals, and people with intellectual disabilities

When comparing the data reported by the three sources of information, we found statistically significant differences in all the

	Socio-sexual norms	Sexual knowledge	Stigma/concerns
Socio-sexual norms	1		
Sexual knowledge	.12*	1	
Stigma/concerns	.02	-.04	1

* $p < .05$.

TABLE 1 Correlation between the different variables with the information reported by people with intellectual disabilities.

TABLE 2 Correlation between the different variables with the information reported by parents.

	Socio-sexual norms	Sexual knowledge	Stigma/concerns
Socio-sexual norms	1		
Sexual knowledge	.22*	1	
Stigma/concerns	.04	.15	1

* $p < .05$.**TABLE 3** Correlation between the different subscales with the information reported by professionals.

	Socio-sexual norms	Sexual knowledge	Stigma/concerns
Socio-sexual norms	1		
Sexual knowledge	.44***	1	
Stigma/concerns	-.01	.14*	1

* $p < .05$.*** $p < .001$.**TABLE 4** Comparison between people with intellectual disabilities, parents, and professionals regarding their scores on the different variables.

	Range	People with intellectual disabilities (1) M (SD)	Parents (2) M (SD)	Professionals (3) M (SD)	F
Socio-sexual norms	0–8	6.05 (1.69)	5.78 (1.27)	6.77 (1.21)	22.22*** (1 < 3, 2 < 3)
Sexual knowledge	0–6	5.41 (1.55)	3.39 (1.90)	4.29 (2.05)	55.15*** (2 < 1, 2 < 3, 3 < 1)
Stigma/concerns	0–3	0.78 (0.72)	0.65 (0.73)	1.05 (0.79)	12.99*** (1 < 3, 2 < 3)

*** $p < .001$.

variables evaluated (Table 4). As for people with intellectual disabilities' socio-sexual norms knowledge, there is a higher and significant mean score in favour to the professionals when they are compared to parents ($\bar{X}_{PR} - \bar{X}_{PA} = .72, p < .001$) and people with intellectual disabilities ($\bar{X}_{PR} - \bar{X}_{PID} = .99, p < .001$). Statistically significant differences were found between the three groups on people with intellectual disabilities' sexual knowledge, with people with intellectual disabilities having higher mean scores than parents ($\bar{X}_{PID} - \bar{X}_{PA} = 2.02, p < .001$) and professionals ($\bar{X}_{PID} - \bar{X}_{PR} = 1.12, p < .001$), and professionals presenting higher mean scores than parents ($\bar{X}_{PR} - \bar{X}_{PA} = .90, p < .001$). Finally, the professionals scored significantly higher than the parents ($\bar{X}_{PR} - \bar{X}_{PA} = .40, p < .001$) and the people with intellectual disabilities ($\bar{X}_{PR} - \bar{X}_{PID} = .28, p < .001$) on stigma/concerns variable.

4 | DISCUSSION

The triangulation of the information on this paper indicates that socio-sexual norms knowledge and sexual knowledge are correlated in the three groups of reporters. These results support that the opportunities to learn about sexuality, whether formal or informal, in turn contribute to improving how sexuality is expressed in a socially acceptable way (Gil-Llario et al., 2023; Lafferty et al., 2012). However, professionals seem to overestimate people with intellectual disabilities' socio-sexual norms knowledge, compared to people with intellectual disabilities and parents. This could be explained, in part, by the efforts professionals put into addressing social-sexual norms with

clients (Gil-Llario, Morell-Mengual, et al., 2022), while parents emphasise the difficulties their children have in understanding socio-sexual norms (Pryde & Jahoda, 2018).

Regarding the sexual knowledge among people with intellectual disabilities, when comparing the information reported by the different groups, it appears that although people with intellectual disabilities have considerable sexual knowledge, parents estimate that their children's sexual knowledge is more limited than it is. In contrast, professionals report that they are quite knowledgeable. The parents may possibly be underestimating the sexual knowledge that their children possess, and possibly it's because they, often, are not aware of the sexual maturity of their adult-aged children with intellectual disabilities and even consider them to be 'eternal children' (Tamas et al., 2019), which could lead them to undervalue and ignore the knowledge about sexuality that they have or they are capable of acquiring. This is not as common among professionals, as they have a much more proactive attitude towards the sexual development of their clients (Morales et al., 2011; Retznik et al., 2022). However, many are concerned about the lack of background they have regarding the sexuality of the people they assist (Brown et al., 2020; Löfgren-Mårtenson, 2012), which is a limitation when aiding people with intellectual disabilities in their sexual development (Baines et al., 2018), and may lead them to underestimate the education these have on sexuality since professionals have not provided them with such information. As some studies highlight, due to the lack of formal training that people with intellectual disabilities receive, they often seek out information on their own in order to find answers for their doubts or concerns, which often leads them to acquire information

that is not tailored to their circumstances and needs (Kijak, 2013; Schaafsma et al., 2015), and even information that may be incorrect (Gil-Llario et al., 2018). Thus, although professionals make assessments closer to those of their clients because they can observe their behaviour with their peers daily and/or because they can have more confidence in them to ask them questions, these results show the importance of training their clients, thus improving not only the quality of the information that people with intellectual disabilities have but also the communication with them. In this regard, it is important to note the lack of communication between the different sources studied. English et al. (2018) and Retznik et al. (2022) reported that young people with intellectual disabilities do not communicate openly with their parents about their intimate relationships and their sexuality to avoid the disapproval of their caregivers and the consequences that this entails, which may explain the differences in the estimates made regarding people with intellectual disabilities' sexual knowledge. Thus, the mismatch between valuations from different sources is a fact and this has important consequences (Gil-Llario, Elipe-Miravet, et al., 2019; Pownall et al., 2012; Stein et al., 2018). If people with intellectual disabilities learn about sexuality but their parents do not perceive this learning, it will not be of much help as they will still not be able to live their sexuality as autonomously as possible according to their support needs. To avoid this, affective-sexual education programs for people with intellectual disabilities should include sessions with their parents to update them on their children's learning progress, as well as joint sessions where they can check their children's progress.

In terms of concerns about different aspects of sexuality of people with intellectual disabilities, when compared to parents and people with intellectual disabilities, professionals express more significant concerns about the potential problems people with intellectual disabilities may have in finding a partner and about their sexual behaviours being misinterpreted by society. These findings could be explained by those of Brown et al. (2020) in their systematic review, in which they conclude that professionals feel a strong responsibility to provide sexual education to people with intellectual disabilities. But this goes even further, as professionals seem to express a more significant concern regarding the sexuality of people with intellectual disabilities whom they believe have received more sexual education. This could explain the reluctance and feelings of ambivalence that parents often experience when it comes to facilitate adequate sexual education and discussing sexual-related topics with people with intellectual disabilities (Pownall et al., 2012; Retznik et al., 2022), as parents think that providing them with information about this aspect of their development will awaken a sexual need that people with intellectual disabilities may not know how to manage properly and that could entail some kind of risk (Tamas et al., 2019). These findings suggest that aspects related to people with intellectual disabilities' sexual development may cause them greater discomfort. In this sense, these results have clear implications. Parents should receive training to improve their attitudes towards the sexuality of people with intellectual disabilities, as well as the benefits of their children receiving training on how to express their sexuality.

In summary, compared to the other two sources, professionals appear to perceive people with intellectual disabilities as having higher levels of knowledge about socio-sexual norms and they seem to present greater concern regarding aspects of people with intellectual disabilities' sexuality. However, people with intellectual disabilities themselves stand out in their assessment of their sexual knowledge, compared to what their parents and professionals believe. Lastly, parents seem to underestimate their children's education regarding different aspects of sexuality compared to the rest of the sources studied.

Further research should consider studying large sample sizes with participants of varying ages to classify participants into age groups to examine the similarities and differences between the perceptions of people with intellectual disabilities, parents, and professionals at varying stages of development. An analysis of how cultural norms may influence perceptions of sexuality among people with intellectual disabilities should be considered (González et al., 2018).

5 | CONCLUSIONS

When studying sexuality, it is essential to gather information from different perspectives in order to yield a truthful and complete report. The research presented here is a demonstration of this and offers a novel analysis of the sexuality of people with intellectual disabilities by comparing the information provided by the different actors involved in their lives (parents, professionals, and people with intellectual disabilities). So, through the triangulation of the three perspectives this study overcomes the appreciative subjectivity based on a single individual, as well as the bias that may involve the use of a single source of evaluation (Denzin, 1990; Gento, 1998), achieving a more realistic and reliable evaluation. This has important implications, as it will allow the development of much more effective affective-sexual education programs for people with intellectual disabilities. Indeed, thanks to studies like this one, these programs will be able to focus on those aspects that parents, professionals, and people with disabilities themselves consider important. Furthermore, in this way, educators will be aware of the real skills and knowledge that people with intellectual disabilities have in relation to their sexuality.

ACKNOWLEDGEMENTS

The authors would like to thank the Agencia Estatal de Investigación (AEI), Ministerio de Ciencia e Innovación (MCIN) and Fondos de la Unión Europea (ERDF) for the financial support granted to this research activity, as well as all study participants and the support service networks for people with intellectual disability that collaborated, for their strong involvement in this project.

FUNDING INFORMATION

This work is part of the R+D+i project RTI2018-095538-B-I00, funded by MCIN/AEI/10.13039/501100011033 and by 'ERDF A way of making Europe'.

CONFLICT OF INTEREST STATEMENT

The authors report no declaration of interest.

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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How to cite this article: Gil-Llario, M. D., Fernández-García, O., Flores-Buils, R., Huedo-Medina, T. B., Morell-Mengual, V., & Ballester-Arnal, R. (2023). People with intellectual disabilities' sexuality from three different perspectives: Parents, professionals, and themselves. *Journal of Applied Research in Intellectual Disabilities*, 1–8. <https://doi.org/10.1111/jar.13154>