LAS PERSPECTIVAS DE LAS MUJERES CON DISCAPACIDAD INTELECTUAL SOBRE LAS RELACIONES AFECTIVOSEXUALES. NECESIDADES, PETICIONES Y ACTUACIONES SOCIOEDUCATIVAS

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Universitat de Girona

TESIS DOCTORAL

DOCTORAL THESIS

Las Perspectivas de las Mujeres con Discapacidad Intelectual sobre las Relaciones Afectivosexuales. Necesidades, Peticiones y Actuaciones Socioeducativas.

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PROGRAMA DE DOCTORADO EN EDUCACIÓN

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Dirigida por:
Maria Pallisera Díaz
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Memoria presentada para optar al título de doctor/a por la Universidad de Girona

Índex

1. Modalidad de la Tesis Doctoral

La presente Tesis Doctoral se presenta en la modalidad de Compendio de Artículos y opta a la mención de Doctorado Internacional, de acuerdo con la Normativa Académica de los estudios de doctorado de la Universitat de Girona aprobada por el Consell de Govern en la sesión número 3/2017, de 31 de marzo de 2017 (eBOU-980), y modificada por el Consell de Govern en las sesiones 5/2017, de 29 de junio (eBOU-1032); 8/2018, de 30 de noviembre (eBOU-1444); 11/2019, de 16 de diciembre (eBOU-1754) y 4/2021, de 23 de junio (eBOU-2294).

Forman parte de este Compendio dos estudios publicados y otros dos enviados para su publicación. Los estudios incluidos en el Compendio de Artículos son los siguientes:

Artículo 1

Beltran-Arreche, M.[1], Fullana Noell, J.[2], & Pallisera Díaz, M[3]. (2023). Perspectives of Women with Intellectual Disabilities Regarding Affective Sexual Relationships: A Systematic Literature Review. *Sexuality Research and Social Policy*, 21(1), 263–278. https://doi.org/10.1007/s13178-023-00911-2

ISSN: 1868-9884

Factor de impacto de la revista (JCR-2022): 2.6

Número de orden (JCR-2022): Social sciences, interdisciplinary Q2 (37/110)

Artículo 2

Beltran-Arreche, M.[1], Fullana Noell, J.[2], Pallisera Díaz, M[3]., Rey Freire, A.[4], Blay, C[5]., & Vinatea, A[6]. (aceptado el 13 de mayo de 2024). Las Relaciones Afectivo-Sexuales de las Personas con Discapacidad Intelectual: Apoyos y Barreras desde la Perspectiva de las Personas con Discapacidad Intelectual. *Siglo Cero.*

ISSN: 2530-0350

Factor de impacto de la revista (SJR-2022): 1.1

Número de orden (SJR-2022): Educación Q3 (2/50)

Artículo 3

Beltran-Arreche, M.[1], Fullana Noell, J.[2], & Pallisera Díaz, M[3]. (under review). What do they think? The opinions of women with intellectual disabilities on affective-sexual relationships. An interview-based study. *Journal of Applied Research in Intellectual Disabilities (JARID).*

ISSN: 1360-2322

Factor de impacto de la revista (SJR-2022): 2.4

Número de orden (SJR-2022): Rehabilitation Q1 (16/73)

Artículo 4

Beltran-Arreche, M.[1], Fullana Noell, J.[2], & Pallisera Díaz, M[3]. (2024). Women with intellectual disabilities and motherhood: barriers, supports and demands. *International Journal of Developmental Disabilities*, 1–11. https://doi.org/10.1080/20473869.2024.2318865

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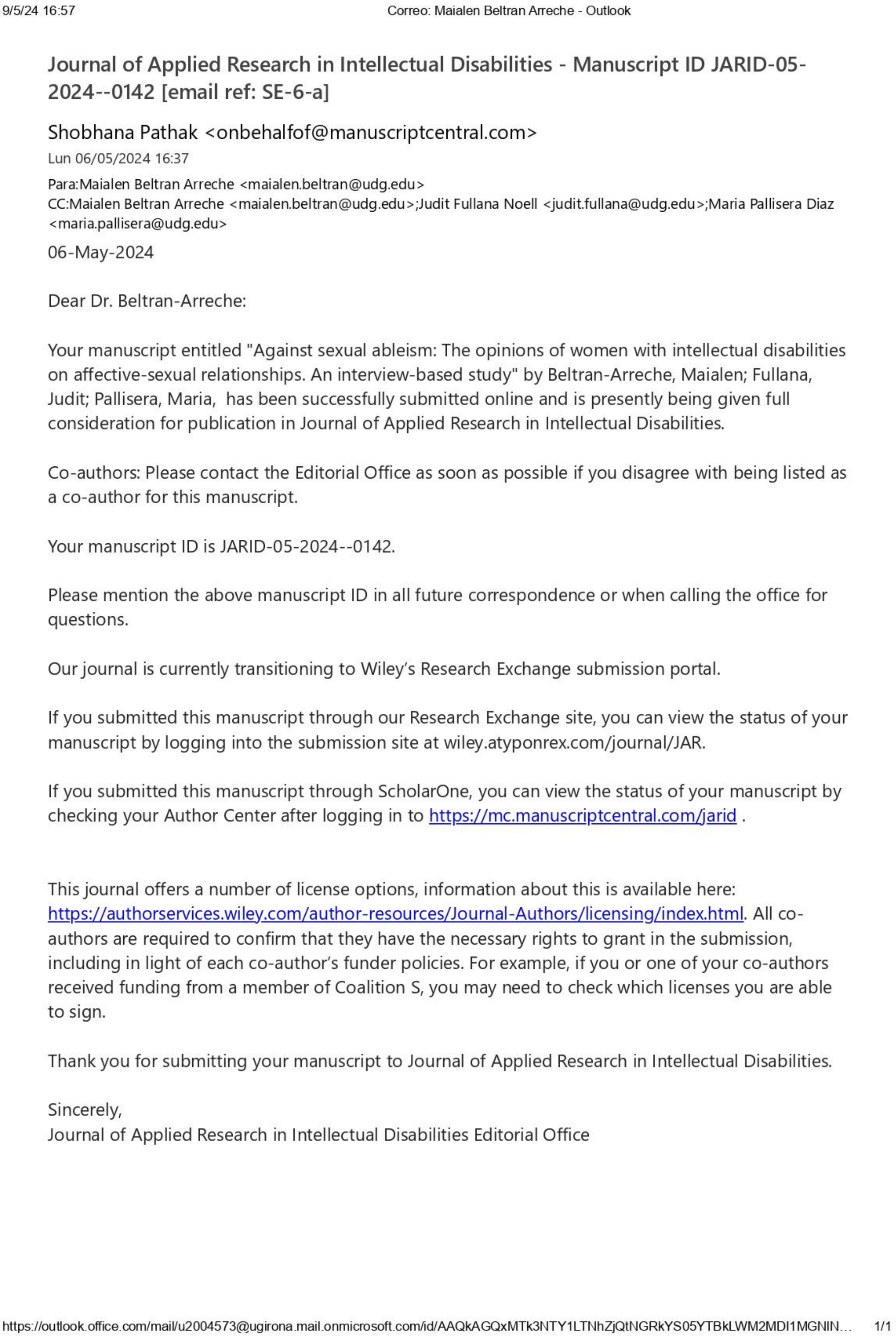
Artículo 3



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06-May-2024

Dear Dr. Beltran-Arreche:

Your manuscript entitled "Against sexual ableism: The opinions of women with intellectual disabilities on affective-sexual relationships. An interview-based study" by Beltran-Arreche, Maialen; Fullana, Judit; Pallisera, Maria, has been successfully submitted online and is presently being given full consideration for publication in Journal of Applied Research in Intellectual Disabilities.

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2. Abstract

The Convention on the Rights of Persons with Disabilities (CRPD) enshrines the right of persons with disabilities to self-determination with respect to their sexual identity and expression, as well as their right to marry and cohabit (United Nations, 2006). While the right to sexual identity and expression is recognised for all persons, individuals with intellectual disabilities continue to face significant limitations in these aspects of their lives. The prevailing myths and stereotypes surrounding their affective-sexual relationships place people with intellectual disabilities, particularly women, in a position of great vulnerability. This doctoral thesis aims to investigate the intersection between intellectual disability and affective-sexual relationships, primarily from the perspective of women with intellectual disabilities.

Firstly, in order to identify the state of the question (GO1), the doctoral thesis examines the perspectives of women with intellectual disabilities on their affective-sexual relationships in existing research through a systematic literature review. In this way, in article 1 a systematic literature review is carried out from which eleven articles are analysed to extract information about barriers and supports on six thematic axes: perceptions about sex and sexuality, experiences of abuse, opinions and experiences about relationships, the LGTBIQ+ community, knowledge about contraception and related experiences, and beliefs about gender roles.

Subsequently, in order to identify the challenges and obstacles that individuals with intellectual disabilities encounter in various contexts, as well as their expectations, desires, and requests regarding their affective-sexual lives (GO2), article 2 presents a study involving men and women with intellectual disabilities who are members of the Advisory Committee of the Diversity Research Group of the University of Girona. This study employs an inclusive research

approach in collaboration with the aforementioned committee members. The Advisory Committee was engaged to explore the barriers and supports that affect affective-sexual relationships, with a view to understanding the experiences and opinions of the participants. Additionally, article 3 addresses the gender-specific situation and difficulties, presenting the perspectives, opinions, and experiences of seven women with intellectual disabilities. The results of the study were obtained through the development of semi-structured individual interviews on the following topics: the LGTBIQ+ community; relationships; contraception and sex; abuse; and finally, family and motherhood.

The results of the systematic literature review (article 1) and the exploration conducted with the Advisory Committee (article 2) indicate the existence of specific concerns related to women with intellectual disabilities. Based on these findings, it was decided to create a workshop on affective-sexual relationships for women with intellectual disabilities only. This workshop serves as a platform for conducting focus groups on topics related to affective-sexual relationships, and it has been observed that motherhood is a significant topic for the participants. Consequently, the objective of article 4 is to examine the perceptions of a group of nine women with intellectual disabilities about motherhood through focus groups. This will enable us to identify the barriers they face or expect to face, the support they have received or believe they will receive, and the demands they make in this regard.

The research presented in this doctoral thesis proposes a series of analyses and changes in different areas of people's lives, with the aim of fostering greater respect for the sexual rights of people, especially women, with intellectual disabilities. Furthermore, the narratives have facilitated the formulation of a list of recommendations that women with intellectual disabilities consider essential, including the provision of quality and adapted sexual education, more research based on their experiences, societal awareness of the challenges they face, and the

eradication of stereotypes. Finally, the research establishes a theoretical basis for the development of future support resources and initiatives, while exploring their possible social and public implications.

Keywords: *Affective-sexual relationships; Women; Intellectual disability; Motherhood; Inclusion.*

3. Resumen

La Convención por los Derechos de las Personas con Discapacidad (CDPD) recoge el derecho de las personas con discapacidad a la autodeterminación con respecto a su identidad y expresión sexuales, así como su derecho a contraer matrimonio y cohabitar (United Nations, 2006). Aunque el derecho a la identidad y la expresión sexuales está reconocido para todas las personas, las personas con discapacidad intelectual siguen enfrentándose a importantes limitaciones en estos aspectos de su vida. Los mitos y estereotipos imperantes en torno a sus relaciones afectivo-sexuales sitúan a las personas con discapacidad intelectual -especialmente a las mujeres- en una posición de gran vulnerabilidad. Es por ello por lo que la presente Tesis Doctoral pretende investigar la intersección entre la discapacidad intelectual y las relaciones afectivosexuales prioritariamente desde el punto de vista de las mujeres con discapacidad intelectual.

Primeramente, con el objetivo de establecer el estado de la cuestión **(OG1),** la Tesis Doctoral explora las perspectivas de las mujeres con discapacidad intelectual sobre sus relaciones afectivosexuales, en las investigaciones existentes mediante una revisión sistemática de literatura. De esta manera, en el **artículo 1** se realiza una revisión sistemática de literatura a partir de la cual se analizan once artículos para extraer información sobre las barreras y apoyos sobre seis ejes temáticos: las percepciones sobre el sexo y la sexualidad, las experiencias de abuso, las opiniones y experiencias sobre las relaciones de pareja, la comunidad LGTBIQ+, el conocimiento sobre la contracepción y experiencias relacionadas, y las creencias sobre los roles de género.

Después, buscando conocer las dificultades o barreras con las que se encuentran en diferentes ámbitos las personas con discapacidad intelectual, así como en las expectativas, deseos o peticiones que tienen en torno a su vida afectivo-sexual **(OG2)** en el **artículo 2** se

presenta una investigación con hombres y mujeres con discapacidad intelectual que forman parte del Consejo asesor del Grupo de investigación en Diversidad de la Universitat de Girona y con el que se trabaja desde el enfoque de la investigación inclusiva. Tratando con este Consejo Asesor las barreras y apoyos que inciden en las relaciones afectivosexuales, se exploran las vivencias y opiniones de las personas participantes. Relacionado también a este objetivo, pero centrando la mirada en la situación y las dificultades particulares por razón de género, el **artículo 3** presenta las perspectivas, opiniones y experiencias de siete mujeres con discapacidad intelectual. Mediante el desarrollo de entrevistas individuales semiestructuradas, se obtuvieron resultados sobre los siguientes temas: la comunidad LGTBIQ+; las relaciones de pareja; la anticoncepción y el sexo; los abusos; y, finalmente, la familia y la maternidad.

A raíz de la revisión sistemática de literatura (artículo 1) y de la exploración hecha con el Consejo Asesor (artículo 2) se observa la existencia de preocupaciones específicas de las mujeres con discapacidad intelectual. A partir de aquí, se decide crear un taller sobre las relaciones afectivosexuales destinado únicamente a mujeres con discapacidad intelectual. Dicho taller sirve de plataforma para realizar grupos focales donde se tratan aspectos ligados a las relaciones afectivosexuales y se ve que la maternidad es un tema significativo para las participantes. Por ello, con el objetivo de realizar una aproximación a las percepciones de mujeres con discapacidad intelectual que sean madres o se lo hayan planteado sobre la maternidad **(OG3)**. El en **artículo 4** se examinan las percepciones de un grupo de nueve mujeres con discapacidad intelectual sobre la maternidad mediante grupo focales con el fin de identificar las barreras a las que se enfrentan o esperan enfrentarse, el apoyo que han recibido o creen que recibirán y las demandas que plantean al respecto.

Gracias a la investigación presentada en esta Tesis Doctoral, se propone el análisis y cambios en diferentes ámbitos de la vida de las personas, en favor de un mayor respeto de los

derechos sexuales de las personas, especialmente de las mujeres, con discapacidad intelectual. Además, los relatos han permitido elaborar una lista de las ayudas que valoran y consideran necesarias las mujeres con discapacidad intelectual, entre ellas una educación sexual de calidad y adaptada; más investigación basada en sus experiencias; la sensibilización de la sociedad sobre los problemas a los que se enfrentan y la erradicación de los estereotipos. Finalmente, la investigación establece una base teórica para el desarrollo de futuros recursos e iniciativas de apoyo, al tiempo que explora sus posibles implicaciones sociales y públicas.

Palabras clave: *Relaciones afectivosexuales; Mujeres; Discapacidad Intelectual; Maternidad; Inclusión.*

4. Resum

La Convenció pels Drets de les Persones amb Discapacitat (CDPD) recull el dret de les persones amb discapacitat a l'autodeterminació respecte a la seva identitat i expressió sexuals, així com el seu dret a contreure matrimoni i cohabitar (United Nations, 2006). Encara que el dret a la identitat i l'expressió sexuals està reconegut per a totes les persones, les persones amb discapacitat intel·lectual continuen enfrontant-se a importants limitacions en aquests aspectes de la seva vida. Els mites i estereotips imperants entorn de les seves relacions afectiu-sexuals situen a les persones amb discapacitat intel·lectual-especialment a les dones- en una posició de gran vulnerabilitat. És per això que la present Tesi Doctoral pretén investigar la intersecció entre la discapacitat intel·lectual i les relacions afectivosexuals prioritàriament des del punt de vista de les dones amb discapacitat intel·lectual.

Primerament, amb l'objectiu d'establir l'estat de la qüestió (OG1), la Tesi Doctoral explora les perspectives de les dones amb discapacitat intel·lectual sobre les seves relacions afectivosexuals, en les recerques existents mitjançant una revisió sistemàtica de literatura. D'aquesta manera, a **l'article 1** es realitza una revisió sistemàtica de literatura a partir de la qual s'analitzen onze articles per a extreure informació sobre les barreres i suports sobre sis eixos temàtics: les percepcions sobre el sexe i la sexualitat, les experiències d'abús, les opinions i experiències sobre les relacions de parella, la comunitat LGTBIQ+, el coneixement sobre la contracepció i experiències relacionades, i les creences sobre els rols de gènere.

Després, buscant conèixer les dificultats o barreres amb les quals es troben a diferents àmbits les persones amb discapacitat intel·lectual, així com en les expectatives, desitjos o peticions que tenen entorn de la seva vida afectiu-sexual **(OG2) l'article 2** presenta una recerca amb homes i dones amb discapacitat intel·lectual que formen part del Consell assessor del Grup de recerca en Diversitat de la Universitat de Girona i amb el qual es treballa des de l'enfocament de la recerca inclusiva. Tractant amb aquest Consell Assessor les barreres i suports que incideixen en les relacions afectivosexuals, s'exploren les vivències i opinions de les persones participants. Relacionat també amb aquest objectiu, però centrant la mirada en la situació i les dificultats particulars per raó de gènere, **l'article 3** presenta les perspectives, opinions i experiències de set dones amb discapacitat intel·lectual. Mitjançant el desenvolupament d'entrevistes individuals semiestructurades, es van obtenir resultats sobre els següents temes: la comunitat LGTBIQ+; les relacions de parella; l'anticoncepció i el sexe; els abusos; i, finalment, la família i la maternitat.

Arran de la revisió sistemàtica de literatura **(article 1)** i de l'exploració feta amb el Consell Assessor **(article 2)** s'observa l'existència de preocupacions específiques de les dones amb discapacitat intel·lectual. A partir d'aquí, es decideix crear un taller sobre les relacions afectivosexuals destinat únicament a dones amb discapacitat intel·lectual. Aquest taller serveix de plataforma per a realitzar grups focals on es tracten aspectes lligats a les relacions afectivosexuals i es veu que la maternitat és un tema significatiu per a les participants. Per això, amb l'objectiu de realitzar una aproximació a les percepcions de dones amb discapacitat intel·lectual que siguin mares o li ho hagin plantejat sobre la maternitat **(OG3)**. A **l'article 4** s'examinen les percepcions d'un grup de nou dones amb discapacitat intel·lectual sobre la maternitat mitjançant grup focals amb la finalitat d'identificar les barreres a les quals s'enfronten o esperen enfrontar-se, el suport que han rebut o creïn que rebran i les demandes que plantegen sobre aquest tema.

Gràcies a la recerca presentada en aquesta Tesi Doctoral, es proposa l'anàlisi i canvis en diferents àmbits de la vida de les persones, en favor d'un major respecte dels drets sexuals de les persones, especialment de les dones, amb discapacitat intel·lectual. A més, els relats han permès elaborar una llista de les ajudes que valoren i consideren necessàries les dones amb

discapacitat intel·lectual, entre elles una educació sexual de qualitat i adaptada; més recerca basada en les seves experiències; la sensibilització de la societat sobre els problemes als quals s'enfronten i l'erradicació dels estereotips. Finalment, la recerca estableix una base teòrica per al desenvolupament de futurs recursos i iniciatives de suport, al mateix temps que explora les seves possibles implicacions socials i públiques.

Paraules clau: *Relacions afectivosexuals; Dones; Discapacitat Intel·lectual; Maternitat; Inclusió.*

5. Estilo y organización

La presentación de la actual Tesis Doctoral sigue las directrices de la 7ª edición del manual de estilo de la American Psychological Association (American Psychological Association, 2019) No obstante, se han realizado algunos ajustes en la alineación del texto y en el formato de los epígrafes para mejorar la legibilidad de este extenso documento. Además, para evitar confusiones con tablas y figuras que tengan el mismo número, se ha añadido el número del capítulo en el que se encuentra el artículo delante del número de la tabla o figura, separado por un punto.

La redacción de este Compendio de Artículos utiliza el término “personas o mujeres con discapacidad intelectual” partiendo un modelo de lenguaje inclusivo que pone a la persona antes de la condición de discapacidad, traducido en los artículos como *“people or women with intellectual disabilities*”. Además, siguiendo la terminología más actual, se ha decidido hacer referencia a necesidades de apoyo generalizado, extenso, limitado e intermitente, en vez de hablar de discapacidad intelectual leve, moderada, grave o profunda. No obstante, en los casos en que se hace referencia directa a otras investigaciones, se ha optado por mantener la misma terminología usada en los artículos.

La estructura propuesta cumple con el Reglamento de la Universitat de Girona para la presentación de una Tesis Doctoral por compendio:

1. *La tesis incluirá un mínimo de tres trabajos que presenten una unidad temática (sobre una misma línea de investigación), de los cuales el doctorando sea el autor principal.*
2. *En caso de que los trabajos sean artículos, como mínimo dos tienen que ser publicados o aceptados en revistas indexadas en bases de datos internacionales, y con índice de impacto situado en la primera mitad del área temática o afines; o alternativamente con la aportación de indicios de calidad que serán valorados en función de su ámbito temático. El tercer artículo estará como mínimo en proceso de revisión en una revista de la misma calidad que las*

anteriores. Los mismos criterios se aplicarán en caso de que se incluyan otros tipos de publicaciones.

3. *Los trabajos tienen que ser publicados, aceptados o enviados para publicación con posterioridad a la primera matriculación del doctorando en estudios de doctorado y como máximo dentro de los seis años previos a la presentación de la tesis.*
4. *Los coautores de los trabajos declararán su conformidad por escrito a la utilización del trabajo como aparte de la tesis del doctorando y lo reconocerán como autor principal del trabajo publicado.*
5. *Los coautores de los trabajos utilizados en una tesis y que no tengan el grado de doctor renunciarán a presentarlos como aparte de otra tesis doctoral.*
6. *La presentación de la tesis bajo esta modalidad se ajustará a lo que establecen los criterios de formato de la tesis doctoral en la Universidad de Girona.*
7. *Los requerimientos de dirección, inscripción, nombramiento del tribunal y defensa de la tesis doctoral para esta modalidad de presentación serán los establecidos en la Normativa académica de los estudios de doctorado de la Universidad de Girona.*

La Universidad de Girona estipula que una parte de la tesis doctoral, al menos el resumen y las conclusiones, se haya redactado y sea presentada en una de las lenguas habituales para la comunicación científica en su campo de conocimiento para cumplir los requisitos de la Mención Internacional. Por esta razón, los apartados de resumen, resultados y conclusiones combinan las dos lenguas. Además, el resumen también se presenta en catalán.

La presentación de la Tesis Doctoral, de acuerdo con lo establecido por la Universitat de Girona para la presentación de la Tesis por Compendio de Artículos, se estructura en los siguientes apartados: Modalidad de Tesis Doctoral, Resumen, Estilo y Organización, Justificación de la Tesis Doctoral, Objetivos, Antecedentes Teóricos, Método, Resultados, Discusión y Conclusión, Bibliografía y Anexos. Además, dichas secciones se describen previamente en un índice de contenido con numeración de páginas, así como dos índices más, uno con las figuras y el otro con las tablas.

6. Justificación de la Tesis Doctoral

Conocer las perspectivas de las mujeres con discapacidad intelectual ofrece una oportunidad excelente para analizar los obstáculos que interfieren con su capacidad para desarrollar relaciones afectivo-sexuales, así como los apoyos con los que cuentan o querrían contar en esta área (McCarthy, 2014). Un análisis exhaustivo de dichos obstáculos, así como de los sistemas de apoyo identificados como facilitadores, es imprescindible para transformar las prácticas de apoyo para el pleno disfrute de sus derechos (Puyaltó et al., 2022).

Centrando nuestra mirada en las relaciones afectivosexuales, según Bernert (2011), es esencial reconocer las voces de las personas con discapacidad intelectual y comprender los factores que influyen en su experiencia de la sexualidad para crear recursos adecuados y significativos, (Bernert, 2011). Por ello, es fundamental que se creen espacios y situaciones para que este grupo participe en el discurso relativo a su sexualidad (Hoorn, 2015).

Aunque la expresión de las propias opiniones y experiencias personales es una herramienta poderosa para la autodefensa y el empoderamiento, especialmente en lo que respecta a un tema tan personal como las relaciones afectivo-sexuales (C. Azzopardi-Lane & Callus, 2015), la literatura que investiga estas perspectivas es aún limitada (Azzopardi Lane et al., 2019; Bernert & Ogletree, 2013; McCarthy, 2014). Además, frecuentemente, las opiniones de las personas con discapacidad se excluyen de la investigación y se sustituyen por las perspectivas de las personas de su entorno como familiares o profesionales (L. Brown, 2017; Hole et al., 2021).

Es por ello por lo que es indispensable que se lleven a cabo más estudios e investigaciones que tengan en cuenta activamente las voces de los hombres y las mujeres con discapacidad intelectual, utilizando sus experiencias y reconociendo su derecho a la autorrepresentación

(Nind & Vinha, 2014). Las personas sin discapacidad intelectual no deben suplir esta falta de información con su propia voz (Hoorn, 2015).

Finalmente, teniendo en cuenta que el disfrute de la propia sexualidad es un derecho de todas las personas (Fish & Björnsdóttir, 2022; United Nations, 2006; World Health Organization, 2017), es necesario investigar la intersección entre discapacidad intelectual y sexualidad, haciendo hincapié en las perspectivas de las mujeres.

7. Doctoral Thesis' Justification

An understanding of the perspectives of women with intellectual disabilities provides an excellent opportunity to analyse the barriers that interfere with their ability to develop affective-sexual relationships, as well as the supports they have or would like to have in this area (McCarthy, 2014). A thorough analysis of these barriers, as well as the support systems identified as facilitators, is essential to transform support practices for the full enjoyment of their rights (Puyaltó et al., 2022).

In order to gain a deeper understanding of the barriers that prevent women with intellectual disabilities from developing affective-sexual relationships, it is essential to focus our gaze on this topic. According to Bernert (2011), it is crucial to recognise the voices of people with intellectual disabilities and to understand the factors that influence their experience of sexuality to create adequate and meaningful resources. Therefore, it is of utmost importance that spaces and situations are created for this group to participate in the discourse around their sexuality (Hoorn, 2015).

Although the expression of one's own personal views and experiences is a powerful tool for self-advocacy and empowerment, especially regarding such a personal topic as affective-sexual relationships (Azzopardi-Lane & Callus, 2015), the literature investigating these perspectives is still limited (Azzopardi Lane et al., 2019; Bernert & Ogletree, 2013; McCarthy, 2014). Moreover, the perspectives of individuals with disabilities are frequently excluded from research studies and replaced by the views of those around them, such as family members or professionals (Brown, 2017; Hole et al., 2021).

It is therefore imperative that further studies and research are conducted which actively consider the perspectives of men and women with intellectual disabilities, utilising their experiences and recognising their right to self-representation (Nind & Vinha, 2014). Those without intellectual disabilities should not attempt to compensate for this lack of information by providing their own voice (Hoorn, 2015).

Finally, it is important to consider that the enjoyment of one's sexuality is a fundamental human right (Fish & Björnsdóttir, 2022; United Nations, 2006; World Health Organization, 2017). Consequently, there is a pressing need to investigate the intersection between intellectual disability and sexuality, with a particular focus on the experiences of women.

8. Objetivos

8.1 Objetivos Generales y Objetivos Específicos

La presente Tesis Doctoral tiene como finalidad estudiar las perspectivas de las personas con discapacidad intelectual, centrándonos después en las mujeres con discapacidad intelectual, sobre las relaciones afectivosexuales y los aspectos relacionados con ellas. Se establecen los objetivos generales (OG) y objetivos específicos (OE) descritos a continuación:

OG1. El objetivo de este estudio es establecer el estado actual del conocimiento sobre las relaciones afectivo sexuales de las mujeres con discapacidad intelectual.

OE1. Analizar literatura nacional e internacional para conocer los temas principales de las investigaciones centradas en las relaciones afectivo-sexuales desde el punto de vista de las mujeres con discapacidad intelectual.

OE2. Analizar literatura nacional e internacional para conocer las necesidades, experiencias y peticiones de las mujeres con discapacidad intelectual sobre sus relaciones afectivo-sexuales.

OG2. Conocer las perspectivas, opiniones y vivencias de las personas adultas con discapacidad intelectual sobre las relaciones afectivo-sexuales centrándonos tanto en las dificultades o barreras con las que se encuentran en diferentes ámbitos (personal, familiar, comunitario...) como en las expectativas, deseos o peticiones que tienen en torno a su vida afectivo-sexual.

OE3. Identificar los apoyos y barreras que contribuyen en la vivencia de las relaciones afectivo-sexuales de las personas adultas con discapacidad intelectual.

OE4. Explorar las opiniones y vivencias acerca de los apoyos recibidos y demandas en cuanto a las relaciones afectivo-sexuales de las personas con discapacidad intelectual.

OE5. Ilustrar la situación y las dificultades particulares por razón de género a las que deben hacer frente las mujeres con discapacidad intelectual en sus relaciones afectivo-sexuales.

OG 3. Considerar las perspectivas de las mujeres con discapacidad intelectual que son madres o se han planteado la maternidad.

OE 6. Analizar las experiencias y opiniones de las mujeres con discapacidad intelectual sobre la maternidad, tanto si ya son madres como si se han planteado serlo.

OE 7. Identificar las principales barreras a las que estas mujeres se han enfrentado o esperan enfrentarse y el apoyo recibido o que esperan recibir en función de sus propias experiencias.

8.2 Relación con los artículos presentados

El **OG1** tiene carácter exploratorio y pretende establecer el estado de las relaciones afectivo-sexuales en las mujeres con discapacidad intelectual**. Mediante la revisión sistemática de literatura presentada en el artículo 1 se analiza la literatura para identificar los temas principales identificados en las investigaciones (OE1)** así como las vivencias, necesidades y peticiones expuestas por las mujeres **(OE2).**

El **OG2** tiene como propósito conocer las perspectivas de las personas adultas con discapacidad intelectual sobre sus relaciones afectivo-sexuales. En relación directa con este objetivo se han desarrollado dos artículos: Por una parte, el **artículo 2 detalla el proceso y resultados de una investigación inclusiva en la que un grupo de investigadores con discapacidad intelectual** identifica los apoyos y barreras a las que se enfrentan en diferentes ámbitos (personal, familiar, comunitario...) **(OE 3).** Por otra parte, **el artículo 3 ilustra las particularidades en este ámbito de las mujeres con discapacidad intelectual por motivo de género, mediante entrevistas individuales las vivencias de un grupo de mujeres con discapacidad intelectual (OE3 y OE5).** Estos dos artículos exploran también, las opiniones y vivencias sobre los apoyos recibidos y las peticiones de un grupo de autogestores y mujeres con discapacidad intelectual, respectivamente **(OE 4).**

Finalmente, el **artículo 4 aborda el OG3 realizando un estudio exploratorio sobre la maternidad de las mujeres con discapacidad intelectual mediante la realización de grupos focales.** Dicha investigación analiza las experiencias y opiniones de un grupo de mujeres con discapacidad intelectual, siendo algunas madres y otras no **(OE6),** e identifica las barreras que se han encontrado o pretenden encontrarse en la toma de decisiones sobre la maternidad, así como los apoyos recibidos, deseados o los que esperan recibir **(OE7).**

9. Objectives

9.1 General Objectives and Specific Objectives

The aim of this doctoral thesis is to study the perspectives of people with intellectual disabilities, focusing on women with intellectual disabilities, on affective-sexual relationships and the aspects related to them. The general objectives (**GO**) and specific objectives (**SO**) described below are established:

GO1. The objective of this study is to establish the current state of knowledge regarding the affective sexual relationships of women with intellectual disabilities.

SO1. To analyse national and international literature to know the main themes of research focused on affective-sexual relationships from the point of view of women with intellectual disabilities.

SO2. To analyse national and international literature to know the needs, experiences and requests of women with intellectual disabilities about their affective-sexual relationships.

GO2. To know the perspectives, opinions and experiences of adults with intellectual disabilities about affective-sexual relationships, focusing both on the difficulties or barriers they encounter in different areas (personal, family, community...) and on the expectations, desires or requests they have about their affective-sexual life.

SO3. To identify the supports and barriers that contribute to the experience of affective-sexual relationships of adults with intellectual disabilities.

SO4. To explore the opinions and experiences about the supports received and demands in terms of affective-sexual relationships of people with intellectual disabilities.

SO5. To illustrate the gender-specific situations and difficulties faced by women with intellectual disabilities in their affective-sexual relationships.

GO3. To consider the perspectives of women with intellectual disabilities who are mothers or have considered motherhood.

SO6. To analyse the experiences and opinions of women with intellectual disabilities about motherhood, both if they are already mothers and if they have considered becoming mothers.

SO7. Identify the main barriers these women have faced or expect to face and the support they have received or expect to receive based on their own experiences.

9.2 Relation to the presented articles

GO1 has an exploratory scope and aims to establish the state of affective-sexual relationships in women with intellectual disabilities. Through the systematic literature review presented in **article 1**, the literature is analysed to identify the main themes identified in the research (SO1) as well as the experiences, needs and requests expressed by the women (SO2).

GO2 aims to understand the perspectives of adults with intellectual disabilities on their affective-sexual relationships. Two articles have been developed in direct relation to this objective: On the one hand, **article 2 details the process and results of an inclusive research in which a group of researchers with intellectual disabilities identify the supports and barriers they face** in different areas (personal, family, community...) (**SO 3**). On the other hand, **article 3 illustrates the particularities in this field of women with intellectual disabilities on the basis of gender, through individual interviews with a group of women with intellectual disabilities** (SO3 and **SO5**). These two articles also explore the views and experiences of a group of self-advocates and women with intellectual disabilities on the support received and the requests made (**SO4**).

Finally, **article 4** addresses **GO3** by **conducting an exploratory study on motherhood among women with intellectual disabilities through focus groups**. This research analyses the experiences and opinions of a group of women with intellectual disabilities, some being mothers and others not (**SO6**), and identifies the barriers they have encountered or intend to encounter in making decisions about motherhood, as well as the supports received, desired or expected to receive (**SO7**).

10. Antecedentes Teóricos

El presente marco teórico ofrece una conceptualización acerca de las relaciones afectivo-sexuales de las personas con discapacidad intelectual, así como aspectos relacionados con ellas. La comprensión de las características inherentes y la terminología asociada se considera fundamental para comprender tanto los objetivos como la metodología propuesta para la Tesis Doctoral.

Este apartado aporta una justificación teórica, comenzando por una presentación general sobre las relaciones afectivosexuales de las personas con discapacidad intelectual, para luego ahondar en aspectos que marcan los artículos presentados, como los derechos sexuales, la sexualidad y la salud sexual, el capacitismo sexual, la esterilización y la anticoncepción, y la educación sexual.

A continuación, se hace un inciso en la necesidad de investigar la intersección entre las relaciones afectivosexuales y la discapacidad intelectual desde el punto de vista de las mujeres.

El tercer punto de este apartado presenta las investigaciones previas desarrolladas en el campo de las relaciones afectivosexuales de las personas con discapacidad intelectual, así como las desarrolladas específicamente con mujeres con discapacidad intelectual. De esta manera, se plantan las bases para justificar la relevancia de la presente Tesis Doctoral.

10.1 Las relaciones afectivosexuales de las personas con discapacidad intelectual

Las relaciones afectivo-sexuales representan un fenómeno complejo, compuesto por elementos emocionales, físicos y psicológicos que convergen para fomentar conexiones interpersonales íntimas (de Jong & Reis, 2016; Ursu & Nicoleta Turliuc, 2018). Estas conforman una parte integral de las personas. Estas están relacionadas con las redes de apoyo, la estabilidad familiar, la salud mental y la resiliencia, entre muchos otros factores de bienestar personal (Ignagni et al., 2016). De la misma manera, el amor y la sexualidad forman parte del espectro de las relaciones afectivas y, aun así, este último aspecto ha sido omitido, e incluso castigado, históricamente, por las implicaciones culturales, religiosas y educativas que acarrea, creando toda una serie de prejuicios desde el punto de vista de la ética cultural (Huaiquián et al., 2018).

Al igual que para la mayoría de la población, para las personas con discapacidad intelectual las relaciones afectivo-sexuales son un aspecto significativo de sus vidas (Black & Kammes, 2019; Carter et al., 2021; Fish & Björnsdóttir, 2022; Hole et al., 2021; Lam et al., 2019; Retznik et al., 2021; Tamas et al., 2019; Wos et al., 2020). Las personas con discapacidad intelectual expresan la necesidad de tener parejas íntimas (Black & Kammes, 2019; Tamas et al., 2019; Wos et al., 2020) y generalmente albergan actitudes positivas hacia las relaciones afectivosexuales (Retznik et al., 2021).

Aunque las personas con discapacidad intelectual son seres sexuales con intereses afectivosexuales (Carter et al., 2021) y necesidades emocionales, psicológicas y sociales de expresar su sexualidad (McCarthy et al., 2020), siguen contando con numerosas barreras en este ámbito (Ignagni et al., 2016; Puyaltó et al., 2022; Scott et al., 2014). La restricción o, incluso, castigo por parte de las familias y cuidadores (Bernert, 2011; Black & Kammes, 2019; Fish & Björnsdóttir, 2022; Healy et al., 2009; Hole et al., 2021; Wos et al., 2020); la falta de privacidad e intimidad (Björnsdóttir & Stefánsdóttir, 2020; Fish & Björnsdóttir, 2022; Hole et al., 2021; Tamas et al., 2019; Wos et al., 2020), la falta de espacios y personas donde poder hablar de las relaciones (Black & Kammes, 2019; Wos et al., 2020) o la falta de conocimientos sobre el tema (Fish & Björnsdóttir, 2022; Lam et al., 2019; Tamas et al., 2019; Wos et al., 2020) son algunas de las dificultades que se suelen mencionar en las investigaciones. Incluso las personas que disfrutan de relaciones se enfrentan a la infantilización y la desexualización de estas, a restricciones (Santinele Martino, 2022) y mínimas oportunidades para estar con sus parejas (Retznik et al., 2021). Además, debido a la segregación y los entornos limitados, algunas personas con discapacidad intelectual llegan a elegir sus parejas en función de la disponibilidad o ven limitada su elección (Retznik et al., 2021).

Es por ello que las personas con discapacidad intelectual se encuentran con oportunidades mínimas, para desarrollar sus relaciones íntimas y su identidad sexual (Santinele Martino, 2022), afectando así su autodeterminación e independencia en relación a la sexualidad (Black & Kammes, 2019). Cabe recordar que, las personas son seres sexuales independientemente de las restricciones que se puedan encontrar y por ello es lógico y esperable que muchas de ellas estén desarrollando su sexualidad escapando de estas normas y barreras (Gill, 2015), hecho que puede llevarlas a realizar actos peligrosos o unhealthy (Black & Kammes, 2019).

Seguidamente, dedicamos un subapartado a introducir diversos temas que se vinculan con las relaciones afectivosexuales de las personas con discapacidad intelectual. Concretamente, nos referimos por este orden a los derechos sexuales (10.1.1), la sexualidad y la salud sexual (10.1.2), el capacitismo sexual (10.1.3), la esterilización y la anticoncepción (10.1.4), y la educación sexual (10.1.5) Con ello, tenemos la intención de contextualizar la problemática del estudio presentado el estado de la cuestión y aclarando términos necesarios para su total comprensión.

10.1.1 Derechos sexuales

La Organización Mundial de la Salud (OMS) remarca que los derechos sexuales son constituidos por la aplicación de los derechos humanos existentes en las áreas de la sexualidad y la salud sexual (World Health Organization, 2017). Los derechos sexuales defienden el respeto a la integridad corporal, la intimidad y la autonomía de las personas para elegir libremente sobre su sexualidad, las relaciones y la planificación familiar contando con los apoyos necesarios (Starrs et al., 2018).

Las Naciones Unidas ratificaron en el 2006 en la Convención por los Derechos de las Personas con Discapacidad (CDPD de aquí en adelante) el derecho de este colectivo a disfrutar en igualdad de oportunidades todos los aspectos de la vida social y política, incluida la sexualidad y la reproducción (United Nations, 2006). Aunque ni la CDPD ni otras convenciones sobre derechos humanos hacen referencia directa a los derechos sexuales (Fish & Björnsdóttir, 2022), la CDPD incluye la necesidad de "eliminar la discriminación contra las personas con discapacidad en todas las cuestiones relacionadas con el matrimonio, la familia, la parentalidad y las relaciones personales, en igualdad de condiciones con las demás" (artículo 23) y en su artículo 25 el derecho a "gozar del más alto nivel posible de salud sin discriminación por motivos de discapacidad" (United Nations, 2006). Cabe remarcar que los derechos sexuales a menudo han sido centrados en la vida familiar, sin mencionar la sexualidad, la agencia sexual o las identidades no heteropatriarcales (Addlakha et al., 2017; Lottes, 2013; Miller, 2000).

El reconocimiento de los derechos sexuales como derechos humanos ratifica la obligación de los 181 países que han firmado la CDPD y sus instituciones a garantizar el disfrute de la sexualidad, hecho que incluye la protección frente al abuso, la explotación y las violencias sexuales (Miller et al., 2015). Pese a la creciente tendencia hacia el reconocimiento de sus derechos, diversos autores afirman que a menudo estos no son cumplidos y las necesidades de las personas con discapacidad intelectual no son satisfechas (Borawska-Charko et al., 2017; Carter et al., 2021; Fish & Björnsdóttir, 2022; Neuman, 2020).

El concepto de la “ciudadanía íntima” (*intimate citizenship*) fue acuñado a finales del siglo pasado haciendo referencia al derecho de cada individuo de decidir sobre “su cuerpo, sus emociones, su identidad, sus relaciones, su género, su erotismo y sus representaciones” (Plummer, 1995, p. 17). En los últimos años se ha observado un cambio de paradigma hacia un modelo centrado en las personas que reconoce el derecho de las personas con discapacidad intelectual a tener relaciones íntimas (Ionescu et al., 2019); aun así, este colectivo sigue enfrentándose a la negación de su “ciudadanía íntima” (Hough, 2012). Aunque la CDPD reconoce el derecho a ser independiente y tomar decisiones propias (United Nations, 2006), las personas con discapacidad intelectual son excluidas de esta área vital debido a las dificultades que encuentran a la hora de decidir sobre sus relaciones o sexualidad (Puyaltó et al., 2022).

10.1.2 Sexualidad y salud sexual

La sexualidad es una parte natural de nuestras vidas y un derecho humano independientemente del género, la edad, la orientación o la discapacidad de la persona, tal y como se recoge en la Declaración de Derechos Sexuales (World Association for Sexual Health, 2014). La sexualidad es un amplio concepto que aborda aspectos tales como las identidades y roles de género, la orientación sexual, el erotismo, el placer, la intimidad, el acto sexual y la reproducción (World Health Organization, 2017). Se erige, asimismo, como una dimensión persistente a lo largo de la vida de los individuos, ejerciendo una influencia significativa en su bienestar (Verdugo et al., 2012). La sexualidad está influenciada por factores psicológicos, culturales, sociales, éticos, biológicos, etc., y es expresada de diversas maneras (pensamientos, actitudes, deseos, prácticas, etc.), aunque no siempre todas sean experimentadas o expresadas por cada individuo (World Health Organization, 2017). La sexualidad es una parte fundamental de la vida de la mayoría las personas, tengan o no discapacidad, que buscan y desean la sexualidad (Frawley y O’Shea, 2019; Gil-Llario et al., 2022; Svae et al., 2022).

10.1.3 Capacitismo sexual

El capacitismo engloba la opresión social, los estereotipos, los prejuicios y la discriminación hacia las personas con discapacidad intelectual (Bogart & Dunn, 2019). Siguiendo a Campbell (2001), el término hace referencia a la red de creencias, procesos y prácticas que asignan un estándar de persona típico y perfecto, presentando al colectivo de personas con discapacidad como un estado inferior del ser humano. Aun así, los colectivos vulnerabilizados son alentados a conformar la norma en la mayor medida posible para aspirar a la inclusión (Baril & Trevenen, 2014). Las formas de interpretar la discapacidad y las suposiciones sobre esta son aprendidas y perpetúan la cultura capacitista; de la misma manera, mediante la problematización de estos sistemas, se pone en descubierto los sistemas sociales que la sustentan (Bahner et al., 2024).

Enfocando la mirada específicamente en el área de la sexualidad, el capacitismo sexual se define como las expectativas sexuales reducidas para las personas con discapacidad que marcan las actitudes individuales, políticas y procedimientos institucionales que marcan las relaciones afectivo-sexuales de estas personas (Mintz, 2022). Dicho sistema basa la aptitud para la sexualidad basándose en el intelecto, la moralidad, el físico, la apariencia, la edad, la raza y la aceptabilidad social del individuo (Gill, 2015).

El capacitismo sexual está muy presente en las vidas de las personas con discapacidad intelectual. Existe una idea generalizada en la sociedad que apunta a la incapacidad de las personas con discapacidad intelectual para la libre expresión de su sexualidad (Huaiquián et al., 2018), hecho que las excluye de ser representadas como seres sexuales (McCarthy et al., 2020). La literatura internacional recoge los prejuicios existentes sobre la sexualidad de las personas con discapacidad intelectual con dos corrientes principales y contrapuestas. La sexualidad de las personas con discapacidad intelectual está cargada de tensiones entre la criminalización, con la creencia de que esta sexualidad no debe ser “despertada” por ser incontrolable y potencialmente peligrosa (Brown, 2017; Feely, 2016; Fish & Björnsdóttir, 2022; Hole et al., 2021; Sandberg et al., 2021; Tamas et al., 2019; Wos et al., 2020), y la desexualización, pensando en las personas con discapacidad intelectual como eternos niños o seres asexuales (Bahner et al., 2024; Baril & Trevenen, 2014; Brown, 2017; Feely, 2016; Frawley & Wilson, 2016; Hole et al., 2021; Löfgren-Mårtenson, 2013; Neuman, 2020; Retznik et al., 2021; Sandberg et al., 2021; Santinele Martino, 2022; Starke et al., 2016; Tamas et al., 2019). Cabe hacer un inciso y apuntar que la asexualidad, definida como la falta de inclinación sexual o sentimental duradera hacia los demás por Bogaert (2015), no resulta problemática per se. Sin embargo, la predominante desexualización y la asexualidad impuesta niega la agencia sexual de las personas con discapacidad intelectual (Sandberg et al., 2021).

El capacitismo sexual no solo niega la agencia sexual de las personas con discapacidad intelectual, sino que pone barreras al desarrollo de sus derechos sexuales y reproductivos (McCarthy et al., 2020). A la hora de mantener relaciones íntimas, las personas con discapacidad intelectual suelen toparse con obstáculos y actitudes discriminatorias (Fish & Björnsdóttir, 2022). A menudo, familias y profesionales de apoyo llegan a disuadir a estas personas de tener relaciones íntimas o sexuales (Lam et al., 2019). El silencio que existe alrededor de los aspectos positivos de sus relaciones afectivo-sexuales tanto en la sociedad, como en los servicios de apoyo, mengua su capacidad de expresión sexual (Bahner et al., 2024; Black & Kammes, 2019; Gill, 2015). El control y la vigilancia ejercida sobre sus relaciones, conduce en ocasiones a las personas con discapacidad intelectual a llevar sus relaciones en secreto o a tomar mayores riesgos en torno a ellas (Bahner et al., 2024; Santinele Martino, 2022). Además, estos hechos tienen un impacto directo en la salud de las personas con discapacidad intelectual y en su autoestima debido al capacitismo que han interiorizado, la discriminación y la marginación estructural (Bahner et al., 2024).

10.1.4 Esterilización y anticoncepción

Cabe remarcar que, aunque los hombres con discapacidad intelectual también han sido y son sometidos a este tipo de prácticas, la esterilización y/o anticoncepción constituye una praxis altamente marcada por el género y enfocada sobre todo a las mujeres (Fish & Björnsdóttir, 2022; McConnell & Phelan, 2022; Tilley et al., 2012). La justificación principal tras la decisión de suprimir la capacidad reproductiva de las mujeres con discapacidad intelectual es su vulnerabilidad hacia el abuso y la prevención del embarazo (Bahner et al., 2024; Björnsdóttir et al., 2017; Fish & Björnsdóttir, 2022), pero cabe recordar que dichas prácticas solo previenen el embarazo y la reproducción y no el abuso (Björnsdóttir et al., 2017; Fish & Björnsdóttir, 2022), además de hacerlo más fácil de encubrir (Fish & Björnsdóttir, 2022).

La sexualidad de las mujeres con discapacidad intelectual ha sido históricamente restringida y sus derechos violados mediante las prácticas eugenésicas como la esterilización forzosa, el uso obligatorio de la contracepción o la coerción reproductiva (Carter et al., 2021; MacLeod et al., 2022; Sandberg et al., 2021; Strnadová et al., 2019), bajo la idea de prevenir los embarazos de las personas con discapacidad intelectual y evitar el nacimiento de descendencia con discapacidad (Fish & Björnsdóttir, 2022; Sandberg et al., 2021); o por la supuesta incapacidad de las mujeres con discapacidad para ejercer la maternidad (Fish & Björnsdóttir, 2022; Höglund & Larsson, 2013; Kroese et al., 2002; McConnell, 2008; Sandberg et al., 2021; Strnadová et al., 2019).

Siguiendo el artículo 23 de la CDPD donde se subraya que las personas con discapacidad deberían tener el mismo derecho a mantener su fertilidad como sus counterparts sin discapacidad (United Nations, 2006), la mayoría de los países en el Global North han prohibido la esterilización sistemática de las personas con discapacidad intelectual (Fish & Björnsdóttir, 2022; Tilley et al., 2012). Las prácticas eugenésicas como la esterilización forzosa de las personas, sobre todo mujeres, con discapacidad intelectual tienen su origen a finales del siglo XIX y principios del siglo XX con el fin de evitar que las personas percibidas como "débiles mentales" se procrearan y tuvieran descendencia similar (McConnell & Phelan, 2022). Aun así, la historia de las esterilizaciones sin consentimiento sigue siendo reciente; en España, país donde se realiza la presente investigación, la esterilización sin consentimiento de la persona esterilizada fue legal hasta el año 2020 (Organic Law, 2/2020 of December 16) y según recoge el Comité Español de Representantes de Personas con Discapacidad (CERMI), en los últimos 10 años que la ley estuvo en vigor, más de mil personas fueron esterilizadas sin su consentimiento (CERMI, 2022). Esta práctica niega a las personas la oportunidad de tomar decisiones significativas sobre su vida, ignorando su autonomía y atentando contra su autoestima, además de revelar una pérdida completa del control sobre el propio cuerpo (Björnsdóttir et al., 2017).

Este cambio de paradigma está dando lugar a un modelo basado en la protección ante los riesgos (Sandberg et al., 2021) y el miedo (Bahner et al., 2024): existe una preocupación hacia el abuso sexual, la reproducción y los embarazos no deseados entre las mujeres con discapacidad intelectual, así como un peligro por la "hipersexualidad" de los hombres y su supuesta condición de potenciales agresores sexuales (Bahner et al., 2024; Starke et al., 2016). Pese a que las legislaciones están cambiando hacia la prohibición de dicha práctica, investigaciones internacionales señalan que las personas con discapacidad intelectual siguen siendo esterilizadas (Fish & Björnsdóttir, 2022; McConnell & Phelan, 2022; Tilley et al., 2012). Según McConnell & Phelan (2022), las prácticas eugenésicas no han sido erradicadas, sino que han cambiado sus formas. La presión de la familia y servicios para realizar dichas operaciones

(Björnsdóttir et al., 2017; McConnell & Phelan, 2022), la falta de información accesible (Björnsdóttir et al., 2017), e el uso de tácticas manipuladoras en la educación sexual(McConnell & Phelan, 2022), las oportunidades y espacios limitados para la expresión sexual y la formación de relaciones (McConnell & Phelan, 2022; Santinele Martino, 2022), la contracepción forzosa y supresión de la menstruación (Fish & Björnsdóttir, 2022; Tilley et al., 2012), los abortos coaccionados (Björnsdóttir et al., 2017) y la retirada de los hijos a las mujeres con discapacidad intelectual (McConnell & Phelan, 2022), son algunos de los ejemplos, que no únicos, que describen autores internacionales. Aunque no todas ellas constituyan practicas eugenésicas per se, todas ellas se alinean con la visión eugenésica de impedir o dificultar la reproducción de este colectivo.

10.1.5 Educación Sexual

Diversos actos jurídicos a nivel internacional abogan por un acceso pleno y equitativo a la educación sexual para todos los ciudadanos independientemente de sus características personales (Wos et al., 2020). Por ejemplo, la UNESCO reconoce el derecho universal a la educación sexual en sus Directrices Técnicas Internacionales sobre Educación Sexual, mediante la creación de entornos y políticas tanto en entornos formales como informales que garanticen el acceso a una educación sexual integral (UNESCO, 2018). Aunque las personas con discapacidad intelectual tienen derecho a recibir educación e información sobre las relaciones (Fish & Björnsdóttir, 2022), a menudo, estas personas no reciben el apoyo y adaptaciones necesarias para conocer sus derechos sexuales (Adams, 2015; Wos et al., 2020) y los programas de educación sexual pasan por alto los problemas específicos relacionados con la educación de los jóvenes con discapacidad (Frawley & Wilson, 2016).

Aunque las personas con discapacidad intelectual exhiben conocimientos sobre la sexualidad y las relaciones afectivas, estos conocimientos suelen ser limitados, especialmente comparándolos con los de sus counterparts sin discapacidad (Jahoda & Pownall, 2014), debido a la privación a una educación sexual integral (Fish & Björnsdóttir, 2022). La falta de información tiene múltiples causas debidas a una compleja interacción de factores (Fish & Björnsdóttir, 2022). La literatura internacional hace hincapié en dos causas principales: la falta de acceso a la educación sexual y los contenidos de esta.

Los prejuicios sobre la sexualidad de las personas con discapacidad intelectual y el legado de las prácticas eugenésicas influyen en la idea de que estas personas son asexuales y deben mantenerse así, "protegiéndolas" del sexo y del conocimiento sobre este (Wamsley & Jarret, 2019). De esta manera, el discurso dominante entre los policy makers se enmarca en la idea de que, si no se habla sobre ella, la personas con discapacidad intelectual no estarán interesadas en la sexualidad (Black & Kammes, 2019; Kulick & Rydström, 2015). Los familiares y cuidadores de las personas con discapacidad intelectual también suelen abogar por la abstinencia y restringen su educación sexual (Bahner et al., 2024; Tamas et al., 2019), por la preocupación de que no sean capaces de controlar sus impulsos sexuales (Tamas et al., 2019) o por el miedo al abuso (Carter et al., 2021; Grove et al., 2018; McConnell & Phelan, 2022; Tamas et al., 2019). Aun así, diversas investigaciones coinciden en que restringir la educación sexual de las personas con discapacidad intelectual solo contribuye a situarlas en una posición más vulnerable a estos peligros (Carter et al., 2021; Fish & Björnsdóttir, 2022; Hollomotz, 2012).

Por otra parte, aunque la provisión varía entre instituciones y contextos culturales (Fish & Björnsdóttir, 2022), el contenido de los programas de educación sexual dirigidos a las personas con discapacidad intelectual se enfoca en los aspectos biológicos y prevención de riesgos (Bahner et al., 2024; Carter et al., 2021; Frawley & Wilson, 2016; Wos et al., 2020). Además, los contenidos impartidos tienen una gran carga de género, patologizando la sexualidad de los hombres con discapacidad intelectual y trabajando con las mujeres la protección ante el abuso y el embarazo, sin poner el foco en ninguno de los casos en el placer (Black & Kammes, 2019; Frawley & Wilson, 2016). En lo referente a la diversidad de identidades sexuales y de género, se ha podido observar una gran incidencia de una educación basada en la cisheteronormatividad, sin hacer espacio a otras identidades (Fish & Björnsdóttir, 2022; Löfgren-Mårtenson, 2012).

Por esta razón, diversos autores abogan por implementar una visión holística de la sexualidad para mejorar la educación sexual (Frawley & Wilson, 2016; Strnadová et al., 2019). Para ello, proponen dar importancia al deseo y placer sexual (Black & Kammes, 2019; Fish & Björnsdóttir, 2022; McCarthy, 2014), comportamientos adecuados para relacionarse (Black & Kammes, 2019; Carter et al., 2021; Huaiquián et al., 2018) o el vocabulario y las capacidades necesarias para denunciar el abuso sexual (Fish & Björnsdóttir, 2022). Las personas con discapacidad intelectual demuestran querer acceder al conocimiento y desarrollar sus conocimientos (Gil-Llario et al., 2018), por ello, se recomienda la creación de programas adaptados y personalizados (Fish & Björnsdóttir, 2022; Tamas et al., 2019), contando con las voces y perspectivas de las personas con discapacidad intelectual (Tamas et al., 2019).

Una educación sexual adaptada a las necesidades de las personas con discapacidad intelectual tiene el potencial de mejorar su salud sexual y reproductiva, así como su bienestar general (Carter et al., 2021; McConnell & Phelan, 2022). En cambio, limitando el acceso a la educación sexual, se pone a las personas delante de un mayor riesgo ante la violencia sexual (Carter et al., 2021; Martinello, 2015; McDaniels & Fleming, 2016; Wos et al., 2020), pueden internalizar una autoimagen negativa (Löfgren-Mårtenson, 2012), son privadas de su derecho a la auto-realización (Swango-Wilson, 2008) y del desarrollo de su identidad social y sexual (Frawley & Wilson, 2016).

Finalmente, cabe destacar que, ante este modelo de riesgo y restricciones, existe un modelo opuesto que apuesta por la educación. Dicho modelo sugiere que es la falta de educación sexual adecuada lo que impide a las personas con discapacidad intelectual participar plenamente en este aspecto. Además, identifica las actitudes sociales negativas hacia la discapacidad y la sexualidad como barreras para una sexualidad adecuada, reconociendo la importancia del fomento de la sexualidad desde las intervenciones educativas (Sandberg et al., 2021).

10.2 Mujeres con discapacidad intelectual y las relaciones afectivo-sexuales

Peta et al. (2017) sostienen que las mujeres con discapacidad intelectual construyen su propia noción de sexualidad y la experimentan de maneras que desafían el discurso dominante basado en el capacitismo y las restricciones. Es por ello por lo que se cree necesaria una investigación que dé voz a las personas con discapacidad intelectual, especialmente a las mujeres, para conocer cuáles son sus puntos de vista, sus necesidades y las dificultades que encuentran para ejercer su derecho a una vida afectivo-sexual plena.

La elección de enfoque de la mayoría de los artículos de la Tesis Doctoral desde las perspectivas de las mujeres con discapacidad intelectual se alinea con el objetivo de conseguir la igualdad de género marcado por las Naciones Unidas para el 2030. Concretamente, esta institución ha establecido las siguientes metas para el año 2030: la eliminación de la discriminación contra las mujeres y las niñas (meta 5.1), la erradicación de todas las formas de violencia contra ellas (meta 5.2), la garantía de su plena participación en los procesos de toma de decisiones (meta 5.3), la provisión de acceso universal a la salud y los derechos reproductivos, la adopción y el fortalecimiento de políticas y legislación aplicable para la igualdad de género (meta 5.9), y la erradicación general de los prejuicios y la promoción de la igualdad de derechos y el respeto para todos los colectivos (United Nations, 2020).

Cuando se habla de interseccionalidad, se hace referencia a la interconexión entre las diferentes categorías sociales y las diferentes capas de opresión que pueden afectar a cada persona (McCarthy et al., 2017). Conocer estas capas de opresión y dominación en el ámbito de las relaciones afectivas, sugiere considerar al colectivo de mujeres con discapacidad intelectual como un grupo donde se aúnan los prejuicios hacia la discapacidad intelectual, con la problemática específica hacia la mujer (Dean et al., 2017). Por esta razón, este trabajo de investigación centra su enfoque en las mujeres con discapacidad intelectual, ya que sufren una discriminación interseccional en este ámbito, situándose “en una posición desigual con respecto a la población en general y hombres con discapacidad en particular” (Morcillo Martínez & Pérez Villar, 2018, p. 63).

10.3 Investigaciones desde el punto de vista de las personas con discapacidad intelectual sobre sus relaciones afectivo-sexuales

Seguidamente procederemos a presentar el estado de la cuestión basándonos en investigaciones a nivel nacional e internacional con el objetivo de poder contextualizar la presente Tesis. Esta sección tiene como objetivo presentar una breve contextualización sobre la literatura previa desarrollada en torno a las relaciones afectivosexuales de las personas con discapacidad intelectual, en general, y de las mujeres con discapacidad intelectual, específicamente. La presente Tesis Doctoral está basada en la idea de "nada sobre nosotros sin nosotros", es por ello por lo que todas las investigaciones que se presentarán a continuación recogen las perspectivas de personas con discapacidad intelectual. La presente sección no busca recoger toda la literatura desarrollada de esta manera, sino presentar cual es el estado de la cuestión.

Primeramente, cabe destacar que el corpus de literatura acerca de esta área vital es aún limitado (Siebelink et al., 2006; J. J. M. T. Stoffelen, 2018) y suele estar enfocado desde la perspectiva de familiares o profesionales, sin tener en cuenta las opiniones de las personas con discapacidad intelectual (J. J. M. T. Stoffelen, 2018).

Aun así, se han podido identificar algunas notables excepciones que investigan las relaciones afectivosexuales desde el punto de vista de las personas con discapacidad intelectual. En Malta (Azzopardi Lane et al., 2019; C. Azzopardi-Lane & Callus, 2015) y en Irlanda (M. Brown & McCann, 2018) se han explorado las percepciones de mujeres y hombres con discapacidad acerca de la sexualidad. Svae et al. (2022) en Noruega aportan una mirada sobre el sexo y las relaciones, centrándose en la privacidad y los límites personales. Retznik et al. (2021) en Alemania y Siebelink et al. (2006) en Holanda abordan el tema de las relaciones afectivosexuales y Mattila et al. (2017) investiga sobre la perspectiva que tienen sobre el amor en Finlandia. En

España, país donde se realiza la Tesis, sobresalen dos investigaciones, las de Puyaltó et al. (2022) y Rojas Pernia et al. (2015) que indagan en las perspectivas de personas con discapacidad intelectual sobre los apoyos y barreras que encuentran en sus relaciones afectivosexuales.

Los resultados de esta investigación muestran la existencia a nivel internacional de barreras comunes que las personas con discapacidad intelectual, concretamente las mujeres, se encuentran en sus vidas afectivosexuales. O'Shea & Frawley (2020) argumentan que, aunque las personas con discapacidad intelectual se enfrentan a estas barreras independientemente de su género, las mujeres tienen que hacer frente a problemas específicos. Mientras que la sociedad ve a los hombres con discapacidad intelectual como seres hipersexualizados y potencialmente peligrosos, las mujeres son percibidas como como víctimas potenciales de abusos y embarazos no deseados, y carentes de deseo sexual (Bahner et al., 2024). Estas ideas derivan en actitudes y prácticas como la sobreprotección por parte de familiares y profesionales (de Wit et al., 2022; Friedman, 2023; Hole et al., 2021), la falta de autonomía y la limitación de opciones para la toma de decisiones (Carter et al., 2021; Wos et al., 2020) o la restricción de sus derechos reproductivos (McCarthy et al., 2020).

Por ello, centrando nuestra mirada en la literatura relativa a las mujeres con discapacidad intelectual, la primera investigación que brindó la oportunidad a mujeres con discapacidad intelectual de hablar sobre sus relaciones con discapacidad intelectual en profundidad fue publicada hace ya veinticinco años (McCarthy, 1999). Aun así, de manera similar a las investigaciones sobre las relaciones afectivosexuales de las personas con discapacidad intelectual independientemente del género, la literatura con la que contamos es aún escasa, contando en la revisión de literatura realizada en el primer artículo de la tesis con sólo 11 artículos identificados. Este punto es abordado en profundidad en el **artículo 1** de este compendio, que presenta una revisión sistemática de literatura desarrollada sobre el tema.

11. Theoretical Framework

This theoretical framework offers a conceptualisation of the affective-sexual relationships of people with intellectual disabilities, as well as aspects related to them. An understanding of the inherent characteristics and associated terminology is considered fundamental to an understanding of both the objectives and the methodology proposed for the Doctoral Thesis.

This section provides a theoretical justification, starting with a general overview of the affective-sexual relationships of people with intellectual disabilities, and then delving into aspects that mark the articles presented, such as sexual rights, sexuality and sexual health, sexual ableism, sterilisation and contraception, and sexual education.

The subsequent section of the paper considers the intersection between affective-sexual relationships and intellectual disability from the perspective of women.

The third point of this section presents the previous research developed in the field of affective-sexual relationships of people with intellectual disabilities, as well as those developed specifically with women with intellectual disabilities. In this way, the bases are laid to justify the relevance of this Doctoral Thesis.

11.1 Affective-sexual relationships of persons with intellectual disabilities

Sexual affective relationships represent a complex phenomenon, comprising emotional, physical, and psychological elements that converge to foster intimate interpersonal connections (de Jong & Reis, 2016; Ursu & Nicoleta Turliuc, 2018). Affective relationships are an integral part of people. These relationships are associated with a number of other factors that contribute to personal well-being, including support networks, family stability, mental health and resilience (Ignagni et al., 2016). Similarly, love and sexuality are part of the spectrum of affective relationships, yet the latter aspect has been historically omitted, and even punished, because of the cultural, religious and educational implications it carries, creating a whole series of prejudices from the point of view of cultural ethics (Huaiquián et al., 2018).

As with the majority of the population, for most people with intellectual disabilities, affective-sexual relationships are a significant aspect of their lives (Black & Kammes, 2019; Carter et al., 2021; Fish & Björnsdóttir, 2022; Hole et al., 2021; Lam et al., 2019; Retznik et al., 2021; Tamas et al., 2019; Wos et al., 2020). It is frequently observed that individuals with intellectual disabilities express a need for intimate partners (Black & Kammes, 2019; Tamas et al., 2019; Wos et al., 2020) and generally hold positive attitudes towards affective-sexual relationships (Retznik et al., 2020).

Although most people with intellectual disabilities are sexual beings with affective-sexual interests (Carter et al., 2021) and emotional, psychological and social needs to express their sexuality (McCarthy et al., 2020), they continue to face numerous barriers in this area (Ignagni et al., 2016; Puyaltó et al., 2022; Scott et al., 2014). Restriction or even punishment by families and caregivers (Bernert, 2011; Black & Kammes, 2019; Fish & Björnsdóttir, 2022; Healy et al., 2009; Hole et al., 2021; Wos et al., 2020); lack of privacy and intimacy (Björnsdóttir & Stefánsdóttir, 2020; Fish & Björnsdóttir, 2022; Hole et al., 2021; Tamas et al, 2019; Wos et al., 2020), lack of spaces and people to talk about relationships (Black & Kammes, 2019; Wos et al., 2020) or lack of knowledge about the topic (Fish & Björnsdóttir, 2022; Lam et al., 2019; Tamas et al., 2019; Wos et al., 2020) are some of the difficulties often mentioned in research. Even people who enjoy relationships are confronted with infantilisation and desexualisation of these relationships, restrictions (Santinele Martino, 2022) and minimal opportunities to be with their partners (Retznik et al., 2021). In addition, due to segregation and limited environments, some people with intellectual disabilities come to choose their partners based on availability or are limited in their choice of partners (Retznik et al., 2021).

It is therefore evident that individuals with intellectual disabilities are significantly constrained in their capacity to develop intimate relationships and sexual identity (Santinele Martino, 2022), which in turn negatively affects their self-determination and independence in relation to sexuality (Black & Kammes, 2019). It is important to acknowledge that individuals are sexual beings, regardless of the restrictions they may face. It is therefore logical and to be expected that many of them are developing their sexuality by escaping from these norms and barriers (Gill, 2015), which may lead them to engage in dangerous or unhealthy acts (Black & Kammes, 2019).

Next, we dedicate a sub-section to introduce various topics that are linked to the affective-sexual relationships of people with intellectual disabilities. Specifically, we refer in this order to sexual rights (11.1.1), sexuality and sexual health (11.1.2), sexual ableism (11.1.3), sterilisation and contraception (11.1.4), and sexual education (11.1.5) With this, we intend to contextualise the problematic of the study by presenting the state of the question and clarifying terms necessary for its full understanding.

11.1.1 Sexual rights

The World Health Organization (WHO) notes that sexual rights are constituted by the application of existing human rights in the areas of sexuality and sexual health (World Health Organization, 2017). The concept of sexual rights is based on the principles of bodily integrity, privacy and the autonomy of individuals to make free choices about their sexuality, relationships and family planning, with the necessary supports (Starrs et al., 2018).

The United Nations ratified in 2006 in the Convention on the Rights of Persons with Disabilities (hereafter CRPD) the right of persons with disabilities to enjoy equal opportunities in all aspects of social and political life, including sexuality and reproduction (United Nations, 2006). Although neither the CDPD nor other human rights conventions make direct reference to sexual rights (Fish & Björnsdóttir, 2022), the CDPD does include the need to "eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others" (article 23) and in article 25 the right to "enjoy the highest attainable standard of health without discrimination on the basis of disability" (United Nations, 2006). It is worth noting that sexual rights have often been focused on family life, with no mention of sexuality, sexual agency or non-heteropatriarchal identities (Addlakha et al., 2017; Lottes, 2013; Miller, 2000).

The recognition of sexual rights as human rights implies an obligation on the part of the 181 countries that have signed the CRPD and their institutions to ensure the enjoyment of sexuality, including protection from sexual abuse, exploitation and violence (Miller et al., 2015). Despite the growing trend towards the recognition of their rights, several authors claim that these are often not fulfilled and the needs of persons with intellectual disabilities are not met (Borawska-Charko et al., 2017; Carter et al., 2021; Fish & Björnsdóttir, 2022; Neuman, 2020).

The concept of "*intimate citizenship*" was coined at the end of the last century, referring to the right of each individual to decide on "their body, their emotions, their identity, their relationships, their gender, their eroticism and their representations" (Plummer, 1995, p. 17). Recent years have seen a paradigm shift towards a person-centred model that recognises the right of people with intellectual disabilities to have intimate relationships (Ionescu et al., 1995, p. 17). Yet, people with intellectual disabilities continue to face a denial of their "intimate citizenship" (Hough, 2012). Although the CRPD recognises the right to be independent and to make one's own decisions (United Nations, 2006) people with intellectual disabilities are excluded from this vital area because of the difficulties they encounter in deciding about their relationships or sexuality (Puyaltó et al., 2012).

11.1.2 Sexuality and sexual health

Sexuality is a natural part of our lives and a human right regardless of a person's gender, age, orientation or disability, as stated in the Sexual Bill of Rights (World Association for Sexual Health, 2014). Sexuality is a broad concept that addresses such aspects as gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, sexual intercourse and reproduction (World Health Organization, 2017). It also emerges as a persistent dimension throughout individuals' lives, exerting a significant influence on their well-being (Verdugo et al., 2017). Sexuality is influenced by psychological, cultural, social, ethical, biological, etc. factors, and is expressed in a variety of ways (thoughts, attitudes, desires, practices, etc.), although not all are always experienced or expressed by each individual (World Health Organization, 2017). Sexuality is a fundamental part of the lives of most people, whether or not they have disabilities, who seek and desire sexuality (Frawley and O'Shea, 2019; Gil-Llario et al., 2022; Svae et al., 2022).

11.1.3 Sexual ableism

Ableism encompasses societal oppression, stereotyping, prejudice and discrimination towards people with intellectual disabilities (Bogart & Dunn, 2019). Following Campbell (2001) the term refers to the network of beliefs, processes and practices that assign a typical and perfect standard of personhood, presenting people with disabilities as an inferior state of being. Yet, vulnerable groups are encouraged to conform to the norm as much as possible in order to aspire to inclusion (Baril & Trevenen, 2014). Ways of interpreting disability and assumptions about disability are learned and perpetuate the ableist culture; similarly, by problematising these systems, the social systems that underpin it are exposed (Bahner et al., 2014).

Focusing specifically on the area of sexuality, sexual ableism is defined as the reduced sexual expectations for people with disabilities that shape the individual attitudes, policies and institutional procedures that mark the affective-sexual relationships of these people. (Mintz, 2022). Such system bases fitness for sexuality on an individual's intellect, morality, physique, appearance, age, race, and social acceptability (Gill, 2015).

Sexual ableism is very present in the lives of people with intellectual disabilities. There is a widespread idea in society that people with intellectual disabilities are incapable of free expression of their sexuality (Huquiquián et al., 2018) which excludes them from being represented as sexual beings (McCarthy et al., 2018). The international literature reflects the existing prejudices about the sexuality of people with intellectual disabilities with two main and opposing currents. The sexuality of people with intellectual disabilities is fraught with tensions between criminalisation, with the belief that this sexuality should not be "awakened" as uncontrollable and potentially dangerous (Brown, 2017; Feely, 2016; Fish & Björnsdóttir, 2022; Hole et al., 2021; Sandberg et al., 2021; Tamas et al., 2019; Wos et al., 2020) and desexualisation, thinking of people with intellectual disabilities as eternal children or asexual beings (Bahner et al., 2024; Baril & Trevenen, 2014; Brown, 2017; Feely, 2016; Frawley & Wilson, 2016; Hole et al., 2021; Löfgren-Mårtenson, 2013; Neuman, 2020; Retznik et al., 2021; Sandberg et al., 2021; Santinele Martino, 2022; Starke et al., 2016; Tamas et al., 2019). It is worth digressing and noting that asexuality, defined as the lack of lasting sexual or sentimental inclination towards others by Bogaert (2015) is not problematic per se. However, the prevailing desexualisation and imposed asexuality denies the sexual agency of people with intellectual disabilities (Sandberg et al., 2021).

Sexual ableism not only denies the sexual agency of people with intellectual disabilities, but also puts up barriers to the development of their sexual and reproductive rights (McCarthy et al., 2020). When engaging in intimate relationships, people with intellectual disabilities often face barriers and discriminatory attitudes (Fish & Björns, 2020). Families and support professionals often discourage people with intellectual disabilities from having intimate or sexual relationships (Lam et al., 2019. The silence around the positive aspects of their affective-sexual relationships both in society and in support services undermines their ability to express themselves sexually (Bahner et al., 2024; Black & Kammes, 2019; Gill, 2015). The control and surveillance exerted over their relationships sometimes leads people with intellectual disabilities to keep their relationships secret or to take greater risks around them (Bahner et al., 2024; Santinele Martino, 2022). Furthermore, these facts have a direct impact on the health of people with intellectual disabilities and on their self-esteem due to internalised ableism, discrimination and structural marginalisation (Bahner et al., 2024).

11.1.4 Sterilisation and contraception

It is worth noting that, although men with intellectual disabilities have also been and are subjected to such practices, sterilisation and/or contraception is a highly gendered and female-focused praxis (Fish & Björnsdóttir, 2022; McConnell & Phelan, 2022; Tilley et al., 2012). The main justification behind the decision to suppress the reproductive capacity of women with intellectual disabilities is their vulnerability to abuse and the prevention of pregnancy (Bahner et al., 2024; Björnsdóttir et al., 2017; Fish & Björnsdóttir, 2022). It should be remembered that such practices only prevent pregnancy and reproduction and not abuse (Björnsdóttir et al., 2024; Björnsdóttir et al., 2017), as well as making it easier to cover up (Fish & Björnsdóttir, 2022).

The sexuality of women with intellectual disabilities has historically been restricted and their rights violated through eugenic practices such as forced sterilisation, compulsory use of contraception, or reproductive coercion (Carter et al., 2021; MacLeod et al., 2022; Sandberg et al., 2021; Strnadová et al., 2019). The idea is to prevent pregnancies of people with intellectual disabilities and to avoid the birth of offspring with disabilities (Fish & Björnsdóttir, 2022; Sandberg et al., 2021); or because of the alleged inability of women with disabilities to become mothers (Fish & Björnsdóttir, 2022; Höglund & Larsson, 2013; Kroese et al., 2002; McConnell, 2008; Sandberg et al., 2021; Strnadová et al., 2019).

Following article 23 of the CRPD, which underlines that persons with disabilities should have the same right to maintain their fertility as their non-disabled counterparts (United Nations, 2006), most countries in the Global North have banned the systematic sterilisation of persons with intellectual disabilities (Fish & Björnsdóttir, 2022; Tilley et al., 2012). Eugenic practices such as forced sterilisation of people, especially women, with intellectual disabilities originated in the late 19th and early 20th century in order to prevent people perceived as "feebleminded" from procreating and having similar offspring (McConnell & Phelan, 2022). Even so, the history of sterilisations without consent is still recent; in Spain, the country where the present research is conducted, sterilisation without consent of the sterilised person was legal until the year 2020 (Organic Law, 2/2020 of December 16) and according to the Spanish Committee of Representatives of People with Disabilities (CERMI), in the last 10 years that the law was in force, more than a thousand people were sterilised without their consent. (CERMI, 2022). This practice denies people the opportunity to make meaningful decisions about their lives, ignoring their autonomy and undermining their self-esteem, as well as revealing a complete loss of control over one's own body (Björnsdóttir et al., 2017).

This paradigm shift is leading to a model based on risk protection (Sandberg et al., 2021) and fear (Bahner et al., 2024). There is concern about sexual abuse, reproduction and unwanted pregnancies among women with intellectual disabilities, as well as a danger of men's "hypersexuality" and their perceived status as potential sexual aggressors (Bahner et al., 2024; Starke et al., 2016). Although legislation is shifting towards prohibiting the practice, international research indicates that people with intellectual disabilities continue to be sterilised (Fish & Björnsdóttir, 2022; McConnell & Phelan, 2022; Tilley et al., 2012). According to McConnell & Phelan (2022) eugenic practices have not been eradicated, but have changed their forms. Some of the examples of such practices described by international authors include: pressure from family and services to perform such operations (Björnsdóttir et al., 2017; McConnell & Phelan, 2022); lack of accessible information (Björnsdóttir et al., 2017); use of manipulative tactics in sex education (McConnell & Phelan, 2022); limited opportunities and spaces for sexual expression and relationship formation (McConnell & Phelan, 2022; Santinele Martino, 2022); forced contraception and suppression of menstruation (Fish & Björnsdóttir, 2022; Tilley et al., 2012); coerced abortions (Björnsdóttir et al., 2017); and the removal of children from women with intellectual disabilities (McConnell & Phelan, 2022). While not all of these may not constitute eugenic practices per se, they all align with the eugenic vision of preventing or hindering reproduction for this group.

11.1.5 Sexuality Education

Various legal acts at the international level call for full and equal access to sexuality education for all citizens regardless of personal characteristics (Wos et al., 2020). For example, UNESCO recognises the universal right to sexuality education in its International Technical Guidelines on Sexuality Education, through the creation of environments and policies in both formal and informal settings that ensure access to comprehensive sexuality education (UNESCO, 2018). While persons with intellectual disabilities have the right to receive education and information about relationships, they are entitled to access comprehensive sexuality education and information (Fish & Björnsdóttir, 2022). Often, people with intellectual disabilities do not receive the necessary support and accommodations to learn about their sexual rights (Adams, 2015; Wos et al., 2015) and sexuality education programmes overlook the specific issues related to the education of young people with disabilities (Frawley & Wilson, 2016).

Although people with intellectual disabilities exhibit knowledge about sexuality and relationships, this knowledge is often limited, especially compared to that of their non-disabled counterparts (Jahoda & Pownall, 2014) due to deprivation of comprehensive sexuality education (Fish & Björnsdóttir, 2022). The lack of information has multiple causes due to a complex interaction of factors (Fish & Björnsdóttir, 2022). The international literature emphasises two main causes: lack of access to sexuality education and the content of such education.

Prejudices about the sexuality of people with intellectual disabilities and the legacy of eugenic practices influence the idea that people with intellectual disabilities are asexual and should be kept that way, "protected" from sex and knowledge about sex. (Wamsley & Jarret, 2019). In this way, the dominant discourse among policy makers is framed by the idea that, if it is not talked about, people with intellectual disabilities will not be interested in sexuality (Black & Kammes, 2019; Kulick & Rydström, 2015). Family members and caregivers of people with intellectual disabilities also often advocate for abstinence and restrict their sexual education (Bahner et al., 2024; Tamas et al., 2019) out of concern that they will not be able to control their sexual urges (Tamas et al., 2019) or fear of abuse (Carter et al., 2021; Grove et al., 2018; McConnell & Phelan, 2022; Tamas et al., 2019). Yet, research agrees that restricting sexuality education for people with intellectual disabilities only contributes to making them more vulnerable to these dangers (Carter et al., 2021; Fish & Björnsdóttir, 2022; Hollomotz, 2012).

Moreover, although provision varies between institutions and cultural contexts (Fish & Björnsdóttir, 2022) the content of sexuality education programmes aimed at people with intellectual disabilities focuses on biological aspects and risk prevention (Bahner et al., 2024; Carter et al., 2021; Frawley & Wilson, 2016; Wos et al., 2020). In addition, the contents taught are highly gendered, pathologising the sexuality of men with intellectual disabilities and working with women on protection from abuse and pregnancy, without focusing on pleasure in either case (Black & Kammes, 2019; Frawley & Wilson, 2016). With regard to the diversity of sexual and gender identities, a high incidence of education based on cisheteronormativity, without making space for other identities, has been observed (Fish & Björnsdóttir, 2022; Löfgren-Mårtenson, 2012).

For this reason, various authors advocate implementing a holistic view of sexuality to improve sexuality education (Frawley & Wilson, 2016; Strnadová et al., 2019). In order to do so, they propose giving importance to sexual desire and pleasure (Black & Kammes, 2019; Fish & Björnsdóttir, 2022; McCarthy, 2014), appropriate relationship behaviours (Black & Kammes, 2019; Carter et al., 2021; Huaiquián et al., 2018) or the vocabulary and skills needed to report sexual abuse (Fish & Björnsdóttir, 2022). People with intellectual disabilities demonstrate a desire to access knowledge and to develop their knowledge (Gil-Llario et al., 2018). Therefore, the creation of adapted and personalised programmes is recommended (Fish & Björnsdóttir, 2022; Tamas et al., 2019) with the voices and perspectives of people with intellectual disabilities (Tamas et al., 2019).

Sex education tailored to the needs of people with intellectual disabilities has the potential to improve their sexual and reproductive health, as well as their overall wellbeing

(Carter et al., 2021; McConnell & Phelan, 2022). In contrast, limiting access to sexuality education puts people at greater risk of sexual violence (Carter et al., 2021; Martinello, 2015; McDaniels & Fleming, 2016; Wos et al., 2020) may internalise a negative self-image (Löfgren-Mårtenson, 2012), are deprived of their right to self-realisation (Swango-Wilson, 2008) and from the development of their social and sexual identity (Frawley & Wilson, 2016).

Finally, it is worth noting that, in the face of this model of risk and restrictions, there is an opposing model that relies on education. This model suggests that it is the lack of adequate sexuality education that prevents people with intellectual disabilities from fully participating in this aspect. In addition, it identifies negative social attitudes towards disability and sexuality as barriers to appropriate sexuality, recognising the importance of sexuality promotion through educational interventions (Sandberg et al., 2021).

11.2 Women with intellectual disabilities and affective-sexual relations

Peta et al. (2017) argue that women with intellectual disabilities construct their own notion of sexuality and experience it in ways that challenge the dominant discourse based on ableism and restrictions. This is why research is needed to give voice to people with intellectual disabilities, especially women, to understand their views, needs and the difficulties they face in exercising their right to a fulfilling affective-sexual life.

The choice of focus of most of the articles in the Doctoral Thesis from the perspectives of women with intellectual disabilities is aligned with the objective of achieving gender equality set by the United Nations for 2030. Specifically, this institution has established the following goals for the year 2030: the elimination of discrimination against women and girls (goal 5.1), the eradication of all forms of violence against them (goal 5.2), the guarantee of their full participation in the decision making processes (goal 5.3), providing universal access to reproductive health and rights, adopting and strengthening policies and enforceable legislation for gender equality (target 5.9), and generally eradicating prejudice and promoting equal rights and respect for all groups (United Nations, 2020).

Intersectionality refers to the interconnectedness between different social categories and the different layers of oppression that may affect each person (McCarthy et al., 2017). Knowing these layers of oppression and domination in the field of affective relationships, suggests considering the group of women with intellectual disabilities as a group where prejudices towards intellectual disabilities are combined with the specific problems of women (Dean et al., 2017). For this reason, this research focuses on women with intellectual disabilities, as they suffer from intersectional discrimination in this field, being "in an unequal position with respect to the general population and men with disabilities in particular" (Morcillo Martínez & Pérez Villar, 2018, p. 63).

11.3 Research from the point of view of persons with intellectual disabilities on their affective-sexual relations

We thereafter proceed to present the state of the question based on national and international research in order to contextualise this Doctoral Thesis. The objective of this section is to provide a concise overview of the existing literature on the affective-sexual relationships of individuals with intellectual disabilities, in general, and of women with intellectual disabilities, specifically. The present Doctoral Thesis is based on the idea of "nothing about us without us", that is why all the research that will be presented in the following section includes the perspectives of people with intellectual disabilities. It should be noted that the objective of this section is not to provide a comprehensive overview of the existing literature on this topic. Instead, it aims to present the current state of knowledge in this field.

Firstly, it should be noted that the body of literature on this vital area is still limited (Siebelink, de Jong, et al., 2006; Stoffelen, 2018) and is often focused from the perspective of family members or professionals, without considering the views of people with intellectual disabilities (Stoffelen, 2018).

Nevertheless, some notable exceptions have been identified that investigate affective-sexual relationships from the point of view of people with intellectual disabilities. In Malta (Azzopardi Lane et al., 2019; Azzopardi-Lane & Callus, 2015) and in Ireland (Brown & McCann, 2018) have explored disabled women's and men's perceptions of sexuality. Svae et al. (2022) in Norway take a look at sex and relationships, focusing on privacy and personal boundaries. Retznik et al. (2021) in Germany and Siebelink et al. (2006) in the Netherlands, address the issue of sex and relationships. in the Netherlands address the issue of affective-sexual relationships, and Mattila et al. (2017) researches on the perspective they have on love in Finland. In Spain, the country where the Thesis is being carried out, two studies stand out, those by Puyaltó et al.

(2022) y Rojas Pernia et al. (2015) which investigate the perspectives of people with intellectual disabilities on the supports and barriers they encounter in their affective-sexual relationships.

The results of this research show the existence of common international barriers that people with intellectual disabilities, particularly women, encounter in their affective-sexual lives. O'Shea & Frawley (2020) argue that while people with intellectual disabilities face these barriers regardless of their gender, women face specific problems. While society sees men with intellectual disabilities as hypersexualised and potentially dangerous, women are perceived as potential victims of abuse and unwanted pregnancies, and lacking sexual desire (Bahner et al., 2024). These ideas lead to attitudes and practices such as overprotection by family members and professionals (de Wit et al., 2022; Friedman, 2023; Hole et al., 2021) lack of autonomy and limited choice in decision making (Carter et al., 2021; Wos et al., 2020) or the restriction of their reproductive rights (McCarthy et al., 2020).

Therefore, looking at the literature on women with intellectual disabilities, the first research that gave women with intellectual disabilities the opportunity to talk about their relationships with intellectual disabilities in depth was published twenty-five years ago. (McCarthy, 1999). Even so, similar to the research on affective-sexual relationships of people with intellectual disabilities regardless of gender, the literature we have is still scarce, counting in the literature review carried out in the first article of the thesis with only 11 articles identified. This point is addressed in depth in **article 1** of this compendium, which presents a systematic review of the literature developed on the subject.

12. Método

De acuerdo con la finalidad de la investigación, estudiar las perspectivas de las sobre las relaciones afectivosexuales y los aspectos relacionados con ellas, para poder comprender en profundidad la visión de las personas con discapacidad desde sus propias voces, se ha optado por una metodología cualitativa. Es esencial aplicar metodologías adecuadas que ayuden a incrementar su participación y ayudar a comprender sus experiencias, el enfoque cualitativo tiene un gran valor para informarnos sobre las perspectivas de las personas con discapacidad intelectual (Beail & Williams, 2014).

Siguiendo el OG 1, establecer el estado de la cuestión, la Tesis comenzó con una revisión sistemática de literatura sobre las relaciones afectivosexuales de las mujeres con discapacidad intelectual en el **artículo 1.** Dicha revisión se llevó a cabo siguiendo la guía propuesta por Petticrew & Roberts (2006) en once bases de datos (BASE; Dialnet; ERIC; La Referencia; Microsoft Academic; Redalyc; REDIB; Redined; Science Direct; Scopus; Web of Science; World Wide Science) de artículos que trataran las relaciones afectivosexuales desde el punto de vista de mujeres adultas con discapacidad intelectual. Una vez realizada la búsqueda en las bases de datos, se procedió a la lectura de los resúmenes de los documentos. De esta manera se identificaron 178 artículos potencialmente relevantes, que fueron evaluados mediante una lectura en profundidad, Finalmente, 11 artículos fueron seleccionados para el análisis final. Los resultados de la revisión sistemática de literatura se estructuraron en seis temas principales: percepciones sobre el sexo y la sexualidad; experiencias de abuso; opiniones y experiencias sobre las relaciones de pareja; el colectivo LGTBIQ+; conocimiento y experiencias con la anticoncepción; y, por último, creencias sobre los roles de género.

En línea con el **OG 2**, conocer las perspectivas, opiniones y vivencias de las personas adultas con discapacidad intelectual sobre las relaciones afectivo-sexuales, se desarrollaron los

artículos 2 y 3. El **artículo 2** se llevó a cabo mediante cuatro grupos focales con el Consejo Asesor formado por 14 hombres y mujeres de entre 24 y 72 años, ya que los focus groups son una herramienta valiosa para la exploración de experiencias y opiniones, así como para la obtención de datos relativos a las vidas de las personas con discapacidad intelectual (Kaehne & O'Connell, 2010). En estos focus groups, los asesores hablaron sobre las barreras con las que se encuentran en el área de las relaciones afectivosexuales y las propuestas que tenían para eliminarlas. Las barreras y apoyos se organizaron en los siguientes temas: las políticas, los profesionales y las organizaciones que prestan servicios a personas con discapacidad intelectual, la familia, las amistades, la pareja, la propia persona con discapacidad y la sociedad. Dado que el objetivo del **artículo 3** era conocer las opiniones y vivencias sobre las relaciones afectivosexuales de siete mujeres con discapacidad intelectual, se decidió diseñar una entrevista para recoger sus percepciones y explorar en profundidad los temas tratados. Se consideró que esta era la mejor forma de proceder, ya que las entrevistas son especialmente adecuadas para recoger las percepciones de los participantes y explorar en profundidad los temas tratados (Cohen et al., 2010). Así, se llevaron a cabo siete entrevistas semiestructuradas individuales estructuradas en cuatro bloques principales: relaciones afectivas; familia y maternidad; anticonceptivos y esterilización; y colectivo LGTBIQ+. Estos temas fueron elegidos partiendo de la revisión sistemática de literatura **(artículo 1).**

El **OG 3** de la presente tesis buscaba realizar una aproximación a las percepciones de mujeres con discapacidad intelectual sobre la maternidad. Por ello, en el **artículo 4**, nueve mujeres, distribuidas en dos grupos, participaron en 20 focus groups. La revisión sistemática de la investigación sobre las perspectivas de las mujeres adultas con discapacidad intelectual sobre las relaciones afectivo-sexuales **(artículo 1)** sirvió de base para diseñar el guion de los grupos focales. Las autoras seleccionaron los siguientes temas para las primeras cinco sesiones del taller: qué son las relaciones afectivas; las relaciones de pareja; la comunidad LGTBIQ; sexo, género y sexualidad; y maternidad. A partir del sexto grupo focal, cada grupo decidió centrarse en temas específicos que habían surgido en los cinco primeros; éstos se eligieron en función de los intereses y preguntas de las participantes. El grupo de la mañana trató los siguientes temas: relaciones y actitudes tóxicas; pareja y prejuicios; LGTBfobia; roles de género; esterilización; y cómo pedir ayuda en situaciones de violencia doméstica. En el grupo de la tarde se trataron los siguientes temas: violencia de género; independencia y sobreprotección; identidad de género y sexualidad; esterilización; y ayudas disponibles en casos de malos tratos. La maternidad, tema de este artículo, se abordó en 15 de las 20 sesiones, con diferentes niveles de profundidad.

En los cuatro artículos, se utilizó el análisis de contenido temático, una técnica que identifica y analiza patrones en un conjunto de datos mediante su lectura y relectura (Fereday & Muir-Cochrane, 2006). Los datos obtenidos en cada una de las investigaciones fueron analizados siguiendo los principios de buenas prácticas en el análisis temático de Braun y Clarke (2021). Para ello, la autora principal leyó los documentos para crear una codificación inicial y, una vez las otras autoras habían revisado esta codificación, la autora principal procedió a la realización de una codificación estructural más detallada. Finalmente, cuando se contaba con la información codificada, se redactaron los resultados presentándolos divididos temáticamente.

13. Resultados

Este apartado presenta los artículos incluidos en el compendio. Siguiendo las normas estipuladas por la Universitat de Girona, el **artículo 1, Perspectives of Women with Intellectual Disabilities Regarding Affective Sexual Relationships: a Systematic Literature Review,** se presenta en la versión post-print ya que se encuentra publicado en acceso abierto.

Los **artículos 2, Las relaciones afectivo-sexuales de las personas con discapacidad intelectual. Apoyos y barreras desde la perspectiva de personas con discapacidad intelectual,** y **3, What do they think? The opinions of women with intellectual disabilities on affective-sexual relationships. An interview-based study**, están en proceso de revisión, por lo que se incluye la versión más recientes de ambos.

El **artículo 4, Women with intellectual disabilities and motherhood: barriers, supports and Demands,** no está disponible en acceso abierto, lo que significa que no se puede acceder libremente a la versión final del artículo. Sin embargo, se adjunta la versión aceptada pre-print, que es la versión del artículo tal como fue aceptada por la revista antes de la revisión por pares y la edición final.

13.1 Perspectives of Women with Intellectual Disabilities Regarding Affective Sexual Relationships: a Systematic Literature Review (Artículo 1):

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Perspectives of Women with Intellectual Disabilities Regarding Affective Sexual Relationships: a Systematic Literature Review

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Abstract

Introduction Despite the recognition of the right to sexual identity and expression for all people, individuals with intellectual disabilities continue to face significant restrictions in these aspects of their lives. The prevailing myths and stereotypes surrounding their sexual-affective relationships place people with intellectual disabilities—especially women—in a position of great vulnerability.

Methods A systematic literature review was conducted, examining the content of the following databases: BASE, Dialnet, ERIC, La Referencia, Microsoft Academic, Redalyc, REDIB, Redined, Science Direct, Scopus, Web of Science, and World Wide Science. A total of 178 potentially relevant articles were identified, out of which 11 met the eligibility criteria. Finally, the themes covered in the articles were identified and analyzed.

Results The results obtained were classified into six categories: perceptions regarding sex and sexuality, experiences of abuse, views and experiences of relationships between couples, the LGTBIQ + community, knowledge about contraception and related experiences, and, finally, beliefs regarding gender scripts.

Conclusions This study offers valuable insights into the knowledge (or lack thereof) and beliefs regarding sex and sexuality, experiences of abuse among women with intellectual disabilities, the lack of independence and external intervention, and the influence of traditional gender scripts. Furthermore, this research also establishes a theoretical foundation for future support resources and initiatives, as well as social and public implications.

Keywords Intellectual disability · Women · Relationships · Sexuality · Gender · Inclusion · Affectivity

Introduction

Achieving gender equality is one of the United Nations' goals for 2030. It strives towards ending discrimination against women and girls (target 5.1), putting an end to all violence towards them (target 5.2), ensuring full participation in decision-making (target 5.3), guaranteeing universal access to reproductive health and rights, adopting and strengthening policies and enforceable legislation for gender equality (target 5.9), and, overall, eradicating prejudice and work towards equal rights and respect for all collectives (United Nations, 2020). The Convention on the Rights of Persons with Disabilities also establishes another of the main theoretical pillars, since it recognizes the right to non-discrimination of people with disabilities and assumes the need to combat all forms of discrimination against women in this group, working towards a social model that puts people at the center and seeks to eliminate barriers in the environment (United Nations, 2006). This organization also enshrines the right to sexual identity and expression, parenthood, marriage, and cohabitation (Ignagni et al., 2016). The World Health Organization defines sexual health as a fundamental aspect of human development which must include a respectful approach to sexuality and the opportunity for pleasurable and safe sexual relations, free from discrimination and violence (World Health Organization, 2017). However, despite the growing trend in the recognition of these rights, they are often unfulfilled, and the needs of people with disabilities are not met (Borawska-Charko et al., 2017; Carter et al., 2022; Fish & Björnsdóttir, 2022; Neuman, 2022).

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There is a generalized idea that people with intellectual disabilities are ill-suited to the free expression of their sexuality (Huaiquián et al., 2018). Myths and stereotypes surrounding the sexuality of people with intellectual disabilities reinforce this notion. These mistaken beliefs range from the conception of them as "asexual beings" or "eternal children," oblivious to sexuality (Neuman, 2022; Retznik et al., 2021; Starke et al., 2016; Tamas et al., 2019) to the conception of them as being promiscuous and dangerous individuals whose sexuality should not be awakened (Fish & Björnsdóttir, 2022; Tamas et al., 2019; Wos et al., 2020). These stereotypes lead people with intellectual disabilities to often apply a "self-censorship in the experience of their sexuality" (Díaz-Rodríguez et al., 2016) or to have a negative self-image about it (Stevens, 2012). A study developed in Spain pointed out that people with intellectual disabilities tend to have a less liberal view on their conception of their own sexuality (6.1% of people have conservative attitudes and 93.9% moderate) comparing them with the attitudes of people without intellectual disabilities (0.5% conservative attitudes, 64% moderate attitudes and 35.5% liberal attitudes), thus excluding themselves from a full, healthy affective-sexual life (Díaz-Rodríguez et al., 2016). It needs to be emphasized that beliefs and attitudes towards sexuality are not universally shared. They are strongly influenced by the individual, relational and sociocultural factors of each person, such as social scripts, religious beliefs, or gendered cultural scripts (Basson, 2000; Hidalgo & Dewitte, 2021).

The lack of research, information, and education on the sexuality of people with intellectual disabilities results in a greater vulnerability to abuse (Ballan & Freyer, 2012). Many investigations have found that people with intellectual disabilities are at greater risk from unsafe practices, manipulation, sexual assault, abuse, and violence in general (Borawska-Charko et al., 2017; English et al., 2017; Futcher, 2011; McCarthy, 2009; Muswera & Kasiran, 2019; Stevens, 2012). At the same time, the lack of information and adapted resources hinder the possibility of both avoiding and also reporting these situations (Borawska-Charko et al., 2017; De Mello et al., 2021; Frawley & O'Shea, 2019; Frawley et al., 2012; Muswera & Kasiran, 2019). Likewise, in cases where this issue is studied, a broad definition of disability is often used, encompassing all types of physical, sensory, and cognitive disabilities under the same umbrella (McCarthy, 2017). In addition, these difficulties are exacerbated by a double discrimination when gender is taken into account since women are "in an unequal position with respect to the population in general, and men with disabilities in particular" (Morcillo & Pérez, 2018, p. 63).

Access to sex education is crucial in the sexual empowerment of people with intellectual disabilities. The lack of sexual literacy excludes them from the possibility of sexual expression and pleasure (Adams, 2015; Alexander & Gomez, 2017). However, recent research has shown that people with intellectual disabilities seldom receive an adequate, reliable sexual education (Adams, 2015; Wos et al., 2020; Namkung et al., 2021; Schmidt et al., 2020). Although some sex education programs aimed at people with intellectual disabilities have been developed (Anderson, 2015; Schaafsma et al., 2013), these have generally been linked to conflictive aspects of affective-sexual relationships such as abuse, or a more biological and medical point of view (Fish & Björnsdóttir, 2022; Wos et al., 2020). Consequently, the knowledge that people with intellectual disabilities have on this subject is quite superficial and limited to aspects such as safe sex, contraception, or sexually transmitted diseases (Schaafsma et al., 2013).

Voicing one's opinions and talking about personal experiences is a powerful tool for self-advocacy and empowerment, especially regarding a topic as personal as sexual-affective relationships (Azzopardi-Lane & Callus, 2014). Nevertheless, although the first research that gave the opportunity to women with intellectual disabilities to talk in-depth about this topic was published almost twenty-five years ago (McCarthy, 1999), literature researching their experiences and opinions is still scarce (Azzopardi Lane et al., 2019; Bernert & Ogletree, 2013; McCarthy, 2014). Discovering the perspective of women with intellectual disabilities is essential to obtain a deep understanding of their experiences. Only by learning about their opinions and experiences will we be able to obtain information about what their needs are and the supports they want (McCarthy, 2014). From a legal perspective, and considering that the enjoyment of one's sexuality is a right for all people (Fish & Björnsdóttir, 2022; United Nations, 2006, 2020; World Health Organization, 2017), it is necessary to investigate the intersection between intellectual disabilities and sexuality, while emphasizing women's point of view.

In order to highlight the voices of women with intellectual disabilities, this systematic literature review focuses on research that has specifically and solely gathered information from women's points of view. The objective of this paper is to explore the main needs, experiences, and concerns expressed by women with intellectual disabilities in relation to their affective-sexual relationships and to reflect on how to advance in the formulation of the desired supports to help women improve this dimension of their lives.

Method

Search Sources and Strategy

This Systematic Literature Review was undertaken following the guidelines proposed by Petticrew and Roberts (2006) and conducted in five steps: (1) searching for potentially relevant articles; (2) reading the abstracts of the articles identified in the previous phase; (3) in-depth evaluation of the articles included in the second phase; (4) identification of the articles relevant for research; and finally, (5) analysis of the selected articles. Additionally, three other papers linked to social sciences were also analyzed (Brown & McCann, 2018; Ferreras-Fernández et al., 2016; García-Peñalvo, 2016) to determine the process. Figure 1 presents the procedure chosen in line with the PRISMA statement (Rethlefsen et al., 2021):

Identification

To access international research in English, 8 databases were chosen: BASE, ERIC, The Reference, Microsoft Academic, Science Direct, Scopus, Web of Science, and WorldWideScience. To retrieve literature from Spanish-speaking countries, the following databases were chosen: Dialnet, REDIB, and Redined. In accordance with the objective of the research, the search terms used are those shown in Fig. 2. The search was undertaken in both the English and Spanish versions.

An additional search of records was carried out by exploring the references of the papers that fulfilled the eligibility criteria described below. Adding the two sources—the databases and the references—116,828 documents were retrieved. Subsequently, 1128 duplicated records were removed, resulting in 115,700 documents to analyze in search of potentially relevant papers.

Eligibility Criteria

Given the objective of the systematic literature review, the following inclusion criteria were established: (1) The participants could only be adult women with intellectual disabilities; therefore, the research studies that contributed to the perspectives of other groups of people were excluded;

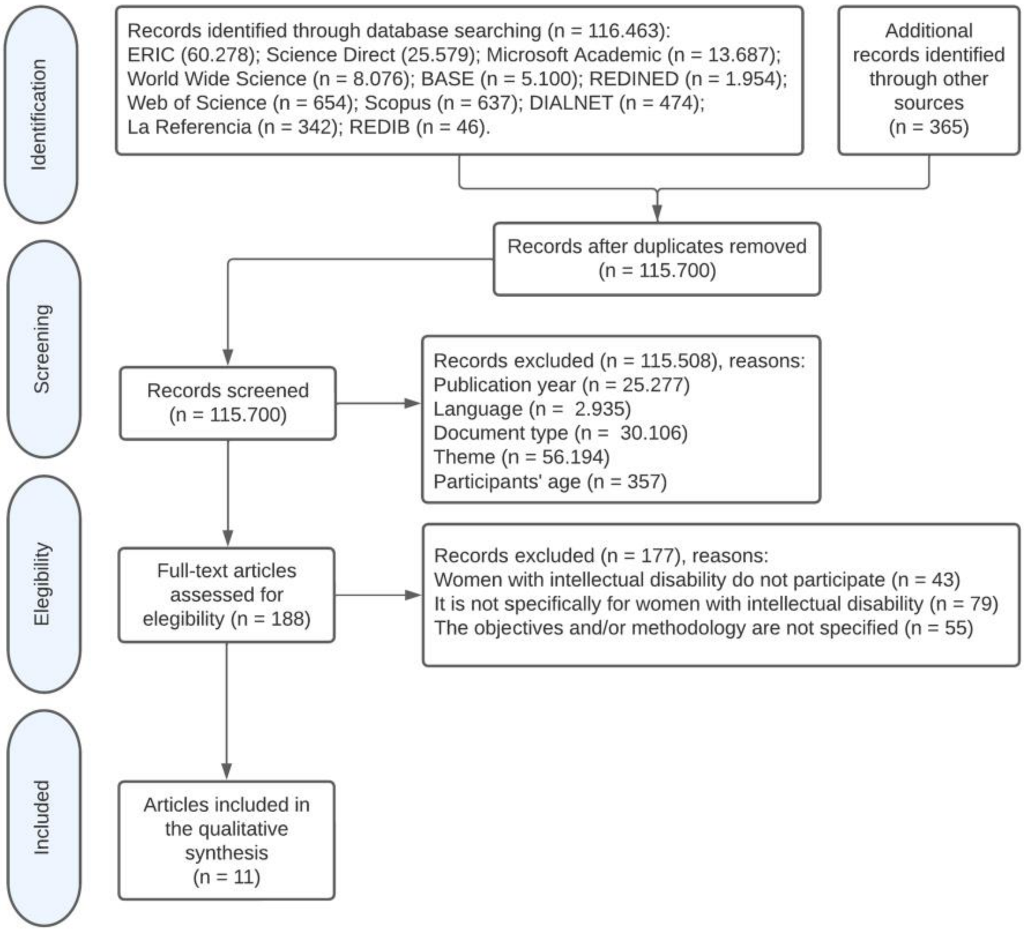

Fig. 1 PRISMA diagram of the systematic literature research process

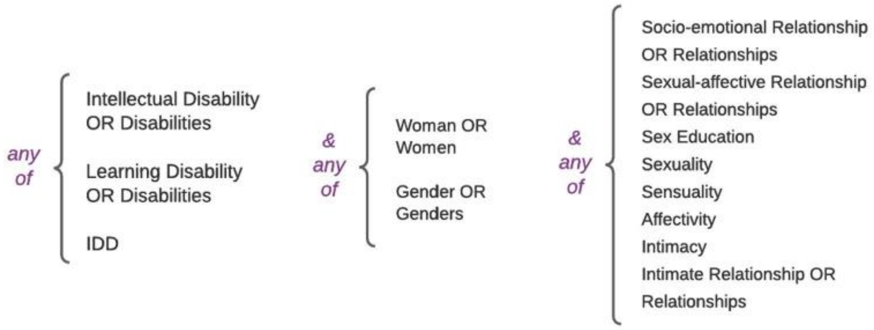

Fig. 2 Search terms and groups used

(2) the documents had to be peer-reviewed papers or doctoral theses; (3) the papers had to clearly specify their objectives and the methodology followed; (4) the papers had to be directly related to the subject of affective-sexual relationships, without treating it from a strictly medical point of view; (5) the documents had to be written in English or Spanish; and (6) only articles published in the last twenty years were included to ensure their validity and suitability, so the articles published before 2002 were excluded from the systematic review of literature.

Screening

A screening of potentially relevant articles was conducted. First, the filters of the year of publication, document type, and language were applied. Documents were then screened for their relationship to the topic by reading the titles and abstracts. In this way, 115,700 documents were located. However, 115,518 were discarded as they did not meet the inclusion criteria. The 182 that did meet all the criteria were selected for the next phase.

Eligibility

The full texts of the 182 papers selected as potentially relevant were read to assess their eligibility by inspecting their methodologies and objectives. The process showed that 11 of these articles met the inclusion criteria and that 171 did not. The reasons for not meeting the criteria are shown in Table 1.

Included

Eleven articles were selected for the analysis, synthesis, and data relationship phase. The information about the selected articles and the research developed in each of them is described in Table 2.

Table 1 Reasons of exclusion after full-text assessment

Reason of exclusion		Number of records ($n=171$)
1	No information about the objectives and/or the methodology of the paper	55
2	No participation of adult women with intellectual disabilities	23
2.1	Professionals ($n=16$)	
2.2	Minors with intellectual disabilities ($n=2$)	
2.3	General public ($n=2$)	
2.4	Men with intellectual disabilities ($n=1$)	
2.5	Family and general public ($n=1$)	
2.6	Family and professionals ($n=1$)	
3	The voice of women with intellectual disabilities is not specifically reflected	82
3.1	Also included other people with intellectual disabilities ($n=48$)	
3.2	Also included other disabilities ($n=11$)	
3.3	Also included professionals ($n=8$)	
3.4	Also included minors with intellectual disabilities ($n=6$)	
3.5	Also included general public, families, and professionals ($n=4$)	
3.6	Also included the general public ($n=2$)	
3.7	Also included families and professionals ($n=2$)	
3.8	Also included families ($n=1$)	

Table 2 Characteristics of the articles selected and the research process

	Reference	Country	Aim of the study	Method
1	(Bornman & Rathbone, 2016)	South Africa	Create four social stories that can be part of sex education and sexual education programs for women with intellectual disabilities	Systematic literature review Focus group made up of women with intellectual disabilities
2	(Burns & Davies, 2011)	UK	Investigate the knowledge and attitudes of women with intellectual disabilities regarding homosexual relationships, and check if they coincide with those of the general population	Three self-reporting questionnaires for the assessment of knowledge and attitudes
3	(Eastgate et al., 2011)	Australia	Explore knowledge about sexuality, experiences with relationships, and protective skills in a group of women with intellectual disabilities	Individual semi-structured interviews with 9 women with intellectual disabilities
4	(Fitzgerald & Withers, 2013)	UK	Investigate the sexuality and gender orientation of women with intellectual disabilities without focusing on issues of abuse, contraception and sexual education	Individual semi-structured interviews with 10 women with intellectual disabilities
5	(Gil-Llario et al., 2014)	Spain	Analyze the effect that various characteristics may have on attitudes, knowledge, and behavior in order to prevent the sexual abuse of which they are often victims	Individual structured interviews with 39 women with intellectual disabilities
6	(McCarthy, 2009)	UK	Investigate the extent to which women with intellectual disabilities are able to make decisions about the use of contraceptive methods	Individual semi-structured interviews with 23 women with intellectual disabilities
7	(O'Shea & Frawley, 2020)	Australia	Understand how gender manifests itself in the lives of young women with intellectual disabilities, and analyze how it can contribute to a better understanding of their lives	Systematic literature review Individual in-depth interviews with 6 women with intellectual disabilities
8	(Pestka & Wendt, 2014)	Australia	Examine how the need for belonging contributes to the vulnerability of women with intellectual disabilities regarding abuse in their intimate relationships	Semi-structured individual interviews with 4 women with intellectual disabilities
9	(Servais et al., 2002)	Belgium	Analyze the proportion of women with intellectual disabilities using contraceptive methods, which are the most used and why	Two questionnaires, one of them focused on the institutional profile and the other on the participant's profile
10	(Stoffelen et al., 2018)	Netherlands	Learning about the experiences of lesbian and bisexual women with intellectual disabilities	Individual semi-structured interviews with 10 women with intellectual disabilities
11	(Walter-Brice et al., 2012)	UK	Learn about the experiences of domestic abuse from the point of view of women with intellectual disabilities who have experienced them in their intimate relationships, and analyze whether intellectual disability affects access to services and help in these cases	Systematic literature review Semi-structured individual interviews with 5 women with intellectual disabilities

Table 3 Characteristics of the participants

	Reference	N. º	Age ranges	Intellectual disability diagnosis	Marital status	Sexuality	Race and ethnicity
1	(Bornman & Rathbone, 2016)	10	20–29 ($n=2$) 40–49 ($n=6$) 50–59 ($n=2$)	*Not specified*	Current partner ($n=7$) Single, previous partner ($n=3$)	*Not specified*	*Not specified*
2	(Burns & Davies, 2011)	27	23–65 *(no ages specified)*	*Not specified*	Single ($n=23$) Married ($n=1$) Divorced ($n=2$) Widowed ($n=1$)	Heterosexual ($n=27$)	White ($n=22$) Black ($n=4$) Mixed race ($n=1$)
3	(Eastgate et al., 2011)	9	20–29 ($n=2$) 30–39 ($n=4$) 40–49 ($n=3$)	Mild ($n=9$)	Current partner ($n=6$) Single, previous partner ($n=2$) Single, no previous partner ($n=1$)	Heterosexual ($n=9$) Past same-sex experiences ($n=2$)	*Not specified*
4	(Fitzgerald & Withers, 2013)	10	19–64 *(no ages specified)*	*Not specified*	*Not specified*	Heterosexual ($n=10$)	White British ($n=10$)
5	(Gil-Llario et al., 2014)	39	27–35 ($n=6$) 36–43 ($n=14$) 44–52 ($n=19$)	Mild ($n=22$) Moderate ($n=17$)	*Not specified*	*Not specified*	*Not specified*
6	(McCarthy, 2009)	23	20–51 *(no ages specified)*	Mild or moderate	*Not specified*	*Not specified*	White British ($n=19$) Black British ($n=2$) Mauritanian ($n=1$) Eastern European ($n=1$)
7	(O'Shea & Frawley, 2020)	6	18–30 *(no ages specified)*	*Not specified*	Single ($n=3$) Married ($n=2$) Engaged ($n=1$)	Heterosexual ($n=5$) Sexually diverse ($n=1$)	Culturally diverse backgrounds
8	(Pestka & Wendt, 2014)	4	20–30 ($n=1$) 40–50 ($n=2$) 60–70 ($n=1$)	*Not specified*	Single ($n=1$) Married ($n=1$) Divorced ($n=2$)	*Not specified*	*Not specified*
9	(Servais et al., 2002)	397	18–46 *(no ages specified)*	Mild ($n=60$) Moderate ($n=177$) Severe ($n=160$)	*Not specified*	*Not specified*	*Not specified*
10	(Stoffelen et al., 2018)	10	20–29 ($n=4$) 30–39 ($n=4$) 40–49 ($n=2$)	*Not specified*	Single ($n=6$) Current partner ($n=2$) Married ($n=2$)	Bisexual and homosexual	Native Dutch ($n=10$)
11	(Walter-Brice et al., 2012)	5	27–50 ($n=5$)	*Not specified*	*Not specified*	*Not specified*	White ($n=5$)

The characteristics of the women participating in the studies were varied. Table 3 shows a summary of some of the characteristics of participants, maintaining the same terminology used in the articles cited.

Characteristics of the Research

A total of eleven studies were analyzed from the following countries: three of them from Australia and two from England. In addition, there was one article from each of the following countries: Belgium, Spain, the Netherlands, and South Africa. Regarding the years of publication, the majority were published in the last ten years.

All but one of the studies solely included participants with sufficient communicative competence to participate in group discussions, formal and informal conversations, communicate in an understandable way, and, finally, be able to independently give their consent to participate in the research. In the case of the study that did not have communicative competence as a criterion for the exclusion of the participants (Servais et al., 2002), the research was undertaken through closed and adapted questionnaires. However, the article did not specify if the women received any type of support when answering.

The age of women participating in the studies ranged from 18 to 89 years, but only a few were at the age extremes mentioned. The adaptive skills and cognitive functioning in relation to daily life ranged from women who lived independently, to those who had direct supervision or those who lived in centers where they received direct assistance. Research participants were cisgender women with and without children, unmarried, engaged, married, divorced, and widowed. As for the sexuality of these, the majority identified themselves as heterosexual, although a few described having had homosexual relations or having them at the time of the research. Finally, the participants come from six different countries—Australia, the UK, South Africa, Spain, Belgium, and the Netherlands—and, although not all articles specify ethnic and cultural origins, a majority of white women can be observed.

Regarding the sample size of the different articles, this ranged from the study with the fewest participants being 4 women (Pestka & Wendt, 2014), to the most numerous research study where a sample of 397 women was analyzed (Servais et al., 2002). Even so, in most of the studies, the sample was around 10 to 15 women.

Observing the objectives of the articles (summarized in Table 4), three of the articles focused on exploring affective-sexual experiences (Fitzgerald & Withers, 2013; O'Shea & Frawley, 2020; Stoffelen et al., 2018); three others referred to experiences of abuse and/or protection from them (McCarthy, 2009; Pestka & Wendt, 2014; Servais et al., 2002). A third objective was to analyze the knowledge they had about sexuality and relationships (Burns & Davies, 2011; McCarthy, 2009; Servais et al., 2002) including knowledge about homosexuality (Burns & Davies, 2011). Some of the studies identified measures that could be taken to protect themselves from abuse (McCarthy, 2009; Servais et al., 2002; Walter-Brice et al., 2012). One of the articles investigated how to create adapted sexuality resources and programs (Bornman & Rathbone, 2016). Finally, only two of the articles focused on the exploration of decision-making capacity linked, in particular, to contraception (Eastgate et al., 2011; Gil-Llario et al., 2014).

Data Analysis

A thematic analysis was carried out following the guidelines defined by Braun and Clarke (2006) where the process is divided into six steps: familiarization with the data collected; generating the initial codes; searching for the themes; reviewing them; defining and naming these themes; and, lastly, producing the report.

The analysis started with a first in-depth reading of the "results" and the "discussion" sections of the selected articles to get acquainted with the information presented in them. Once this first step was concluded, a set of initial codes was created. These were determined by the ideas and the data shown in the papers. In this way, eleven categories were identified: beliefs and attitudes; experiences; knowledge; sources of information; reporting; consequences; support and help; mental health; reasons; relationships; and, finally, belonging. After this process, a second reading was undertaken to find the themes covered by each of the initial codes. Six themes were identified: perceptions regarding sex and sexuality; experiences of abuse; views and experiences of relationships between couples; the LGBTIQ + collective; knowledge about contraception and experiences; and beliefs regarding gender scripts. Finally, a report of the findings was developed, and the results are described in the results section. Table 5 presents the codes, themes, and articles that covered each of them.

Results

The results are presented following the structure presented in Table 5, moving from the most common codes to the least used codes. Likewise, the topics within these codes have also been organized from highest to lowest prevalence in the

Table 4 Objectives of the articles analyzed

	Objective	References
1	To explore affective-sexual experiences	Fitzgerald and Withers (2013) O'Shea and Frawley (2020) Stoffelen et al. (2018)
2	To explore decision-making capacity regarding contraceptives	Eastgate et al. (2011) Gil-Llario et al. (2014)
3	To analyze knowledge on sexuality, relationships and protection from abuse	McCarthy (2009) Servais et al. (2002)
4	To create adapted sexuality resources and programs	Bornman and Rathbone (2016)
5	To analyze knowledge and attitudes towards homosexuality	Burns and Davies (2011)
6	To explore their experiences of abuse	Pestka and Wendt (2014)
7	To identify the ways to prevent sexual abuse	Walter-Brice et al. (2012)

Table 5 Relation between the codes, themes, and references

	Codes	Themes	References
1	Perceptions regarding sex and sexuality	Knowledge	Bornman and Rathbone (2016) Eastgate et al. (2011) Fitzgerald and Withers (2013) Gil-Llario et al. (2014)
		Beliefs and attitudes	Fitzgerald and Withers (2013) Gil-Llario et al. (2014) O'Shea and Frawley (2020)
		Experiences	Eastgate et al. (2011) Fitzgerald and Withers (2013) Gil-Llario et al. (2014)
		Sources of information	Eastgate et al. (2011)
2	Experiences of abuse	Consequences	Eastgate et al. (2011) Pestka and Wendt (2014) Stoffelen et al. (2018) Walter-Brice et al. (2012)
		Experiences	Eastgate et al. (2011) Pestka and Wendt (2014) Stoffelen et al. (2018) Walter-Brice et al. (2012)
		Reporting the abuse	Eastgate et al. (2011) Walter-Brice et al. (2012)
		Support and help	Walter-Brice et al. (2012)
3	Views and experiences of relationships between couples	Beliefs and attitudes	Eastgate et al. (2011) O'Shea and Frawley (2020) Pestka and Wendt (2014)
		Belonging	O'Shea and Frawley (2020) Pestka and Wendt (2014)
		Experiences	O'Shea and Frawley (2020)
4	LGTBIQ + collective	Experiences	Stoffelen et al. (2018)
		Beliefs and attitudes	Burns and Davies (2011)
		Knowledge	Burns and Davies (2011)
		Support and help	Stoffelen et al. (2018)
		Mental health	Stoffelen et al. (2018)
5	Knowledge about contraception and experiences	Experiences	McCarthy (2009) Servais et al. (2002)
		Knowledge	McCarthy (2009)
		Reasons	McCarthy (2009)
6	Beliefs regarding gender scripts	Beliefs and attitudes	Burns and Davies (2011) O'Shea and Frawley (2020)

articles analyzed. The number of participants who agreed with each result obtained has been detailed in the cases that were possible because the articles specified this information.

Perceptions Regarding Sex and Sexuality

This was the most frequently discussed topic in the literature selected for this review, with five of the eleven articles chosen dealing with the perceptions regarding sex and sexuality (Bornman & Rathbone, 2016; Eastgate et al., 2011; Fitzgerald & Withers, 2013; Gil-Llario et al., 2014; O'Shea & Frawley, 2020). Within this code, four themes were identified: *the knowledge they have about sex and sexuality, the beliefs and attitudes held by the participants, their experiences, and sources of information*.

Four articles analyzed women's *knowledge on the subject:* Bornman and Rathbone (2016), Eastgate et al. (2011), Fitzgerald and Withers (2013), and Gil-Llario et al. (2014). The four of them described different views: One described how the women interviewed knew how to manage their sexuality and displayed healthy sexual behavior (Bornman & Rathbone, 2016); in a second study, the knowledge of the participants varied from a very simplistic understanding—apparently not understanding the process of sexual relationships—to a broad comprehension of the subject (Eastgate et al., 2011), Fitzgerald and Withers (2013) pointed out that most of the women interviewed did not have knowledge regarding sex or sexual health, thus denying their options to experience their sexuality fully; and finally, Gil-Llario et al. (2014) noted that, although women had formed behaviors and attitudes—especially those who went to residential centers—there was a necessity for affective-sexual education adjusted to their needs.

Three studies asked participants about *their beliefs and attitudes regarding sex and sexuality:* Fitzgerald and Withers (2013), Gil-Llario et al. (2014), and O'Shea and Frawley (2020). The answers obtained in the different studies did not show a uniform result. In any case, a pattern was observed where younger women tended to have a more positive attitude, while older participants were less favorable with regard to sex and sexuality (Gil-Llario et al., 2014). Participants who described the issue in negative terms showed difficulty in talking about it because they saw it as a taboo subject. These women also denied their own sexuality as they saw sex as a dirty, disgusting act, associated with disease. The eight participants of Fitzgerald and Withers' study (2013) said that sex could be something pleasant and desired, not for them, but for other people. In general, sex was perceived as a secret and unpleasant activity that was undertaken to meet the biological needs of men. In the case of women who were in favor of sex, it was perceived not only as a source of pleasure but also as a resistance to the system that treated them as asexual people or individuals with a highly restricted sexuality (O'Shea & Frawley, 2020).

Three studies analyzed *women's experiences with sex and sexuality*: Eastgate et al. (2011), Fitzgerald and Withers (2013), and Gil-Llario et al. (2014). Research showed that women were highly regulated by their environment, especially by family and staff members (Fitzgerald & Withers, 2013). Some of the interviewees specified limitations such as being advised not to have children, needing permission from the center to have sex, having their interactions restricted to kissing and hugging, or being fearful of the staff discovering them having sex (Fitzgerald & Withers, 2013). The nine participants in one of the studies (Eastgate et al., 2011) were able to describe strategies for initiating a relationship as well as appropriate locations for sexual activity. However, none of the female participants described themselves as having initiated contact (Eastgate et al., 2011; Fitzgerald & Withers, 2013), and only one woman described having perceived sexual pleasure (Fitzgerald & Withers, 2013).

Finally, Eastgate et al. (2011) analyzed the *sources of knowledge and information* that they had at the time of the research. The participants mentioned having received training programs, as well as having read books or having talked with sex educators, counselors, or family members. Even so, the women acknowledged that they had not had any regular source of information since leaving school.

Experiences of Abuse

Four of the articles addressed experiences of abuse (Eastgate et al., 2011; Pestka & Wendt, 2014; Stoffelen et al., 2018; Walter-Brice et al., 2012). Four themes could be identified within this code: *the consequences of the abuse, the experiences of abuse, the reporting of the abuse, and the support and the help received.* Three studies were focused on the experiences of women in heterosexual relationships (Eastgate et al., 2011; Pestka & Wendt, 2014; Walter-Brice et al., 2012), while a fourth investigated the narratives of abuse of lesbian and bisexual women (Stoffelen et al., 2018). This study shows that abuses suffered by women of the LGTBIQ+group did not occur between the couple.

The four studies discussed the *consequences of abuse and ill-treatment*: Eastgate et al. (2011), Pestka and Wendt (2014), Stoffelen et al. (2018), and Walter-Brice et al. (2012). The women described the psychological impact it had had on both them and their children. Women who had been sexually abused described consequences such as the inability to have sex or a fear of having sex and/or avoiding it (Eastgate et al., 2011; Stoffelen et al., 2018). Some said that they had developed mental health problems, and a few women even described self-harm and suicidal thoughts (Pestka & Wendt, 2014; Stoffelen et al., 2018; Walter-Brice et al., 2012).

Four articles analyzed *their experiences*: Eastgate et al. (2011), Pestka and Wendt (2014), Stoffelen et al. (2018), and Walter-Brice et al. (2012). These studies showed the women were willing to talk about *their experiences*, in addition to conveying the need to be heard, believed, and supported (Eastgate et al., 2011). Participants described abuses that occurred in childhood and adolescence, where stories of rape-based domestic violence predominated (Eastgate et al., 2011; Pestka & Wendt, 2014). However, most of the stories developed in adulthood. Women reported having experienced different types of violence: physical, psychological, and emotional abuse, sexual abuse, verbal harassment, theft, and revictimization. In addition, when the abuse occurred within the couple, the aggressors had threatened and harassed their partners to trap the women in the relationship through fear (Walter-Brice et al., 2012). Many women reported serious physical assaults, in some cases life-threatening, with the use of various types of weapons (Pestka & Wendt, 2014). Sexual violence was also common, as several women reported sexual assault (Stoffelen et al., 2018).

Two articles analyzed the experiences of women when *reporting the abuse*: Eastgate et al. (2011) and Walter-Brice et al. (2012). All five women in the research of Walter-Brice et al. (2012) reported the situation to the police, and most did so to the Social Services; these women described having received inadequate or useless responses. The injustice they had experienced was a common experience and they expressed feelings of anger, annoyance, and frustration at the lack of effective action (Eastgate et al., 2011; Walter-Brice et al., 2012). The two women with children who had reported the abuse to Social Services described how their initial pleas were ignored and that, when the abuse intensified, they took custody of the children away from them (Walter-Brice et al., 2012). The injustice and lack of understanding experienced were common in all interviews. Those assaulted stated that the experience of being interrogated and cross-examined made them feel as if they were the ones accused. Often, services seemed to protect aggressors' rights more than women's; yet, despite the injustice suffered, all participants agreed that abuse should be reported (Eastgate et al., 2011; Walter-Brice et al., 2012).

Finally, one article analyzed *the support and help received*: Walter-Brice et al. (2012). The participants described how most of them experienced help from women's organizations. They also described having found a safe place to share their experiences and reduce physical and emotional isolation. In addition, they mentioned that being heard and believed by services made them feel comforted and supported.

Views and Experiences on Couple Relationships

The topic of couple relationships was investigated in three articles (Eastgate et al., 2011; O'Shea & Frawley, 2020; Pestka & Wendt, 2014). Three main themes were identified: *the beliefs and attitudes of the participants, the feeling of belonging, and their experiences.* All of which dealt with relationships from a solely heterosexual perspective.

All three articles analyzed the *beliefs and attitudes regarding couple relationships:* Eastgate et al. (2011), O'Shea and Frawley (2020), and Pestka and Wendt (2014). It was seen that the participants exhibited positive attitudes and described couple relationships as an important part of their lives (Eastgate et al., 2011; O'Shea & Frawley, 2020; Pestka & Wendt, 2014). Most of the participants showed in the interviews that they clearly preferred non-sexual relationships, others that they wanted physical intimacy but not sexual relationships, while another smaller group wanted to have satisfactory sexual relationships (Eastgate et al., 2011; O'Shea & Frawley, 2020).

Two papers dealt with the *feeling of belonging*: O'Shea and Frawley (2020) and Pestka and Wendt (2014). Participants in one of the studies (Pestka & Wendt, 2014) described feeling rejected in their childhood. Instead, when they talked about their adulthood, they identified being married, in love, or being mothers with a great feeling of happiness, love, and belonging (O'Shea & Frawley, 2020; Pestka & Wendt, 2014). According to their testimonies, these examples of traditional heterosexual relationships gave meaning to their lives (O'Shea & Frawley, 2020).

One of the studies analyzed *women's experiences of their relationships:* O'Shea and Frawley (2020). A recurring theme was the intervention and often the lack of acceptance of such relationships by families. Even so, women found ways to continue their relationships without their knowledge. This way of resisting external intervention, although satisfactory, required a significant effort to be able to experience their relationships. In addition, these ways of experiencing them led the general population to treat their relationships as imaginary or not to take them seriously because they did not coincide with traditionally established canons.

LGTBIQ + Collective

Two of the selected articles dealt with the theme of the LGTBIQ + collective: Burns and Davies (2011) and Stoffelen et al. (2018). Within this code, the following themes were identified: *experiences as people in the LGBTIQ + collective, beliefs and attitudes towards homosexuality, knowledge on the subject, support and help received, and mental health.* One of them took a group of heterosexual women with intellectual disabilities as a reference (Burns & Davies, 2011), and the other examined the perspective of lesbian and bisexual women with intellectual disabilities (Stoffelen et al., 2018).

Stoffelen et al. (2018) asked bisexual and lesbian women about their *experiences as people in the LGBTIQ + collective.* Participants talked about coming out of the closet between the age of 13 years and adulthood. Some of the women received support in this process, and others had to navigate this process alone. All the participants of the study described feeling insecure when talking for the first time about their sexual orientation with their friends and acquaintances. The reactions they received from doing this varied: For seven of them, the reactions had been positive; one woman had both positive and negative reactions; and finally, another woman mentioned having received negative reactions due to her sexuality. When interviews were conducted, six of the ten participants said that they openly expressed their sexuality in their everyday environments (Stoffelen et al., 2018).

Burns and Davies (2011) analyzed the *beliefs and attitudes* heterosexual women had regarding the LGBTIQ + collective. The group of heterosexual women held mostly negative attitudes towards homosexuality. Although the attitudes of the participants towards male and female homosexuality did not show great differences, the women felt homosexuality in men was something more unnatural. However, they presented more opposing views on marriage between women. In addition, it was observed how some women accompanied their responses with hostile comments towards female homosexuality.

In the same study (Burns & Davies, 2011), the authors also examined the *knowledge of the subject* observed in the group of heterosexual women. The authors found that these opposing attitudes and beliefs towards homosexuality might have been related to the lack of knowledge on the subject and observed that 74% of the participants did not respond correctly when asked about the meaning of homosexuality; although the percentage of knowledge was higher when asked about the word "gay," the information about it remained sparse.

Stoffelen et al. (2018) analyzed *the support received* from professionals when it came to women with intellectual disabilities finding their way in the LGTBIQ + community. The paper showed that more than half of the participants were satisfied with the support received from the professionals when it came to finding their way in the LGTBIQ + community and felt safe and accepted by them. Other women complained about the lack of confidence to talk about certain issues with workers, such as sex. Therefore, some women had had to seek information about this without any support or contribution from third parties.

Finally, this same study analyzed the *mental health of LGTBIQ + women with intellectual disabilities* (Stoffelen et al., 2018). The women openly described feelings of great loneliness and mental problems such as depression, alcohol addiction, anxiety, or harassment arising from experiences related to their sexuality.

Knowledge About Contraception and Experiences

The two studies that deal with the issue of contraception (McCarthy, 2009; Servais et al., 2002) analyzed three main themes: *women's experiences, women's knowledge, and the reasons for the use of contraceptives.*

Both studies *analyzed the experiences the women regarding the use and prescription of contraceptives*: McCarthy (2009) and Servais et al. (2002). Women reported that they played a generally passive role in their interactions with doctors. Most of the women in McCarthy's study (2009) appreciated having been accompanied to the medical consultation so as to have been able to count on someone they trusted, but also for their role as an intermediary or interpreter. All the participants agreed that they would have appreciated accessible information on contraception from health workers (McCarthy, 2009). Servais et al. (2002) observed how neither medical nor personal factors usually influenced the decision-making process. In most of the cases, the decision was made by the family or staff members of the services they attended. However, some women had decided to use contraceptive measures and which methods to use; it should be highlighted that these women were among those who needed the least support.

McCarthy (2009) analyzed the lack of *knowledge on contraception and reproduction*. The participants stated that they had received some training in the services they were attending. Still, a general lack of knowledge was noted: Most did not know or could not imagine how their method of contraception worked. There was also a lack of knowledge regarding reproduction, such as not knowing about the menopause or the relationship between fertility and the need for contraception. In addition, while some women explained that they had received information on the subject too early, others said that they had not known anything until after they had become pregnant.

This same study (McCarthy, 2009) also analyzed the *reasons for the use of contraceptives*. The majority alluded to the need to avoid pregnancy; however, only a minority of these women made it clear that they were sexually active. Some other women used them to regulate their periods. A participant said that she took them as she was considered especially vulnerable to sexual abuse; although from the testimonies of women, it can be assumed that this can also be the case of many others. When asked about the decision to stop the use of contraceptives, most said that they would have to ask permission from a third party as it was not under their own control or because they thought other people would be better informed about the issue.

Beliefs Regarding Gender Scripts

Two studies analyzed gender scripts (Burns & Davies, 2011; O'Shea & Frawley, 2020) and centered on the *beliefs and attitudes around them.*

Both these articles agreed that women with intellectual disabilities presented stereotypical and traditional beliefs regarding male and female gender scripts. Some participants (Burns & Davies, 2011) perceived men as the dominant gender, these being harsher and technically more efficient, while identifying women as the weaker and more emotional gender. From what was perceived in the interviews, gender and classical femininity had become a source of "power" that made them feel desired, valid, and productive through the reproduction of traditional cultural scripts (O'Shea & Frawley, 2020) contrary to the tendency to classify people with intellectual disabilities as people without gender.

Discussion

This study aimed to review the perspectives of women with intellectual disabilities regarding their sexual-affective relationships and reflect on the policy implications that might arise from these perspectives. The results obtained offer valuable insights (*understanding*) into the needs, experiences, and knowledge of adult women with intellectual disabilities from different parts of the world. These findings can be used as a valuable resource or foundation for families and professionals when providing assistance, supporting, and educating in the field of affective-sexual relationships. Recognizing their voices and understanding the factors that impact their experience of sexuality is vital to creating appropriate and meaningful resources (Bernert, 2011).

Spaces and situations must be created for this group to talk about their sexuality; people without intellectual disabilities should not fill this lack of information with their own voices (Hoorn, 2015).

The selected studies present varying perspectives on knowledge about sex and sexuality; however, the studies concur on the need for information and education tailored to women's specific needs, something which aligns with results from previous literature (Brkić-Jovanović et al., 2021; Friedman, 2023; McClelland et al., 2012). Although the articles present diverse and even contradictory scenarios in some cases on attitudes towards this topic, they coincide with other research in presenting a more negative outlook on sex and sexuality among women with intellectual disabilities than that of the rest of the population (Gil-Llario et al., 2021; Siebelink et al., 2006). These negative perceptions often stem from the belief that sex is risky and is a desirable act only for men (Schaafsma et al., 2015). The inability to express one’s sexuality positively increases personal vulnerability (Anderson, 2015; Hughes et al., 2012) and the risk of mental health problems (Conder et al., 2015).

Unfortunately, the experience of abuse was a shared experience among the women; most of these had happened in adulthood and within the couple (Anderson, 2015; Ballan & Freyer, 2012; Dixon & Robb, 2016; Morcillo & Pérez, 2018). Compared to the rest of the population, people with intellectual disabilities are more likely to be sexually abused and less likely to report it (Tomsa et al., 2021; Wilson, 2016). Many women described feeling ignored, judged, and revictimized when reporting their abuse to the police. It is important that the reporting processes are adapted to their needs and that professionals know how to properly address these needs (McCarthy et al., 2017; Tomsa et al., 2021). At the same time, the women had felt safe and supported in women’s organizations or in the services they had attended.

The lack of knowledge and accessible information is another common point that has been noted. The lack of information about the LGTBIQ+collective led to negative, even hostile, attitudes towards it among the heterosexual women while bringing about feelings of loneliness and isolation in the case of bisexual and lesbian women. Another area in which this lack of knowledge could be appreciated was that of contraception. It is necessary to provide accessible information and sex education tailored to the needs of each person. In addition, it is crucial to consider the needs of future recipients and the participation of the target group in the development of these resources (Schaafsma et al., 2013).

Another common point was the lack of independence and external intervention. It has been seen how the environment significantly regulates their lives and decisions. People with intellectual disabilities often experience resistance from their loved ones when exercising their sexual rights (Wos et al., 2020). In most cases observed, these interventions are perceived as an intrusion into their lives and their rights.

Finally, the reproduction of traditional heteropatriarchal roles in their couple relationships makes women feel empowered in the sense of making them feel desired, valid, and productive. These roles offer women a mechanism of power and defense against the citizen’s vision of them as people without gender. Being married, in love, or being a mother makes them feel desired, happy, and loved, in addition to developing a greater sense of belonging. The influence of the classical vision of gender can be also reflected in the stereotypical beliefs regarding male and female roles, identifying the former with the dominant gender and themselves with the weak gender (Hoorn, 2015; Huaiquián et al., 2018).

During the development of this research, it has been possible to observe a series of limitations that must be considered when interpreting the results obtained, since they may have given rise to unknown biases.

The primary limitation is associated with the systematic literature review process itself. The limited selection of literature analyzed may not provide a comprehensive understanding of the differences in perceptions and beliefs regarding sex and sexuality derived from the participants’ cultural backgrounds. However, it does comprise a sample of 540 women from seven countries of the world with different realities, experiences and characteristics.

Another limitation was the lack of representation, since the sample of participants was entirely made up of cisgender women and dissident sexual orientations were underrepresented. Therefore, for future research, it is recommended to pay attention to this aspect, seek a more diverse sample of participants, and give a voice to the LGTBIQ+collective with intellectual disabilities.

Conclusions: Policy Implications

Thanks to the systematic literature review conducted and the resulting findings, it has been possible to derive four main conclusions that are further developed below, all of which are related to *social and public policy implications.*

This study provides results in terms of the knowledge, or lack thereof, that we have regarding the topic; so, the first conclusion that has been drawn from the current systematic review of literature is the need to investigate the socio-affective relationships of women with intellectual disabilities. Many of the studies were discarded for not undertaking research from the point of view of the collective of women with intellectual disabilities, so we want to remember the need for and importance of listening to the voices of these women. Research into their opinions, experiences, and needs has the potential to contribute to the improvement of the lives of this group—a group which is doubly punished and vulnerable by jointly suffering both as women and also as people with intellectual disabilities. The results of this study not only show the need for research but also suggest that the women in the studies analyzed have significant problems when it comes to developing positive sexual identities. Research shows that women with intellectual disabilities often have negative perceptions regarding sex and sexuality, often leading to self-imposed abstinence based on fear of relationships or intimacy.

Therefore, the first implication is related to the need for a continuous affective-sexual education beyond the schooling stage. The support and knowledge must adapt to the different phases and life challenges faced by the users of this service and break with the traditional health model of sex education. This study highlights that, in addition to the prevention of risks and contraceptive methods, socio-affective issues need to be addressed, working on self-esteem, sensuality, limits, homosexual relationships, and gender scripts, among others.

The second conclusion shows the need to make room for dissident forms of sexuality and gender within affective-sexual education. On the one hand, it is important to work on the issue of gender and the roles associated with it, since there is a tendency to see women with intellectual disabilities as “not real women” who do not experience gender-related issues, but as eternal children or people without gender. However, for some women, gender becomes a point of resistance to fight against restrictive ideas about their disability. It has been possible to see how not only alternative gender scripts create these places of resistance, but that women who voluntarily choose to follow traditionally female gender scripts also perceive them as valuable and productive. On the other hand, it is necessary to create awareness and knowledge about dissident sexualities and genders. This must be done in such a way that these are not an “extra” or something out of the ordinary but treating them in an interwoven way with traditional constructs both in research and in practice. In addition, it has been found that women with intellectual disabilities, in general terms, are less aware of these types of relationships and identities and that they harbor more traditional and stereotyped beliefs, sometimes even negative, towards them than the general population. This makes it clear that there is a need to address this issue, as well as the issue of gender in affective-sexual education raised previously. Finally, the need to conceptualize sex education in this way is emphasized to promote the social identification of LGBTIQ + women within the group of women with intellectual disabilities to end the invisibility and internalized homophobia that they suffer in some cases.

Thirdly, this literature review also aims to highlight the importance of creating and distributing accessible information on topics related to affective-sexual relationships. The need for information on dissident sexualities, contraception, or abuse support structures is revealed through the articles investigated. It also stresses the need for services as intermediaries and distributors of this information, since if it is created but does not reach the target group, the effort to create adapted information using images and easy-to-read texts would have been in vain.

Finally, this review suggests developing and enhancing training for the family, for services and the creators of policies related to the socio-affective relationships of women with intellectual disabilities. The negative vision that society frequently has towards the socio-affective relationships of people with intellectual disabilities is added to the tendency to restrict the sexuality of women in general. This fact ends up affecting not only the perceptions of these women but also the knowledge, resources, and supports they can count on. This is why we want to emphasize the importance of training for the people and institutions that accompany them so that they do not perpetuate these trends and attitudes. It has been seen that these behaviors often come from an attempt to protect the women against unpleasant experiences since it is a group that is particularly vulnerable to harassment, abuse, and mistreatment. However, sometimes this idea has led to the curtailment of these women’s freedom of sexual expression. This review contributes to highlighting the need to provide women with better defense mechanisms. For this reason, it is necessary for professionals and families to receive training that enables them to accompany women with intellectual disabilities in a positive way in their affective-sexual relationships. This support must be based on the idea that they, with the necessary aids and resources, are able to prevent negative sexual consequences and develop safe, healthy, affective-sexual relationships.

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Declarations

Ethics Approval This study was performed in line with the principles of the Ethics Committee's normative. Approval was granted by the Ethics Committee of the University of Girona (April 25th, 2022/No. CEBRU0009-22).

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Competing Interests Not applicable.

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13.2 Las relaciones afectivo-sexuales de las personas con discapacidad intelectual. Apoyos y barreras desde la perspectiva de personas con discapacidad intelectual (Artículo 2)

Abstract

Introduction This research focuses on the barriers and supports that influence the development of affective-sexual relationships as perceived by a group of people with intellectual disabilities.

Method 14 adults with intellectual disabilities participated in the study, and focus groups were conducted over 4 sessions. These were recorded and transcribed. The results were grouped into 7 themes: policy, professionals and services, families, friends, partners, the disabled people themselves and society.

Results Participants criticise the lack of knowledge about disability policy; they emphasise that they do not receive enough support from professionals, while describing the rules of support services as limiting; families are perceived as conditioners of sexuality; they highlight the difficulty of forming friendships and denounce society's prejudices, among others.

Discussion In recent years there has been a paradigm shift towards recognising the right of people with intellectual disabilities to have intimate relationships, but they continue to face denial of their "intimate citizenship". Analyses and changes in different areas of people's lives are proposed in favour of greater respect for CRPD rights, especially in relation to sexuality.

Keywords: *Intellectual disability, affective-sexual relationships, sexuality, inclusive research.*

Marco teórico

El bienestar es un concepto intangible que varía dependiendo de la percepción de cada persona. Aun así, en rasgos generales, puede describirse como la manera en la que se siente una persona mental, física, social y medioambientalmente, interactuando cada aspecto con los demás y variando su impacto según la persona (Kiefer, 2008). Las Naciones Unidas establecen la promoción del bienestar de todas las personas como uno de sus objetivos para el 2030 (meta 3.4) (United Nations, 2020). Además, en la Convención por los Derechos de las Personas con Discapacidad (CDPD) esta misma institución aboga por garantizar la calidad de vida de las personas con discapacidad intelectual mediante la garantía de sus derechos (United Nations, 2006).

Un estudio desarrollado en el Reino Unido clasifica las descripciones de un grupo de adultos con discapacidad intelectual sobre la "buena vida" en cuatro categorías: las relaciones, la participación en la comunidad, la independencia y los planes de futuro (Scott et al., 2014). Esta investigación centra su atención en la primera de ellas, las relaciones, abordando de manera específica las relaciones afectivo-sexuales.

La sexualidad es un concepto amplio que abarca cuestiones cómo las identidades y roles de género, la orientación sexual, el erotismo, el placer, la intimidad, el sexo y la reproducción (World Health Organization, 2017). Se trata, además, de un aspecto que perdura durante toda la vida de la persona e influye en su calidad de vida (Verdugo et al., 2012). La sexualidad es una parte fundamental de la experiencia humana y por ello todas las personas, tengan o no discapacidad, buscan y desean la sexualidad (Frawley y O'Shea, 2019; Gil-Llario et al., 2022; Svae et al., 2022). Investigaciones previas indican que las personas con discapacidad intelectual dan importancia a establecer relaciones íntimas y subrayan su papel en la consecución de una "vida buena" (O'Shea y Frawley, 2020), además de ayudar a aumentar su independencia (Scott et al., 2014). Sin embargo, estas personas ven sus derechos en materia de sexualidad vulnerados (Frawley y O'Shea, 2019; Ignagni et al., 2016; Puyaltó et al., 2019; Scott et al., 2014). A menudo, este colectivo ve denegada la posibilidad de mantener relaciones, querer o tener hijos y cuidar de ellos (Ignagni et al., 2016). Frawley y O'Shea (2019) remarcan la opresión que sufren en relación con su intimidad y dignidad, y Jaramillo (2017) por los prejuicios que relacionan la discapacidad con el hecho de ser incompetente, incapaz o asexual. Se trata de situaciones que dificultan e incluso pueden imposibilitar el desarrollo de una autonomía sexual (Retznik et al., 2021).

Cabe remarcar que, a menudo, las investigaciones cuentan por un enfoque ciego al género, ignorando los patrones de desventajas sociales relacionados al género (Frohmader, 2014; Peta et al., 2017), pensando que las experiencias de las personas con discapacidad intelectual no están marcadas por este (Björnsdóttir et al., 2017; O'Shea & Frawley, 2020). Aun así, diversas investigaciones apuntan a una visión marcada por estereotipos de género que marca la sexualidad de los hombres como peligrosa por su "hipersexualidad" y a las mujeres como sujetos a proteger del abuso sexual y maternidades no deseadas (Bahner et al., 2024; Starke et al., 2016).

Aunque un estudio realizado en España concluyó que la mayoría de adultos con discapacidad intelectual sentían interés por la sexualidad y un 96,4% de ellos tenían o habían tenido parejas (Gil-Llario et al., 2017), la literatura acerca de esta área vital es todavía escasa (Autores et al., 2023; Gil-Llario et al., 2017; Siebelink et al., 2006; Stoffelen et al., 2018). Además, es común que se investigue el tema desde la perspectiva de familiares o profesionales, sin tener apenas en cuenta las voces de las personas con discapacidad intelectual (Stoffelen et al., 2018). Algunas excepciones son los estudios de Azzopardi-Lane y Callus, 2015; Azzopardi Lane et al., 2019; Brown y McCann, 2018, que investigan los puntos de vista de mujeres y hombres con discapacidad intelectual sobre la sexualidad; los de Puyaltó et al (2022); Retznik et al(2021); Rojas et al (2015); Siebelink et al (2006) sobre las relaciones afectivo-sexuales; y los de Svae et al (2022) sobre el sexo y las relaciones con la privacidad y los límites personales. En Mattila et al (2017) se investigan las perspectivas de las personas con discapacidad sobre el amor. Algunos estudios se han centrado en las perspectivas de mujeres con discapacidad intelectual sobre las relaciones LGTBIQ+ (Burns y Davies, 2011; Stoffelen et al., 2018), las relaciones afectivo-sexuales (Beltran-Arreche et al., 2023), así como el sexo y la sexualidad (Bernert, 2011; Fitzgerald y Withers, 2013; O'Shea y Frawley, 2020). Los resultados de estos estudios apuntan las principales barreras a las que se enfrentan las personas con discapacidad para gozar de una vida afectivo sexual deseada. Entre estas, destacan los estereotipos y falsas creencias que niegan las oportunidades sexoafectivas (Azzopardi Lane et al., 2019; C. Azzopardi-Lane & Callus, 2015; Beltran-Arreche et al., 2023; Retznik et al., 2021); la escasa e inapropiada educación sexual recibida (Abbott & Burns, 2007; Beltran-Arreche et al., 2023; Fitzgerald & Withers, 2013; Retznik et al., 2021; Rojas Pernia et al., 2015; Siebelink et al., 2006; J. M. T. Stoffelen et al., 2018; Svae et al., 2022); y la falta de oportunidades para tener espacios íntimos y relaciones afectivosexuales (Azzopardi-Lane & Callus, 2015; Azzopardi Lane et al., 2019; Bernert, 2011; Brown & McCann, 2018; Retznik et al., 2021; Stoffelen et al., 2018).

Las personas con discapacidad intelectual aportan una perspectiva única en el análisis de las barreras que les dificultan gozar de unas relaciones afectivo-sexuales que contribuyan a su bienestar personal y con ello, a una mejor calidad de vida. Profundizar en dichas barreras, y en los apoyos percibidos como palancas de mejora, partiendo de las experiencias y opiniones de las propias personas con discapacidad debe permitir tomar conciencia de los cambios necesarios a implementar, a distintos niveles, en nuestro contexto, para mejorar la calidad de vida de estas personas. Esta es la base que orienta la investigación presentada en este artículo, en el que se analizan las percepciones de un grupo de personas con discapacidad que son miembros de un Consejo Asesor que colabora en investigaciones sobre discapacidad sobre las barreras y facilitadores (o apoyos) que inciden en el desarrollo de sus relaciones afectivo-sexuales.

Método

La investigación desarrollada se ha llevado a cabo desde el planteamiento de la investigación inclusiva (Walmsley et al., 2018; Walmsley & Johnson, 2003). Este enfoque de investigación parte del reconocimiento del derecho de las personas con discapacidad a participar en las investigaciones sobre temas que las afectan y de la valoración de sus experiencias en la vivencia de la discapacidad. La investigación inclusiva busca incidir en la transformación de las prácticas educativas y sociales y debe contribuir a la inclusión social de las personas con discapacidad (Walmsley et al., 2018), incidiendo en la mejora de las condiciones de vida a través de la defensa de sus derechos (García Iriarte et al., 2014; Johnson et al., 2014). Desde hace más de dos décadas se han desarrollado a nivel internacional investigaciones con personas con discapacidad intelectual siguiendo este modelo. En estas investigaciones las personas con discapacidad han ejercido funciones como asesoras, co-investigadoras o líderes de los procesos de investigación (Bigby et al., 2014).

El Grupo de Investigación (anonimizado) creó en (anonimizado) un Consejo Asesor formado por personas con discapacidad intelectual que han ido desarrollando su función participando como asesoras, co-investigadoras o liderando investigaciones sobre asuntos que son de su interés (Autores et al., 2022). El acceso al Consejo Asesor es libre y cada año pueden incorporarse todas aquellas personas que así lo deseen, sin ningún tipo de proceso de selección, con el único requisito de tener autonomía para desplazarse hasta la universidad y poder comunicarse oralmente. Durante el curso 2022-23 el Consejo Asesor decidió llevar a cabo una investigación inclusiva sobre qué elementos ayudan a tener una "vida buena". A partir del mes de marzo el grupo decidió centrar su trabajo en las relaciones afectivo-sexuales como elemento importante para tener una vida buena. El trabajo se llevó acabo entre marzo y julio de 2023. Finalizada la investigación, el Consejo Asesor decidió difundir los resultados a través de una exposición de posters, que fueron elaborados con el apoyo de las investigadoras (WEB) con el objeto de difundir la investigación a profesionales y servicios, familiares, otras personas con discapacidad, y ciudadanía del territorio. Este artículo, elaborado por las investigadoras, constituye la acción de difusión acordada con el Consejo Asesor para diseminar los resultados al colectivo profesional e investigador. El estudio se enmarca en una investigación sobre la sexualidad de las personas con discapacidad intelectual aprobada por el Comité de Ética de la universidad (Ref. Comité de ética: CEBRU0009-22).

Participantes

Durante el curso 2022-23 el Consejo Asesor estuvo formado por 12 personas de entre 24 y 72 años (6 mujeres y 6 hombres) que participaron regularmente en las reuniones, de los cuales 7 trabajan en una empresa ordinaria, 4 trabajan en un centro ocupacional y 1 no trabaja; en cuanto a la situación residencial, 6 viven en el hogar familiar, 3 viven de forma independiente con apoyos y otros 3 viven en un hogar tutelado. En la Tabla 1 se detalla el perfil de cada uno de los participantes.

Tabla 1: Perfil de los participantes en el estudio.

Participante	Edad	Experiencia con relaciones de pareja	Situación laboral	Residencia
1	24	No	Trabaja	Hogar familiar
2	25	No	No trabaja	Apoyo personalizado en el propio hogar

3	34	Sí	Trabaja	Hogar familiar
4	29	No	Centro ocupacional	Hogar familiar
5	72	Sí	Centro ocupacional	Hogar tutelado
6	64	Sí	Centro ocupacional	Hogar tutelado
7	35	Sí	Trabaja	Hogar familiar
8	31	Sí	Trabaja	Hogar familiar
9	38	Sí	Trabaja	Apoyo personalizado en el propio hogar
10	52	Sí	Trabaja	Apoyo personalizado en el propio hogar
11	40	Sí	Trabaja	Hogar familiar
12	61	Sí	Centro ocupacional	Hogar tutelado
13	?	Sí	Trabaja	Propio hogar
14	?	Sí	Centro Especial de Empleo	Propio hogar

Instrumento

El instrumento seleccionado para la recogida de información fueron los grupos de discusión que se realización durante las 4 sesiones de trabajo con el consejo asesor. Los grupos de discusión favorecen la creación de un entorno de confianza en el que los participantes pueden exponer sus puntos de vista (Krueger & Casey, 2009).

En estos grupos de discusión los asesores debatieron sobre las barreras que las personas adultas con discapacidad intelectual encuentran para establecer relaciones afectivo-sexuales y hacer propuestas de mejora que permitan cambiar y eliminar dichas barreras.

Procedimiento

El Consejo Asesor se reúne habitualmente una vez al mes, en sesiones de 2 horas de trabajo. Para realizar esta investigación se llevaron a cabo 4 reuniones (Tabla 2).

Tabla 2: Reuniones realizadas para realizar la investigación.

Reunión	Fecha	Participantes	Estructura y temas de la reunión	Material
1	02/03/2023	12 participantes divididos en dos grupos.	Contextualización del tema de la buena vida y las relaciones afectivo-sexuales. Trabajo en 2 grupos de discusión para explorar qué ayuda y qué no ayuda a establecer relaciones afectivo-sexuales.	Notas tomadas de los dos grupos de discusión. Grabación en audio de los dos grupos de discusión.
2	16/03/2023	12 participantes.	Puesta en común de las idees de los dos grupos de discusión de la sesión 1. Presentación de la investigación Rojas Pernia *et al.* (2015) y contraste con aportaciones previas.	Grabación en audio de la sesión.
3	27/04/2023	11 participantes divididos en dos grupos	Exposición de las aportaciones de las dos reuniones previas. Explorar acciones de mejora que puedan ayudar a cambiar y eliminar barreras. Explorar posibles acciones de difusión del trabajo realizado.	Notas tomadas de los dos grupos de discusión. Grabación de los dos grupos de discusión.
4	25/05/2023	9 participantes divididos en 2 grupos	Distribuidos en dos grupos, los participantes seleccionan textos que recogen las principales contribuciones de las reuniones previos.	Grabaciones del trabajo resultante de los grupos y los textos elaborados.

En la reunión del mes de marzo el Consejo decidió que quería trabajar el tema de las relaciones afectivo-sexuales y el trabajo finalizó en mayo. Los participantes firmaron al inicio del curso un documento de consentimiento informado en el que las personas manifestaron su voluntad de participar en las reuniones del consejo asesor. Se les informó de que la información que proporcionaran en las sesiones sería tratada de forma confidencial y que si se acordaba la publicación de trabajos derivados de la actividad del consejo asesor serían consultados y los datos proporcionados sería anonimizados.

Una investigadora académica, en cada uno de los grupos creados en las distintas sesiones, dinamizó el trabajo de los grupos. Se prepararon materiales de apoyo para facilitar la organización de la discusión. Después de la primera y tercera sesión se elaboraron presentaciones organizando las ideas por temas que sirvieron para recordar lo que se había trabajado en la anterior sesión. En la segunda sesión se preparó una presentación de la investigación de Rojas et al (2015).

Análisis de datos

Los audios de los grupos de discusión fueron transcritos. Se llevó a cabo un análisis de contenido temático de las transcripciones, con el apoyo de las notas tomadas y puestas en común en las distintas sesiones. Las autoras siguieron los principios de buenas prácticas sugeridos por Braun y Clarke (2021). Una vez hechas las transcripciones se codificaron y se agruparon por temas. Este proceso se realizó para cada sesión puesto que el análisis era la base para seguir con la discusión. Así, las barreras y facilitadores de las relaciones afectivo-sexuales se organizaron finalmente en los siguientes temas: las políticas, los profesionales y las organizaciones que prestan servicios a personas con discapacidad intelectual, la familia, las amistades, la pareja, la propia persona con discapacidad y la sociedad.

Resultados

A continuación, se presentan los hallazgos más relevantes de la investigación, de acuerdo con los temas indicados. Se aportan referencias textuales extraídas de los grupos de discusión para complementar y profundizar en los distintos temas, indicando en cada caso de qué grupo de discusión se trata.

Política

Los participantes identifican como principales barreras el desconocimiento de la discapacidad y de las necesidades diferenciadas que experimentan las personas con discapacidad y la falta de interés de los representantes políticos en escuchar las demandas de las personas con discapacidad. Valoran que una mayor representación de las personas con discapacidad en partidos políticos y en la propia administración contribuiría a un mejor conocimiento de sus necesidades y derechos. Además, perciben que es necesario una intervención a nivel de política social para mejorar ciertas prácticas de apoyo que no se alinean con los derechos de las personas con discapacidad en el ámbito de la sexualidad:

> *P6: "Se deberían hacer leyes que dieran derechos en temas de sexualidad a las personas con discapacidad. Porque nos encontramos con casos de asociaciones y fundaciones que no dejan tener relaciones… O familias que no dejan tampoco que las personas con discapacidad tengan relaciones" (GD1)*

Profesionales y servicios

En cuanto a las barreras, los testimonios de los participantes indican, en primer lugar, que en muchos casos no encuentran en servicios y profesionales la voluntad de escuchar y dar respuesta a las demandas que realizan en el ámbito de la sexualidad:

> *P10: "Yo creo que no se quieren involucrar en estas cosas. No quieren ser intermediarios con los padres y todo esto" (GD 1).*

Las normas de funcionamiento interno de ciertos servicios de apoyo dificultan, o directamente impiden, las relaciones de las personas usuarias. Las personas perciben que sus vidas están controladas, y sus relaciones condicionadas por situaciones como la falta de espacios íntimos, la imposición de momentos y tiempos para estar con la pareja, o la prohibición de invitar al hogar donde viven a otras personas. Mencionan reiteradamente que las condiciones vinculadas con la institucionalización de sus vidas, en el caso de los residentes en hogares tutelados, dificultan el ejercicio de muchos de sus derechos, y concretamente las relaciones afectivo-sexuales.

> *P2: "Es que es imposible. Tendría que haber más profesionales. O menos personas, o más educadores. Que puedan estar más por nosotros. Por los problemas que tenemos. Que no lo están." (GD3).*
>
> *P12: "Tenemos una horita para estar juntos (…) que es de nueve a diez de la noche. En esta hora podemos hablar y estar sentados juntos allí al comedor (…) No podemos ir a la habitación." (GD 1.2.)*
>
> *P6 (Cuando se pregunta si hay personas que tengan parejas de fuera del piso-residencia en el que viven): "No, porque no nos dejan tener (relaciones) de fuera del piso" (GD 1.2)*
>
> *Critican que profesionales y servicios toman decisiones en nombre de la persona, sin consultar ni tener en cuenta su opinión.*
>
> *P14: "Si eres menor de edad se entiende que haya una persona de apoyo que te impida hacer cosas por la posibilidad de que tengas problemas, como quedarte embarazada (se refiere a embarazo no deseado) (…) pero cuando eres mayor de edad, ¿qué? (…). La pareja, los dos, son los que deben decidir si quieren tener sexo" (GD 2)*

Además, a veces no se sienten suficientemente escuchados, por lo que no tienen la confianza necesaria con los profesionales de apoyo para preguntar aspectos relacionados con la sexualidad.

Valoran, por lo tanto, que un apoyo necesario desde el ámbito de profesionales y servicios es disponer de una persona de apoyo que les ofrezca confianza para poder plantear cuestiones vinculadas a la sexualidad:

> *P12: "(…) si no tienes confianza con el profesional, no expresas según qué cosas. y si no expresas según qué cosas, no te pueden ayudar o aconsejar" (GD 3.2)*

Indican que posiblemente una persona del mismo género permitiría establecer una relación de mayor confianza:

> *P2: "Para mí es más cómodo hablar con una persona del mismo sexo. Es más fácil (…) quizás para la profesional también será más fácil" (GD 1)*

También reclaman una educación sexual "que se entienda" (accesible), que permita tomar decisiones sobre todo lo relacionado con la sexualidad, como por ejemplo los anticonceptivos:

> *P8: "Yo pondría también a los servicios a darnos información, porque, por ejemplo, yo cuando empecé a tener relaciones sexuales no se me informó de qué clase de anticonceptivos había, donde tenía que ir (para obtener información), y si debía ir a un ginecólogo porque nadie me lo había explicado" (GD 1.1)*

Además, indican que servicios y profesionales deberían ofrecer oportunidades para poder gozar de espacios de intimidad.

Por último, reclaman un trato personal no infantilizador, ser tratadas como personas adultas.

Familia

La familia es percibida como un ámbito que condiciona en gran medida el disfrute de la sexualidad. Los participantes relatan experiencias personales en las que las familias han influido negativamente en sus relaciones, sea por no aceptar la relación o la pareja, o por intentar imponer ciertas condiciones:

> *P8: "Mi madre me ha dicho muchas veces que yo no puedo tener una pareja que no tenga discapacidad" (GD 1.1)*

Se percibe como una barrera el hecho de que desde el ámbito familiar no se ofrezca información suficiente ni adecuada sobre la sexualidad, ni tampoco se genere la confianza necesaria para poder intercambiar opiniones sobre el tema. Ello les obliga a buscar y obtener información por su cuenta, utilizando otros medios:

> *P13: "En mi caso no me han dado información. Yo he estado preguntando por fuera, no por mi madre porque con ella es imposible" (GD 1.1)*

Al igual que en el caso de los profesionales y servicios, los participantes se sienten controlados, en este caso, por la familia. La familia impone normas y toma decisiones sin consultarles, lo que afecta directamente su vida sexual y sus relaciones íntimas.

- *P3: "Lo que yo debo hacer es tomarme las pastillas (refiriéndose a que lo que debe es hacer lo que sus padres dicen)"*
- *P2: "Pero eso es algo que tus padres no pueden decidir por ti. Al fin y al cabo, debes ser tú, no tus padres los que te prohíban tener sexo"*
- *P3: "Pero yo vivo con mis padres y no puedo hacer nada"*
- *P2: Tus padres no tienen por qué decirte que no, porque es una cosa que tu deseas.*
- *P10: A veces se pone de por medio la suegra también…*

(GD 1.2)

En algunos casos, la familia prohíbe tener relaciones sexuales; en otros les prohíben tener hijos.

- *Investigadora: "Tus padres te lo prohíben (tener relaciones sexuales)?"*
- *P3: "Sí, sí"*
- *P2: "Pero ¿tú tienes ganas, en este caso?"*
- *P3: "Es muy difícil porque mis padres me dicen eso"*
- *Investigadora: "¿Y te dicen que está prohibido?"*
- *P3: "Si quieres tener parejas o novio o el que sea, sí que puedes hacerlo, pero ¿el sexo? Eso es una cosa que puedes quedarte embarazada y tener hijos y eso mis padres no"*

(GD1.1)

> *P8: "Yo me tuve que imponer en este aspecto, por lo que me decían con mi primera pareja… Recuerdo que me decían que tener pareja si pero relaciones sexuales que ni se me ocurriese!" (GD 1.1)*

> *P8: "Yo, por ejemplo, mi madre siempre me ha dicho que no puedo tener hijos porque tengo discapacidad (…) Hay mucha gente con discapacidad que tiene criaturas. ¿Por qué yo no puedo tener?" (GD 2).*

En cuanto a los apoyos correspondientes al ámbito familiar, las personas participantes coinciden a reclamar apoyos basados en la escucha, consejo y facilitar información para que puedan tomar decisiones informadas:

> *P 2: "A la larga, la sexo-afectividad como en la vida independiente… no sabemos hacer nada. (…) si me proteges de esta forma, me estás dando a entender que no sabré hacer nada. Déjame hacer, ¿sabes? (…) Yo lo que necesito es eso, que no me protejan tanto. Cuando era pequeño sí, pero ahora ya no" (GD 3.2)*

También apoyo en aceptar y respetar a la pareja. y que la familia no ponga trabas a vivir con la pareja, y que no controlen ni la sexualidad ni impongan que no puedan tener hijos.

Amistades

En cuanto a las amistades, una de las barreras que se menciona es la dificultad para poder establecer y mantener una red de amistades:

> *P4: "No tener amigos, no ayuda… cuesta más conocer otra gente" (GD1.2)*

También indican que a veces puede ser una barrera las dificultades para diferenciar una relación de amistad con una relación de pareja, es decir, con una persona con la que tener una relación íntima:

> *P 10: "Saber diferenciar cuando es amistad y cuando es algo sexual. Esto puede ser negativo, porque puede haber problemas y confusiones".*

En cuanto a los apoyos, se valora las amistades la ayuda en los buenos, pero sobre todo en los malos momentos que afectan las relaciones de pareja.

> *P11: "Los amigos me ayudaron cuando dejé a la pareja. Todos me apoyaron" (GD 1.1.).*
>
> *P14: "(…) Cuando tienes momentos de bajón o que tienes momentos de estos que lo dejas con la pareja y todo, ¿sabes? Cuando tienes problemas, sabes quién está y quién no está" (GD 2)*

Disponer de amistades con las que poder hablar en confianza de las relaciones sexo-afectivas se valora como en elemento facilitador.

Pareja

La propia pareja es analizada como un factor que en ocasiones puede dificultar las relaciones. Valoran el respeto y la comunicación, que se compartan momentos y gozar de manifestaciones de afecto.

- *P9: "Bueno, (…) creo que lo más importante en una relación romántica es la comunicación y el respeto, porque si no hay comunicación y respeto, la relación no es buena, ¿no?"*
- *P14: "Aceptar sus aficiones y compartir y convivir con el que le gusta a una persona, convivir con eso. Y así, la otra persona también puede convivir con el que le gusta al otro"*
- *P9: "Las manifestaciones afectivas. Hacer un cumplido ¿sabes? (…) Yo, la verdad, me gusta mucho dar abrazos, me gusta dar besos y creo que es una buena manera de…"*
- *Investigadora: "¿De que la relación vaya por buen camino?"*
- *P9: "Sí"*
  (GD1.2)

La propia persona

En el ámbito estrictamente personal, los participantes en la investigación han identificado ciertos aspectos individuales que dificultan sus oportunidades para gozar de la sexualidad. Son conscientes, en primer lugar, de las actitudes de rechazo que genera la condición de ser una persona con discapacidad.

> *P2: "También la discapacidad hace mucho porque yo tengo ganas de conocer gente, de tener pareja, y en muchos casos me pasa que les digo que soy así (se refiere a la discapacidad) y se quedan de piedra (…) Ah, ¿porque soy un discapacitado soy un bicho raro? Pues no" (GD1.1)*

Como apoyos indican la información acerca de la sexualidad. También la propia actitud juega un papel importante en el sentido de estar abierto a tener una relación, por todo lo que implica en establecer nuevas dinámicas no sólo personales sino también sociales:

> *P12: "Cuando tienes pareja conlleva más relaciones, ¿no? Porque hay su familia, sus amigos, y tienes más vida social. (GD 2).*

Se indica la importancia de tener una actitud proactiva: tener iniciativa para preguntar dudas, solicitar información y, en definitiva, aprovechar los espacios y personas de confianza para poder hablar de la sexualidad. Consideran que tener autoestima contribuye a disponer de mayores oportunidades para tener relaciones sexo-afectivas.

> *P9: "Yo creo que primero de todo, la autoestima es muy importante. Porqué si tienes baja autoestima, aunque estés muy a gusto con una persona… tienes que quererte a ti mismo antes de querer a otra persona" (GD 1.2).*

La autodeterminación también es básica para poder luchar por los propios derechos. Y tomar decisiones sobre la sexualidad y las relaciones

Sociedad

Las personas participantes denuncian como principal barrera social los prejuicios que perciben a través de las actitudes de otras personas en su interacción social:

> *P8: "Hay personas, por ejemplo, que piensan que el sexo con personas con discapacidad (…) es raro, que está mal visto." (GD 2)*

Reconocen que la sociedad tiene dificultades para aceptar relaciones de tipología diversa. Sienten que se percibe que las personas con discapacidad sólo pueden tener relaciones afectivas y sexuales con personas que tienen una discapacidad, y que se les cuestiona su capacidad para convertirse en padres o madres. También valoran que las mujeres con discapacidad pueden tener dificultades añadidas.

> *P7: "Yo he tenido parejas, todas ellas con discapacidad, pero, ¿qué pasa si me enamoro de una persona que no tiene (discapacidad) o ella (se enamora) de mí? ¿qué pasa? No pasa nada" (P8) "Lo que importa es que sea buena persona para ti y que no te haga daño" (GD 2)*

La escasa representación de las personas con discapacidad en los espacios sociales se percibe como otra barrera al impedir que la ciudadanía pueda disponer de oportunidades para visualizar el potencial de las personas con discapacidad en cuanto a contribuciones sociales.

En las discusiones se enfatiza que, para transformar esta visión social repleta de prejuicios, es importante que la sociedad tenga mayor conocimiento de la discapacidad. Para ello, es necesario que desde los servicios de apoyo se promocione la participación comunitaria de las personas con discapacidad:

> *P 2: "Yo propongo que nos ayuden a hacer actividades para poder conocer mejor a la gente. Y así tener un entorno más amplio. No tanto rodearnos de personas con discapacidad, sino con personas que no tienen discapacidad" (GD 3.2)*

Un mayor conocimiento genera mayor empatía:

> *P9: "Que se pongan en la piel de una persona con discapacidad" (GD3.1.)*

Además, deben establecerse acciones para que la sociedad reconozca los derechos de las personas con discapacidad, y entre ellos el derecho a disfrutar de la sexualidad. Finalmente, uno de los participantes expone que sería de ayuda la existencia de aplicaciones de citas o búsqueda de pareja para personas con discapacidad.

Discusión y Conclusiones

Aunque los últimos años han mostrado un cambio de paradigma hacia un modelo centrado en las personas que reconoce el derecho de las personas con discapacidad intelectual a tener relaciones afectivo-sexuales (Ionescu et al., 2019), este colectivo se continúa enfrentando a numerosas barreras para tomar decisiones sobre su vida afectivo-sexual (Puyaltó et al., 2022).

Los resultados de la investigación, en los apartados coinciden con los de investigaciones previas realizadas tanto en nuestro país (Puyaltó et al., 2022; Rojas Pernia et al., 2015) como en el ámbito internacional (Bernert, 2011; Fitzgerald & Withers, 2013) en las que participantes con discapacidad intelectual reflexionan sobre las barreras que se encuentran en los ámbitos correspondientes a organizaciones y profesionales, y familia. En este sentido, las principales dificultades señaladas son las medidas restrictivas que dificultan espacios de intimidad, y las prohibiciones que impiden las relaciones. A nivel social, los resultados del presente estudio se alinean con investigaciones anteriores que señalan la incidencia negativa de los prejuicios y creencias sociales en las oportunidades de gozar de relaciones afectivo-sexuales deseadas (Azzopardi Lane et al., 2019; O'Shea & Frawley, 2020). La realización de varios grupos de discusión secuenciales ha permitido profundizar en las perspectivas de las personas con discapacidad participantes en dimensiones que complementan la mayoría de las investigaciones previas. Así, a nivel político, se han aportado condicionantes y propuestas de mejora dirigidas a incrementar la representación de las personas con discapacidad en partidos políticos y en la propia administración, además de incidir en propuestas legales que potencien políticas sociales realmente alineadas con los derechos de las personas con discapacidad, y que por tanto puedan contribuir a superar las barreras detectadas en los servicios sociales, en los profesionales de apoyo, y en las propias familias. A nivel individual, a diferencia de Brown y McCann (2018) no se acusa la posible vulnerabilidad generada por la discapacidad, pero sí que las personas participantes indican que la condición de discapacidad (el estigma asociado) puede influir en la creación de parejas y en la propia vivencia de las relaciones sexuales. En este sentido, indican la necesidad de una autoestima suficiente, a la que sin duda contribuye una educación sexual accesible, suficiente y adecuada.

De las observaciones de las personas participantes se extrae la necesidad de superar las visiones y creencias tradicionales sobre la sexualidad de las personas con discapacidad intelectual (Scott et al., 2014), contando con apoyos a distintos niveles: a nivel político para asegurar que los servicios y profesionales desarrollen apoyos ajustados a los derechos; a nivel de profesionales, servicios y familias, garantizando relaciones de confianza que permitan plantear demandas de apoyo personalizados, y la adecuada y accesible educación sexual.

Además, teniendo en cuenta las dificultades para poder gozar de una red social de apoyo diversa (English et al., 2017; Puyaltó et al., 2022), profesionales y familias pueden contribuir a unas buenas relaciones afectivo-sexuales creando oportunidades de relación en entornos inclusivos, y concretamente desde espacios de participación comunitaria, para establecer y fortalecer las redes personales de apoyo que pueden acompañar desde la confianza a sus integrantes en su recorrido relacional, incluyendo las relaciones afectivo-sexuales.

La mala situación del apoyo social en las vidas de las personas con discapacidad intelectual se refleja en la falta de amigos/as proveedores de apoyo, de entornos informales para que se desarrollen las relaciones y, en definitiva, la falta de interacción con variedad de personas, tal y como señalan tanto los estudios previos como la presente investigación. Esto provocan que los jóvenes con discapacidad intelectual, a menudo, no tengan más opción que acudir a sus familiares o a profesionales cuando tienen algún problema o necesitan algún tipo de apoyo o ayuda (Beltran-Arreche et al., 2024; Puyaltó et al., 2022). De este modo, una intervención que puede mejorar su situación es la de crear o abrir espacios informales de relación en la comunidad. Para ello, en primer lugar, la población debe estar concienciada sobre la importancia de las relaciones de apoyo en la vida de las personas, y, en segundo lugar, abierta a incluir y respetar a las personas con discapacidad intelectual en diferentes ámbitos informales de la comunidad.

Además, para que las personas con discapacidad estén incluidas en la vida comunitaria, es necesario contar con el apoyo de las personas cuidadoras, tanto profesionales de apoyo como familias, prestando atención a sus actitudes, ya que estos son agentes mediadores entre las demandas de las personas con discapacidad y la “sobreprotección” (Rushbrooke et al., 2014). En este sentido, se debe procurar la formación en el campo de las relaciones afectivo-sexuales que favorezcan el cumplimiento de las demandas y derechos de las personas con discapacidad intelectual, permitiendo mayor libertad.

Un análisis en profundidad de las experiencias y opiniones de las personas con discapacidad intelectual sobre estas barreras y el apoyo que necesitan para poder disfrutar plenamente de sus derechos es esencial si se quieren transformar las prácticas de apoyo (Puyaltó et al., 2022).

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13.3 What do they think? The opinions of women with intellectual disabilities on affective-sexual relationships. An interview-based study (Artículo 3)

Abstract

Introduction It is a widely held assumption that women with intellectual disabilities are unable to express their sexuality freely due, in part, to a lack of research and information on the topic.

Aim The aim of this article was to discover the perspectives regarding affective-sexual relationships of a group of women with intellectual disabilities through their experiences and opinions.

Method Individual interviews were conducted and analysed thematically.

Results The results are divided into five areas: the LGTBIQ+ community; couple relationships; contraception and sex; abuse; and family and motherhood.

Discussion The participants perceive that their relationships are shaped by the unique challenges posed by their disability, often resulting in limitations from their families and professionals. Their accounts allowed us to compile a list of the support they deem necessary, such as adapted sex education; further research based on their experiences; the creation of specific resources; and raising general awareness in society.

Keywords *Intellectual disability; Women; Affective-sexual relationships; Support; Inclusion*

Lay summary

- Relationships of women with intellectual disability are marked by sexual ableism and prejudices.
- The barriers these women face can be overcome through support mechanisms and information.
- Women with intellectual disabilities construct their own idea of sexuality and experience it in ways that defy the dominant discourse.

Introduction

The Convention on the Rights of Persons with Disabilities defends the right to sexual identity and expression, marriage and co-habitation. It places the individual at the heart of the matter and aims to eliminate the barriers that they may face (United Nations, 2006). Despite the advances in the recognition of the rights of people with intellectual disabilities, their lives are affected by sexual ableism, defined by Mintz (2022) as individual attitudes, institutional policies and procedures that are based on reduced sexual expectations for people with disability. This both de-sexualizes them, by branding them as non-sexual or eternal children, and criminalizes them, through the idea that their sexuality is potentially dangerous and should not be awakened (Brown, 2017; Fish & Björnsdóttir, 2022; Hole et al., 2021; Löfgren-Mårtenson, 2013; Tamas et al., 2019; Wilson et al., 2016). The result of such attitudes result is the denial of their rights, and precludes them from being represented as sexual beings (McCarthy et al., 2020). Nonetheless, they have the same sexual needs and desires as other people, and it is equally important that they have the chance to satisfy them (de Wit et al., 2023; Friedman, 2023; Gil-Llario et al., 2022; Tamas et al., 2019).

While people with intellectual disabilities face these barriers irrespective of their gender, women encounter specific problems (O'Shea & Frawley, 2020). Whereas men are seen as hyper-sexualized, potentially dangerous beings, society views women with intellectual disabilities as potential victims of abuse and unwanted pregnancies, and lacking sexual desire (Bahner et al., 2023). For this reason, instead of focusing solely on gender, which ignores the patterns of gender-related social disadvantages (Frohmader, 2014; Peta et al., 2017), this article examines the experiences and perspectives of women with intellectual disabilities with the aim of understanding the particularities arising from gender.

The voices of those with a disability are often excluded from research in favour of others in their circle (Brown, 2017; Hole et al., 2021). However, if we let them share their experiences and opinions on sexuality, we give them an important tool in empowerment (Azzopardi-Lane & Callus, 2014). Thus the aim of this article is to listen to the voices and experiences of a group of women with intellectual disabilities, and discover how they view affective-sexual relationships, leading to the establishment of future support resources.

Methods

Participants

Prior to participation in this study, all subjects had completed a workshop on affective-sexual relationships. This was done to ensure a common understanding of the subject. The inclusion criteria for the aforementioned workshop were based on several key characteristics. Firstly, only women were invited, as the aim is to analyse the specific experiences of intersectional discrimination they face because of being women and having intellectual disabilities. Secondly, it was crucial that they were sufficiently motivated to actively participate and contribute to the discussions. Thirdly, they also needed to have sufficient time to attend the scheduled focus groups to ensure their commitment and the quality of their contributions. Finally, participants were required to be able to travel independently to the university where the focus groups would be held.

Researchers invited the nine women who had participated in the workshop to participate in the interviews. Some organisations in the territory that support people with intellectual disabilities assisted in disseminating information about the invitation, or facilitated contact with women who might be interested.

Seven women were interviewed for this study. All lived in region X, country Y (information eliminated to ensure anonymity), and had links to foundations that provide support for people with intellectual disabilities; and required intermittent or limited support. Table 1 shows their characteristics and the pseudonyms they chose to preserve their anonymity. The women were familiar with the subjects covered in the interviews, having previously attended a five-month-long fortnightly workshop on affective-sexual relationships in 2022 (author's name eliminated to guarantee anonymity).

Table 3: Characteristics of participants (n= 7)

	Name	Age	Personal Situation	Previous Partners	Sexual Orientation	Children	Work Situation	Level of Education Achieved
1	Lua	28	Has a partner, but does not live with him.	Yes	Heterosexual	No	Ordinary company	Mandatory Education
2	María	34	Has a partner, and lives with her.	Yes	Bisexual	No	Ordinary company	University Degree
3	Estrella	34	Has a partner, but does not live with him.	Yes	Heterosexual	No	Ordinary company	Mandatory Education
4	Ainhoa	37	No partner, lives alone with support at home.	Yes	Bisexual	No	Ordinary company	Mandatory Education
5	Toni	39	Has a partner, and lives with her.	Yes	Lesbian	Two with a previous male partner. She does not have custody of them.	Ordinary company	Mandatory Education
6	Lulú	46	Divorced, lives with one of her children.	Yes	Heterosexual	Two with a previous male partner. Both are adults, and one does not live at home.	Sheltered work setting	Mandatory Education
7	Helena	56	Divorced, lives with one of her children.	Yes	Heterosexual	Three with a previous male partner. All three are adults, and two do not live at home.	Sheltered work setting	Mandatory Education

Instrument

An interview was designed as it is particularly suited to gathering perceptions of the participants, and exploring the subjects covered in depth (Cohen et al., 2010). It was considered to be the best way meet the study's aims.

Seven semi-structured individual interviews were held, one with each of the participants. Following the introductory section, the interviews were structured in four blocks: affective relationships; family and motherhood; contraception and sterilization; and the LGTBIQ+ community. These were chosen following a systematic review of the literature on the affective-sexual relationships of adult women with intellectual disabilities (Authors deleted for anonymity), which identified them as key concepts. For each of the blocks, the women were asked about their previous training; experiences; sources of support; decision making; the barriers they have faced; and their requests. Table 2 provides examples of the questions in each of the areas.

Table 4: Examples of questions by area.

Area	Example question
Previous training	*Had you previously discussed the subject of the LGTBIQ+ community?* *If so, where?*
Experiences	*Do you think that having an intellectual disability has influenced your relations with your partner?* *Have you ever experienced any prejudice towards your sexuality?*
Decision making	*If you are a mother, or wish to be one in the future:* *Who made or will make this decision?* *Who or what has influenced the decision to take contraceptives?*
Sources of support	*Who do you ask if you need information regarding contraception?* *Are you aware of any specific support for mothers with intellectual disabilities?*
Barriers	*Have you ever faced a barrier when asking for information regarding contraception?* *Do you believe that there is prejudice towards the motherhood of women with intellectual disabilities?*
Requests	*What kind of support do you think necessary in order to form a family?* *How would you like information on the LGTBIQ+ community to be?*

Procedure

The first author telephoned the nine women who had attended the workshop on affective-sexual relationships and asked them to take part in the interviews (name of author eliminated for anonymity). The research project was presented to the women, outlining the objectives, methodology, issues to be addressed, and the nature of their participation. All questions related to the research process were answered. This information was given orally, with the support of easy-to-read documents. Two of the women refused the invitation; the seven who accepted had links to three organizations that provide support services to people with intellectual disabilities. They were given the choice of having the interviews in the university, guaranteeing a place that they knew and felt comfortable in, or any other location they trusted. All seven chose the university.

Before the interview began, an accessible informed consent form was either read out to the participant or they read it out themselves, depending on their preference. This covered information regarding anonymity, consent, and confidentiality, and used easily readable documents and images to facilitate comprehension. All participants signed the document once they said they had understood it and any doubts had been clarified. The project was approved by the Ethics Committee of the university (not named for anonymity), with a reference number (also not given).

The first author conducted the interviews, they ensured that all the women could freely answer the questions, and stressed that it was their decision whether or not to respond. Direct, clear language was used to aid understanding, and questions were reformulated when necessary (McFarland et al., 2024). While the questions followed a pre-established script, additional questions were asked when the interviewer felt that further information was needed. The interviews took place between January and March 2023 and lasted an average of 90 minutes.

In order to make the participants feel at ease, the interviews began with a simple preliminary question, such as "*What is your current relationship status?"* or *"What training have you had regarding affective-sexual relationships?".* More specific questions then followed on each of the blocks to gain a deeper understanding, such as *"What or who has helped you in the context of relations with partners?* or *"How can we improve the help given to mothers with intellectual disabilities?"*

Analysis

Once the interviews had finished, the first author transcribed the audio files and read the transcriptions closely in order to produce an initial coding of the interviews. Thematic content analysis was used to identify and analyse patterns in the data through reading and re-reading (Fereday & Muir-Cochrane, 2006). The authors followed Braun and Clarke's (2021) principles of good practice in thematic analysis.

The initial coding identified the following subjects: contraception and sex; family and motherhood; the LGTBIQ+ community; abuse; and relations with partners. The other two authors reviewed this coding, which led to the structural and descriptive coding of all seven transcriptions (Saldaña, 2009). In this second stage, words and short phrases were assigned to codify the transcriptions and identify themes and sub-themes. This was reviewed by authors two and three. Finally, all three authors compiled the definitive list of codes and sub-codes. Table 3 shows the subjects, codes, and sub-codes, ordered from greater to lesser frequency of mentions in the transcriptions.

Table 5: Subjects, codes, and sub-codes for thematic content analysis

	Subjects	*Codes*	*Sub-codes*
1	LGBTIQ+ community	*Training and knowledge regarding community*	*Sources of support*
			Information and training
			Experiences
		Discrimination	*Inequalities and prejudices*
			Information and training
			Perceptions
			Experiences
		Support for LGTBIQ+ people	*Sources of support*
			Information and training
2	Sexual Autonomy: Family Dynamics and the Need for Support	*Limitations for having a partner*	*Inequalities and prejudices*
			Sources of support
			Perceptions
			Experiences
		Support mechanisms	*Requests*
3	Contraception and sex	*Knowledge*	*Inequalities and prejudices*
			Information and training
			Requests
		Decision making	*Rights*
			Inequalities and prejudices
			Experiences

		Lack of opportunities	*Rights*
			Inequalities and prejudices
4	Abuse	*Violent partners and toxic attitudes*	*Inequalities and prejudices*
			Experiences
		Support and defence mechanisms in case of abuse	*Sources of support*
			Requests
5	Family and motherhood	*Forming of families*	*Inequalities and prejudices*
			Experiences
		Support for maternity	*Sources of support*
			Requests
			Experiences
		Access to family housing	*Inequalities and prejudices*
			Requests
			Experiences

Results

The results of the interviews are presented below in the same order as in table 3.

LGTBIQ+ community

The most frequently mentioned subject in the interviews was the LGTBIQ+ community; within this, the following codes were identified: *training and knowledge regarding the community; discrimination;* and *support for LGTBIQ+ people.*

Training and knowledge regarding the community

The participants had received little information and training on the subject of the diversity of sexual orientations and gender identities. Some degree of training had been given to three women by the foundation that provides them with support; and two of the three women, who both form part of the LGTBIQ+ community, said they had used the Internet to find information and better understand their own sexuality.

> *TONI: I searched and found information only because I realized I was what I was, and what I liked.*

The difficulty in finding information on the LGTBIQ+ community that could help them discover and understand gender identities and sexualities distinct from cisheteronormativity was referred to by three participants. The same difficulty arose regarding information that could aid them in understanding their own sexual orientation. The two bisexual women said that they had been unaware of the existence of bisexuality, and that being equally attracted to women and men had led them to feel confusion regarding their own sexuality; they said they had felt “lost” on not seeing themselves reflected in the models of homosexuality and heterosexuality that they were aware of. However, the women later discovered bisexuality and agreed that this, allied with feeling an identification with it, had been a great relief.

> *MARÍA: Well, there are things I’ve discovered recently. There were things I didn’t even know existed, like bisexuality. I didn’t know it existed. I thought it was something abnormal or wasn’t logical.*

Discrimination

The analysis of the interviews shows that the women are aware of the discrimination that LGTBIQ+ people face, and six of them noted that those with intellectual disabilities faced a dual discrimination if they formed part of the LGTBIQ+ community.

> *HELENA: Being LGTB and also having an intellectual disability, well, poor thing…if it’s only now that people are coming out, imagine that with an intellectual disability!*

Reference was made by two participants to the fact that society seems unable to imagine such a possibility, and assumes that people with intellectual disabilities are either non-sexual or heterosexual.

> *AINHOA: I think it’s hard for them to imagine it. They think it’s very strange that someone with an intellectual disability isn’t heterosexual. Because, if I tell them I have an intellectual disability and am also bisexual, it blows their minds!*

The sole lesbian in the study explained that she tended to avoid mentioning her intellectual disability when with LGTBIQ+ people for fear of being rejected.

> *TONI: You don’t know if they’ll accept you when they discover the truth. You don’t know if they’ll disapprove, or how they’ll treat you for having a disability. It’s better not to say anything than for them to know.*

Support for LGTBIQ+ people

The importance of counting on the necessary support to face the above-mentioned barriers was emphasized by six participants. When the three non-heterosexual women were asked about the support they had received, and the resources available when they came out, they highlighted the importance of support professionals working in the foundations; belonging to an LGTBIQ+ association; other female members of the community with intellectual disabilities; and the Internet.

> *AINHOA: I'd spoken on the Internet with other similar people, but the first person I told was my support professional. Then, a few years later, I told my sister, and then decided to tell my parents, but with my sister there.*

The support they would like available was mentioned by four of the women; this included specific programmes for people with intellectual disabilities who also form part of the community; more information on the subject; and emotional counselling, above all for those who did not have the support of their families.

> *HELENA: I think there could be support groups for people who are (LGTBIQ+), especially if they don't have the support from their family.*

Sexual Autonomy: Family Dynamics and the Need for Support

The second-most frequently mentioned theme was that of the relations with their partner; this was given two codes: *limitations for having a partner,* and *support mechanisms.*

Limitations for having a partner

The women felt that society was prejudiced and placed more barriers in their way, making their experiences in this field differ from those of their counterparts who had no disability.

In five of the interviews the women said they had faced more barriers than people with no intellectual disabilities; three of them mentioned the over-protection of relatives and support professionals; one of them said she felt pressured by her family and was considering either keeping her relationship a secret or going out with someone just to "irritate them".

> *AINHOA: I often feel I could go out with someone, but then I think "What will my parents say?" or "What will my sister say?" and that gets me down. Sometimes I think about this over-protection (…) But I feel that if they said no and couldn't give me a good reason, then I'd go out with this person just to annoy them.*

The fact that some of the group homes they knew separated couples or placed obstacles in the way of their intimacy was referred to by two of the participants. It is important to note that in the context of Spanish social services, group homes are collective living accommodations for individuals with disabilities, wherein they reside alongside their peers and receive assistance 24 hours from professionals.

> *LULÚ: Partner? Oh, no… They separate you. If they find out, they separate you. There can't be anything "carnal", that's the condition they set.*

The participants were also aware of the prejudices that existed towards their relationships, saying that society views women with intellectual disabilities as eternal children with no interest in having a loving relationship or sex.

> *AINHOA: It's very easy to infantilize us and think that we have no desire to have sex or relationships, or that we can't. They think that we don't grow up and always remain girls.*

Support mechanisms

In order to overcome the barriers mentioned, the women suggested a range of support mechanisms. These included the need for accessible education and information, which was mentioned by three of the participants, while a further two said they would like to have a reference person to speak to regarding their doubts, or help them when there was a conflict with other people in their circle. Lastly, three mentioned the importance of greater education of society in general in order to break the above-mentioned prejudices.

> *AINHOA: There needs to be more information and education on these issues. Not only among people with disabilities, but throughout society.*

Contraception and sex

The third most-frequently mentioned topic was contraception and sex; within this the research distinguished three codes: *knowledge; decision making;* and *the lack of opportunities.*

Knowledge

The main barrier was a lack of information, and the information that exists is generally of poor quality. This was referred to by six of the women, with four of them emphasising that this left them all, but particularly those living in group homes, in a vulnerable position.

> *HELENA: I think they (group home's staff) should explain it well to people, one of the girls said they had given her contraception without telling her. It's something that happens, and more often in group homes.*

All of the interviewees agreed that people with intellectual disabilities find it hard to understand the information they receive on contraception and sex; three of them said they found these subjects difficult to comprehend, the remaining four felt that, although they had no problems, others might.

> *ESTRELLA: The main problem I have with this (contraception) is that there are things I don't know. Sometimes is hard for me to understand the information.*

Just one of the women (María) said she had received adequate training through a number of workshops on sexuality carried out at the support service she attends. Other support sources mentioned were *health professionals; the Internet; school; the foundation they attend; mothers; partners;* and *Family Planning services.*

> *ESTRELLA: The doctor speaks with my mother and then she tells me. My mother does it because if the doctor does, then I don't understand it, you know?*

In order to overcome these barriers, one woman chose to request that information was better explained and, through the use of images and simple language, adapted to the needs of people with intellectual disabilities. Another two said it was necessary to create and give courses that were adapted to their needs.

> *AINHOA: Since I have little experience, I'd like some kind of training that taught the practical parts of sexual relations. But, of course, it's complicated. Somebody would say "You can watch porn". But it's not the same.*

Decision making

A total of five women said that their right to decide to use contraception was often infringed, and that it was generally the people around them who took the decision; they said this was due to stereotyping and over-protection.

> *LUA: It's more difficult for us to decide, maybe because they see us as children and want us to be careful. In my own case, I haven't come across any problems so far. But in society it's generally difficult.*

The decision regarding the use of contraception had not been taken by four participants, while two said that, despite feeling influenced by their parents, they had finally made the decision themselves.

> *AINHOA: In my case, I've been able to choose. My parents have said things and so on, but the final decision has been mine.*

In spite of the experiences of some of the women, they stressed that women with intellectual disabilities are capable of making their own decisions regarding the use of contraception.

> *LUA: We should decide about this, whether we have a disability or not, because we also can say "I want to have a tubal ligation because I don't want to have any more children". They shouldn't decide for us, because we can do it perfectly well ourselves.*

Lack of opportunities

The feeling that people with disability, in general, and those with intellectual disabilities in particular, had fewer opportunities to experience their sexual relations freely was referred to by three of the women. They related this to societal prejudices, such as not conforming to the ideal of beauty, and that they were seen as girls who would never have sexual desires or experiences.

> *AINHOA: I think that people feel we don't have sexual desires and we don't want to have sex with other people. I think they find it hard to contemplate that two people with intellectual disabilities are going to do more than just hold hands and hug each other.*

The workplace is another barrier these women face, as two women described how the company they worked for prohibited inter-staff relationships; this leads people they know to keep their relationships a secret. A further barrier mentioned was the shortage of physical spaces available for this degree of intimacy with their partner.

> *LULÚ: If I want to have a partner, I obviously won't tell them (people responsible for the job). Everyone has their own life. And if they tell me something, they can go to hell... I'll do what I want to do, not what they tell me to do.*

The use of sexual assistants as a possible solution was referred to by two of the participants, although they did not feel it was an option they wanted for themselves.

> *AINHOA: Once they suggested that someone came to my home and taught me [to have sexual relations], but I didn't like the idea. I haven't got anything against it, but I can't see myself paying for something like that. It makes me feel a little...well...desperate? I know it's not the case, but emotionally it's complicated.*

Abuse

Regrettably, one of the other recurring themes was that of abuse. This was given two codes: *violent partners and toxic attitudes;* and *support and defence mechanisms in the case of abuse.*

Violent partners and toxic attitudes

Of the interviewees, four had suffered physical and psychological violence by their partners, and had also received threats once the relationship was over.

> *TONI: I've had problems with my partners. The father of my children physically and psychologically abused me.*
>
> *ESTRELLA: I had a complicated life with my first partner, they hurt me and there are lots of things I don't want to remember, but the person I'm with now makes life very easy.*

Another two participants described having recognized toxic attitudes in ex-partners, specifically emotional manipulation, although they did not class such behaviour as abuse. Both women said they had terminated the relationship before the situation could escalate.

> *AINHOA: It wasn't an abusive relationship because I think I finished it in time. But it could easily have become one.*

The sensation that women with intellectual disabilities were more vulnerable to gender-based violence was mentioned by three of the participants.

> *LUA: It's easier to harm women with intellectual disabilities, because it would be easier to rape us. When a woman with no disability is on her own, she can use logic more, but for us it would be harder.*

Support and defence mechanisms in the case of abuse

The participants referred to a number of sources of support when abuse occurs; these included the *foundation they attended; friends; the police; the telephone helpline,* and *their current partner.* The fact that they might not be aware of all forms of support available was mentioned by two of the women.

> *HELENA: The police helped me, the gender-based violence unit. I suppose there are more things now. I know about the police and their helpline. I don't know about anything else, but there must be more…*

Court cases can be stressful experiences for everyone, and this is perhaps even more so for people with intellectual disabilities. This stress can be reduced, one of the women who had suffered abuse suggested, by emphasising the need to inform everybody involved (lawyers, court clerks, and judges, among others) of the disability of witnesses. The proceedings could thus be adapted to the needs of people with intellectual disabilities.

> *HELENA: Have someone to support you when you go to court. When you're in front of the judge, they should know that you have an intellectual disability. If my lawyer had said "this person has an intellectual disability", I'd have felt more supported.*

Four of the participants mentioned the importance of making society aware of what abuse is, how it affects women with intellectual disabilities, and informing the latter of the support mechanisms available. In order to achieve this, the women felt that research was needed, and conferences organized where professionals and women who had suffered abuse could share their knowledge.

Family and motherhood

While family and motherhood were frequently spoken of, it was the subject least-mentioned by the participants. Within this subject, the following codes were allotted: *forming families; support for motherhood;* and *access to family housing.*

Forming families

According to the participants, women with intellectual disabilities have more problems when they become mothers or want to form a family than those without. This was mentioned by five of the women, and one of the barriers spoken of by two participants was the prejudice that they were not sufficiently responsible or able to take care of their children. Related to this, four of the women explained that those around them, in particular their parents, had been against their desire or decision to become mothers.

> *AINHOA: I spoke once with my parents about having children and decided not to mention it again for years. I'd said I wanted to be a mother and they talked about sterilization. I think it was something they really couldn't understand.*

In two cases, women who worked in a company specialized in contracting people with intellectual disabilities said that the firm had encouraged them to use contraception, and had even threatened to take custody away from workers who became pregnant.

> *LULÚ: They told one of our colleagues that if she had a baby, they'd give it away in adoption without her consent. That's pretty heavy, isn't it?*

The right to be mothers and form families was spoken of by five of the women, they underlined the fact that, with the right help, they were able of having children and looking after them. In two cases, women spoke of the "luck" they had had in being able to take this decision themselves.

Adoption had been considered by three participants, although one mentioned that her intellectual disabilities would make it difficult, this was an idea that the other two seemed unaware of.

> *AINHOA: I don't know if I'll have children. I'm getting to an age where it's harder. I sometimes think about adoption, but of course, I guess it would be very complicated in my case. They're making huge changes to the civil code, but still…*

Support for motherhood

On asking the three women who were mothers about the support they had received, two mentioned the family, while the third said she had not received any kind of help or information.

> *TONI: No help, no nothing. I found out I was pregnant at three months, thanks to the doctor. I didn't have any help from anyone, no advice, nobody talked to me about this, nothing at all. I was on my own. That really hurts (...) If someone had told me "Look, if you're with a man this can happen".*

All participants were asked about the support mechanisms for motherhood they knew of in general, and for women with intellectual disabilities in particular; three said they knew of no such support; one spoke of the foundation; and one mentioned a plan developed in one of the foundations to support her in decision making.

Regarding the support mechanisms the women would like to count on, four felt more support needed to be given to motherhood in general; three said that it was important to receive more orientation and information adapted to their circumstances; and two thought that further research should be carried out into the subject from the perspective of women with intellectual disabilities.

Access to family housing

Forming a family and having affective relationships is helped or hindered depending on whether the woman has their own home, and this was referred to by six of the women. The lack of one means that women find it harder to be intimate with their partner, which they have to do without their parents' knowledge; to decide whether to have children or not, and have somewhere to raise them.

> *LULÚ: It's important to have a home and somewhere stable for the family, but it's not at all simple.*

Further barriers to leaving home that were mentioned are the lack of financial means and the fear of telling their parents.

Some property owners are reluctant to let their property to people with a disability, a fact that four of the women referred to. In order to access the rental market, they are forced to find covert strategies; two of the women gave the example of trying not to present an employment contract since it would show that they worked for a company that employed people with a disability. Another woman said that she had found a flat because her partner had no disability, and a fourth said her mother had made the contacts.

> *AINHOA: A few months ago, I spoke with my support person and they said that it might be a good idea for my mother to call the flats on my behalf saying I was at work. Things got a bit better then.*

Discussion

The aim of this article was to discover the perspectives regarding affective-sexual relationships of a group of women with intellectual disabilities through their experiences and opinions. In line with previous research, the article has shown how such relationships are marked by sexual ableism and prejudices arising from beliefs regarding intellectual disabilities. The barriers these women face can be overcome through support mechanisms and information on a range of subjects, therefore the research aimed to obtain information on the support they had received, and that which they would like to have in order to establish the bases for future support resources and thus aid in decision making.

The participants described how their intellectual disabilities made them feel that their relationships were different from those of the people they knew. According to Peta et al. (2017), women with intellectual disabilities construct their own idea of sexuality and experience it in ways that defy the dominant discourse based on ableism and restrictions. The women had experienced limitations and over-protection by their families and professionals, this finding matches that of earlier research (de Wit et al., 2022; Friedman, 2023; Hole et al., 2021). When working on and researching the relationships of people with intellectual disabilities, it is important to emphasize their autonomy while recognizing that they may need support in helping them develop their abilities as much as possible (Kulick & Rydström, 2015).

In the case of lesbian and bisexual women with intellectual disabilities, we note that they face discrimination based, on one hand on prejudices towards women with intellectual disabilities, and on the other, the barriers that the LGTBIQ+ community faces (Hole et al., 2021; Löfgren-Mårtenson, 2013; Wilson et al., 2016). The social discourse on sexuality and sexual health takes heteronormativity as a given in people with intellectual disabilities (Hole et al., 2021), and this is reflected in some of the comments made by the women. Society often thinks that intellectual disabilities is sufficiently “different” to also differ from cisheteronormativity (Löfgren-Mårtenson, 2013).

A number of studies show that women with intellectual disabilities are more likely to suffer abuse than those without (de Wit et al., 2023; Hole et al., 2021), indeed, four of the seven participants described their experiences of abusive relationships, while a further two mentioned toxic attitudes. Despite this, Gil-Llario et al. (2022) state that the rates of reports of abuse made by women with intellectual disabilities are a third of those made by their support professionals.

Thanks to the participants’ accounts, it has been possible to compile a list of support that the women value as both necessary and positive. In line with earlier research (De Wit et al., 2022; Hole et al., 2021; Löfgren-Mårtenson, 2013), a generalized lack of information and knowledge is noted regarding the LGTBIQ+ community; relations with partners; contraception and sex; and abuse. People with intellectual disabilities want and need adequate sex education, this not only improves their knowledge and abilities, but also lets them take conscious decisions on their own sexuality (Friedman, 2023). Linked to the lack of information, the women felt it necessary for their opinions to form the base of further research, in order for them to know more about their affective-sexual relationships, create specific resources, and make society aware of the existing problems and break stereotypes. According to Peta et al. (2017), the feminist movement can and should provide the platform that enables women with disability to express their concerns in these subjects, and thus, increase the amount of support services available.

Although the above-mentioned support may serve in all the subjects discussed, the participants had their own, specific requests. Regarding their relations with partners, the women wanted to have adapted couple’s therapy, as well as someone they trusted who could solve problems and who they could turn to at times of conflict with others in their surroundings. The only woman who had reported her abuser to the police said she would have liked the trial to have been adapted to her needs, in line with that posited by Bowen & Swift (2019), who say that people who have an intellectual disability and are victims of partner violence need specific support, such as adapted interventions and professionals who have been trained in the subject. Finally, regarding the LGTBIQ+ community, the women underlined the need for specific programmes for those with intellectual disabilities, as is the case of the participants in the research of Wilson et al. (2016). Furthermore, they felt it necessary to count on specific advice for LGTBIQ+ people with intellectual disabilities and those in their circle. Support personnel and families can have a significant impact on the sexual expression of people with intellectual disability, it is therefore important to address possible prejudices in order to promote healthy, satisfactory relationships (De Wit et al., 2022).

Before finishing, we should note the possible limitations of this study. The experiences and opinions of the participants may not be representative of all women with intellectual disabilities as the sample was small and did not include transgender women, or those with bigger and more general needs. A further limitation may be that experiences and opinions could be affected by the women's socio-cultural context. Despite this, the results of this study coincide with previous research, and the methodology used has led to a deeper understanding of the lives of these seven women.

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13.4 Women with intellectual disabilities and motherhood: barriers, supports and demands (Artículo 4)

Abstract

Background: For many women with intellectual disabilities, motherhood is both important and highly desired. However, barriers to, and prejudices against, their maternity still exist.

Aims: To explore the perceptions of a group of nine women with intellectual disabilities regarding motherhood, whether they have children or have contemplated this option, in order to identify the barriers they face or expect to face, the support they have received or think they will receive, and the demands they make in this regard.

Methods and Procedures: Nine women, distributed in two groups, participated in 20 focus group sessions discussing affective-sexual relationships. The subject of maternity was covered in 15 of these sessions. The focus groups were recorded, transcribed, and analysed thematically.

Outcomes and Results: The results are structured around four main axes: barriers, perceptions, demands, and support.

Conclusions and Implications: The women defended their right to decide whether to become mothers and expressed their rejection of the stigma attached to it. The barriers identified were difficulty in access to accommodation, and a lack of resources, information and training adapted to their needs. To overcome these barriers, the women suggested the formation of groups of mothers with intellectual disabilities, support in finding housing and pre- and post-natal training. Finally, the women also noted how important it was that their voices be heard, and that they be represented.

Keywords: *Motherhood · Intellectual Disabilities · Woman · Barriers · Support.*

Introduction

The Convention on the Rights of Persons with Disabilities stipulates that people with intellectual disabilities must enjoy the same rights in reproductive health as their counterparts with no such disability (United Nations, 2006). The same institution argues for the fundamental right of all couples and individuals to make free decisions regarding the number of children they want; family planning; and access to information and resources that enable them to make these decisions consciously.

Nonetheless, the reproductive rights of people with intellectual disabilities have been restricted and violated throughout history. Their lives have been marked by eugenic practices such as forced sterilization, the obligatory use of contraception and reproductive coercion (Carter et al., 2021; MacLeod et al., 2022; Strnadová et al., 2019). Although the situation is changing, in Spain – the country where this study was carried out – forced sterilization was legal until 2020 (Organic Law, 2/2020 of December 16). However, despite legislative changes, people with intellectual disabilities continue to suffer injustices related to their reproductive rights (Wiseman & Ferrie, 2020). Some European authors have stated that the allegation made by those opposed to women with intellectual disabilities becoming mothers is that they are incapable of correctly fulfilling their parental role (Höglund & Larsson, 2013; Kroese et al., 2002; McConnell, 2008; Strnadová et al., 2019). Nonetheless, there is insufficient evidence of a link between intellectual disabilities and inadequate parenting (Aunos et al., 2008; MacLeod et al., 2022; McConnell, 2008).

While parenthood brings with it great responsibility, and taking care of and raising children is demanding for any parent, the diagnosis of a disability raises social barriers that make these challenges even more taxing (Pethica & Bigham, 2018) Despite this, a number of studies developed across Western countries have shown that, with the necessary support, women with intellectual disabilities are capable of being effective parents (Aunos et al., 2008; Carter et al., 2021; Strnadová et al., 2019).

Over the past twenty years, there has been increased interest in researching the experiences of maternity among women with intellectual disabilities in high-income countries, especially through quantitative methods and including both women with and without intellectual disabilities(Carter et al., 2021). That being said, international research has recently focused this topic on the point of view of women with intellectual disabilities themselves, mostly highlighting the point of view of women who were already mothers (Malouf, McLeish, et al. 2017b, Pethica & Bigham 2018, and Kroese et al. 2002, in the UK; Aunos et al. 2008, and Potvin et al. 2019, in Canada; Höglund & Larsson 2013, and Starke 2011, in Sweden; Mayes & Llewellyn 2012, in Australia; Strnadová et al. 2019, in the Czech Republic; Sheerin et al. 2013, in Ireland; and Traustadóttir & Sigurjnsdttir 2008, in Iceland). Thus, only a few studies have included childless women (Kaspar & Kroese 2017, in the UK) or expecting mothers (McConnell 2008 in Australia). Some other studies have explored the concept of maternity among mothers with intellectual disabilities by also including the views of their relatives or professionals (Jamieson et al. 2016, MacLeod et al. 2022, in the UK). The most-commonly treated subjects have been pregnancy, support networks and the loss of custody.

Research has indicated that the process of pregnancy may be difficult for many women with intellectual disabilities to understand and recommends that pregnancy be made more approachable through the creation of specially-adapted information, together with training for health and social care professionals who work with pregnant women (Höglund & Larsson 2013, Jamieson et al. 2016). The experiences and knowledge of women who have been pregnant can inform and shape the provision of support for mothers or future mothers with intellectual disabilities in this regard (Mayes et al., 2006; Potvin et al., 2019).

Research on support networks has shown that they are crucial during pregnancy and maternity (Conder et al., 2011; Malouf, Henderson, et al., 2017; Starke, 2011), and that women with intellectual disabilities can negotiate their support networks by actively intervening in their creation, as well as exclusively choosing people who support their role as a mother as being central (Mayes et al., 2008). That being said, one UK-based study found that social networks for mothers with intellectual disabilities are smaller than those without (Kroese et al., 2002).

Recent research indicates that the main barriers facing women with intellectual disabilities in relation to motherhood are: a lack of accessible training and information opportunities (Baum & Burns, 2007; Mayes & Llewellyn, 2012; Wickström et al., 2020; Wiseman & Ferrie, 2020); the isolation and the lack of a comprehensive support system for motherhood (Friedman, 2023; McConnell et al., 2009; Neuman, 2021); prejudices and infantilization by society as a whole and professionals (Friedman, 2023; Neuman, 2021; Wiseman & Ferrie, 2020); forced sterilization and contraception (Tilley et al., 2012; Wiseman & Ferrie, 2020); the invisibilization of the collective from the mainstream feminist narrative, as women with intellectual disabilities are not usually included in this narrative (Wiseman & Ferrie, 2020); and the fear of losing custody of one's children (Mayes & Llewellyn, 2012; Sheerin et al., 2013). In short, research has shown how the majority of barriers to motherhood do not stem from the characteristics of the individual, but are rather generated by social policies and institutional practices (Malacrida, 2009).

Little research has been done on the maternity of women with intellectual disabilities in Spain, the location of this project. Only four published studies have been found, and only one of them investigates the present topic from a social point of view, describing the attitudes of relatives, professionals and the general population (Olavarrieta et al., 2013). This study showed that families had the most negative attitudes towards motherhood for this group. Families believed that their daughters would not be fit to be mothers, so the family would eventually have to take care of their daughter's children.

The present study explores the perceptions that nine women with intellectual disabilities have regarding motherhood, with the aim of identifying the main barriers these women expect to face and the support they expect to receive based on their own experiences, whether they are already mothers or wish to become one. By way of conclusion, the article outlines suggestions these women make to improve their situation.

Method

Participants

The participants comprised nine women with links to organizations that provide support for people with intellectual disabilities. They were adequately motivated, had enough time to attend the focus groups, and were able to travel independently to the university where the focus groups were conducted. All participants lived in the same province, and required intermittent or limited support. The average age of the participants was 36, with a standard deviation of 11 years. Regarding ethnicity, eight of the participants were Caucasian and one (Llum) was Arab.

To encourage attendance and engagement, two groups were formed. Five women (participants 1, 2, 3, 8, and 9) met in the mornings; the second group of four women (participants 4, 5, 6, and 7) met in the afternoons. Table 1 shows the characteristics of the participants, the name they chose to ensure anonymity, and the number of focus groups they took part in.

Table 6: Characteristics of participants (N = 9).

Name	Age	Group	Personal Situation	Previous Partners	Sexual Orientation	Children	Focus Groups
Ana	23	Morning	Has a partner, but does not live with them	Yes	Heterosexual	No	9
Llum	23	Morning	No partner, lives with her family	No	Heterosexual	No	9
Lua	28	Morning	Has a partner, but does not live with them	Yes	Heterosexual	No	9
María	34	Afternoon	Has a partner, lives with them and her partner's family	Yes	Bisexual	No	7
Estrella	34	Afternoon	No partner, lives with her family	Yes	Heterosexual	No	9
Ainhoa	37	Afternoon	No partner, lives with her family	Yes	Bisexual	No	9
Toni	39	Afternoon	Has a partner, lives with them and her family	Yes	Lesbian	Yes, 2 from a previous male partner. The participant does not have custody.	8
Lulú	46	Morning	Separated, lives with her children	Yes	Heterosexual	Yes, 2 from a previous male partner. Both are independent adults.	9
Helena	56	Morning	Divorced, lives with her children	Yes	Heterosexual	Yes, 3 from a previous male partner. All are adults, two are independent and one daughter lives with her.	9

Instrument

Ten work sessions were carried out with each group, and a focus group was carried out in each. Following a systematic review of research into the perspectives of adult women with intellectual disabilities on affective-sexual relationships (Beltran-Arreche et al., 2023), the focus groups were organized taking into account the following themes: perceptions regarding sex and sexuality; experiences of abuse; views and experiences on couple relationships; the LGTBIQ+ collective; knowledge of and experiences with contraception; and, lastly, beliefs regarding gender roles. The authors selected the following topics for the first five sessions on the basis of these general themes: what affective relationships are; relationships with partners; the LGTBIQ+ community; sex, gender and sexuality; and motherhood.

From the sixth focus group on, each group decided to focus on specific topics that had arisen in the first five; these were chosen based on the interests and questions of the participants. Although the process was similar in both groups, there were some differences in the topics covered. The morning group discussed the following: toxic relationships and attitudes; partners and prejudice; LGTB-phobia; gender roles; sterilization; and how to ask for help in situations of domestic violence. The afternoon group discussed: gender violence; independence and over-protection; gender identity and sexuality; sterilization; and available support in cases of abuse. Motherhood, the subject of this article, was addressed in 15 of the 20 sessions, with different degrees of depth. It should be noted that, while only three of the women were mothers, motherhood was a subject that was repeatedly discussed. In Table 2, an asterisk indicates the sessions in which the theme of motherhood arose, regardless of the topic of the session.

Table 2: Themes and attendance by group

	Morning group		Afternoon group	
	Topic	**Participants**	**Topic**	**Participants**
1	What are affective relationships? *	Ana, Helena, Llum, Lulú	What are affective relationships? *	Ainhoa, Estrella, Toni
2	Relationships with partner *	Ana, Helena, Llum, Lua, Lulú	Relationships with partner *	Ainhoa, Estrella, María, Toni
3	The LGTBIQ+ community *	Ana, Helena, Llum, Lua, Lulú	The LGTBIQ+ community	Ainhoa, María, Toni
4	Sex, gender and sexuality *	Ana, Helena, Llum, Lua, Lulú	Sex, gender and sexuality *	Ainhoa, Estrella
5	Motherhood *	Ana, Helena, Llum, Lua, Lulú	Motherhood *	Ainhoa, Estrella, María, Toni
6	Toxic relationships and attitudes	Ana, Helena, Lua, Lulú	Gender violence	Estrella, María, Toni
7	LGTB-phobia *	Ana, Helena, Llum, Lua, Lulú	Independence and over-protection	Ainhoa, María, Toni
8	Gender roles *	Ana, Helena, Llum, Lua, Lulú	Gender identity and sexuality *	Ainhoa, Estrella, María, Toni
9	Sterilization *	Helena, Lua, Llum	Sterilization	Ainhoa, Estrella
10	How to ask for help against domestic violence? *	Ana, Helena, Llum, Lua, Lulú	Support available in cases of abuse *	Ainhoa, Estrella, María, Toni

The (*) refers to the sessions where the theme of motherhood arose.

Procedure

Three organizations that provide services to people with intellectual disabilities were contacted by the researchers. The research project was presented to representatives of these service providers, specifying the aims, methodology and topics that would be covered. Any questions regarding the process were answered. Professionals from these organizations were then asked to select women who might be willing to share their experiences and explain to them that their participation in the sessions involved participating in focus groups. Ten women agreed to attend an introductory session at the university, where the project was presented and they were informed what participation would involve. This information was given orally, with the support of easy-read documents and an accessible digital presentation with images and text.

With the support of a researcher, the participants read an accessible consent form, which covered anonymity, consent and confidentiality using simple language and pictures. All participants signed the consent form after confirming that they had understood it and that their questions had been answered. One of the women left the project during the first session, so her contributions were not included in the analysis. The project was approved by the University of (deleted for anonymization purposes) Ethics Committee, with reference number (deleted for anonymization purposes). The sessions were held fortnightly at the university between February and June 2022, each lasting between one and a half and two hours. Each focus group session started with an introduction to the topic, followed by an exploration of the women's perspectives on it. The session ended by thanking the participants for their attendance and participation and asking them to briefly evaluate the session. The focus groups were facilitated by the lead author, who took particular care to ensure that all of the women were able to participate freely. Two strategies employed to ensure participation of all of the women were using pictures and reading information aloud. Clear vocabulary and direct language were also used to facilitate understanding, and the questions were reformulated whenever necessary. Participation was high, with most of the women attending nine focus groups, one attending eight and two attending seven.

Data analysis

Thematic content analysis was used to analyse the data obtained, a technique which identifies and analyses patterns in a dataset by reading and re-reading the data (Fereday & Muir-Cochrane, 2006). The authors followed the principles of good practice in thematic analysis suggested by Braun and Clarke (2021). Once the ten sessions had been completed with each group, the focus groups held in each session were transcribed, thus obtaining twenty transcriptions. The first three were then carefully read by the first author to produce an initial coding, resulting in identification of the following themes pertaining to motherhood: barriers, perceptions, demands and supports. After this first coding had been reviewed by the other two authors, structural coding and descriptive coding phases were undertaken, as outlined in Saldaña (2009). The first author then proceeded with a more detailed structural coding of three different focus groups from the previous step, assigning short sentences to encode the transcriptions. The descriptive coding phase followed, which entailed assigning words or short phrases to identify sub-themes. Authors 2 and 3 reviewed this coding, and the three authors agreed on the final list of themes and sub-themes that would be used to encode the rest of the fourteen focus groups (Table 3). The table also includes the number of sessions in which each of the sub-themes was discussed.

Table 3: Maternity – themes and sub-themes.

Themes		Sub-themes	Number f focus groups
1	Barriers	Interference by family, professionals, or institutions	12
		Prejudices against intellectual disability	9
		Difficulties living with family	5
		Fear of negative consequences	3
2	Perceptions	Maternity as a right	10
		Maternity as care	7
		Perception of training needs	3
3	Demands	Value placed on their experience	7
		Adapted and specific training	6
		Resources for mothers and families	5
		Change of paradigm	4
4	Support	Sources of support	5
		Need for support	2

Results

The main results of the analysis pertaining to the focus groups are presented below, ordered according to the themes shown in Table 2.

Barriers

Barriers to maternity that the women expected to face comprised the most frequently discussed theme, being mentioned by eight women in fourteen of the fifteen focus groups. These barriers have been divided into the following four sub-themes: *interference by family, professionals or institutions; prejudices against intellectual disabilities; difficulties in living with family;* and *fear of negative consequences.*

Interference by family, professionals or institutions

The main barrier that the participants had faced or expected to face when pursuing their wish to have a child was external interference. Eight of the women mentioned this sub-theme in twelve of the focus groups. The participants stated that they felt highly controlled, and even limited, by their environment. In most cases, the family acted as a barrier to their motherhood and their ability to freely take decisions regarding it.

> *LUA: My mother said to me about motherhood, "I don't want to talk about this topic". I don't think my sisters agreed either* (Morning Group, *Focus Group 4*).

Other barriers mentioned were the influence of society and institutions, and the opposition of some professionals.

> *LULÚ: And I'll tell you something: if the doctor is old school, he'll say "Have an abortion, dear, you've got a disability"* (Morning Group, *Focus Group 3*).

The women felt they had to convince those around them that they could be good mothers in order to eliminate any barriers and enable them to count on the support of their families.

They said that if they proved their abilities, the families would not oppose their decision to become a mother.

> *LUA: I'm sure that, when it comes to it, my mother (...), will end up accepting me, but first I've got to show I can look after myself in a number of ways, work or whatever, and then, when I'm ready, okay...* (Morning Group, *Focus Group 8*).

Prejudices against intellectual disability

Seven women discussed prejudices against their maternity in nine of the focus groups. It was evident that, although motherhood was important to them, they felt highly restricted by society and their environment. They emphasized their belief that the diagnosis of their disability did not mean they would be bad mothers.

> *AINHOA: And then there's that thing of why can't a person with a disability be a mother or father? Nothing says that someone with a disability can't... I mean, there may be cases, but there are also cases of someone with a disability who's had children and you see how well it's gone* (Afternoon Group, *Focus Group 8*).

The participants felt judged, and that society was opposed to their motherhood. They stressed that any problem or negative repercussion the child had was blamed on the mother's disability.

> *HELENA: If the child has a disability, mother's fault, if they have anything, it's the disability's fault...* (Morning Group, *Focus Group 1*).

They also felt judged by a society that doubted their ability to be mothers.

> *LUA: (...) they're not sure that they* [women with a disability] *can, not sure that they'll look after the child "since you've got a disability, you won't be able to..." But then you think "And how do you know if I will or not? You're not me, you know."*
>
> *LULÚ: Sometimes they don't give you the chance to be a mother, and that's really serious* (Morning Group, *Focus Group 8*).

Difficulties in living with family

Not having one’s own suitable living space was referred to as a barrier to maternity in five of the focus groups. Moreover, the challenge of moving away from the family household poses a hindrance to establishing one's own family, experiencing parenthood and raising children.

> *LUA: I also still live with my parents… at his home or mine we can be alone, but of course, if they go out, we can do things, but while they’re in...* (Morning Group, *Focus Group 4*).

Difficulties in having one’s own home and being able to live as a family were also mentioned as barriers to maternity by six participants in five of the focus groups. The participants were aware of the problems involved in renting their own home or sharing group homes. In the Spanish context, group homes are social facilities where people with disabilities share housing and receive support from professionals. Living in a group home is an obstacle to forming a relationship and having children, since users do not choose who they live with, making it difficult to start a family. Some said that they had been able to obtain a flat because their partners had no disability.

> *HELENA: I was lucky to rent a flat because my partner wasn’t… didn’t have a disability* (Morning Group, *Focus Group 2*).

The women described the importance of counting on the support of the family, or should this be lacking, that of organizations that provide services such as helping them find their own home. They recognized that their diagnosis hindered their ability to rent a flat.

> *LUA: I think that, too* [referring to the problems in renting accommodation]. *People have to change a bit and be more understanding, and if they don’t, then having the support of the Foundation,* [the organization that offers her support] *which can help you, or someone who’s prepared to help you* (Morning Group, *Focus Group 4*).

Fear of negative consequences

The idea of motherhood created fear in four of the women in three of the focus groups. They feared that if they had a child their family would reject them, or they would lose custody. This fear led three of the women to consider having children behind their families' backs in order to avoid their intervention.

> *LUA: In the end, I won't tell my mother and I'll do it anyway. In the end, it'll be like that, because if they don't let me…* (Morning Group, *Focus Group 6*).

They also highlighted that when a mother with no intellectual disability does things wrong the repercussions from society and institutions are more lenient, and they believe that mothers lose custody less frequently in this case. In fact, of the three participants in the focus groups who were mothers, one had lost custody of her children.

Perceptions

Perceptions regarding a range of issues related to motherhood were addressed by eight participants in twelve of the fifteen focus groups. The results related to perceptions have been divided into three sub-themes: *maternity as a right; maternity as care;* and *preparation needed.*

Maternity as a right

The right to choose whether or not to become a mother was debated by seven women in ten of the fifteen focus groups, revealing that most of the participants either were, or wished to become, mothers. They also explained their deep desire to form their own families, which in many cases they had felt since they were very young.

> *ANA: Do you know how long I've wanted to have children?*
>
> *LUA: Since you were little?*
>
> *ANA: Since I was three.*
>
> *LUA: I think I'll be very happy when I'm a mother* (Morning Group, *Focus Group 6*).

On the other hand, two of the women gave different reasons for not wanting to become mothers: one feared motherhood, and the other did not like children.

The participants agreed that it should be the individual who chooses to have a child, and that nobody else should interfere in this choice. They noted that becoming a mother is a right, but should not be an obligation. Two of them also stated that external factors such as a fear of illness could hinder this right.

> *HELENA: Because, according to the question, you say "Should everyone have the right to be a mother?" Well, everyone has that right (...). You could become ill,... but the right? Nobody can take that away from you.* (Morning Group, *Focus Group 8*).

Maternity as care

The women saw maternity as a complex question. In seven of the focus groups, seven of the women related maternity to care, tenacity, love and affection. They agreed that motherhood was about "*being there for better or worse*" (Lulú, mother of two, Morning Group, *Focus Group 8*). They also stressed that motherhood was an arduous task for everybody, whether they had a disability or not.

> *LULÚ [mother of two]: It's hard. It takes time, and one step at a time.*
>
> *HELENA [mother of three]: It's a learning process right from the start (Morning Group, Focus Group 8).*

When debating the role of the mother, they thought that it was vital to show trust in their children, and to give affection and support. Three of the women mentioned the importance of arranging medical appointments, dealing with the school, and managing financial matters, while others felt this was secondary and that it was more important to be strong and always help their children.

> [Speaking about fundamental aspects of motherhood]
>
> *LUA: Financially also, no? Of course, you've got to...*
>
> *HELENA: People talk about 'financially', and it's not that important*
>
> *HELENA and LULÚ: It's secondary (Morning Group, Focus Group 8)*

Preparation needed

The importance of being prepared for motherhood before taking the decision was highlighted in three of the groups by four participants. This preparation included having a job and money, living with the partner, and getting married; they also alluded to the need to be mentally prepared, and certain before beginning the process.

> *HELENA: Are you mentally and physically prepared?*
>
> *LUA: I don't know.*
>
> *HELENA: Ah... you've got to be really sure about it, right? (Morning Group, Focus Group 7)*

Demands

Regarding their own demands, these were expressed by eight of the women in eleven of the fifteen focus groups. They have been divided into the following four sub-themes: *value placed on their experience; adapted and specific training; resources for mothers and families;* and *a change of paradigm.*

Value placed on their experience

The first demand is linked to the role of mothers and women with intellectual disabilities as experts on their own experiences and was mentioned by eight of the participants in seven groups. The women stressed how important it was that relatives and professionals heard their voices and opinions regarding maternity.

> *LULÚ: I think they shouldn't talk about us anywhere; they should let us speak, and listen to our voices* (Morning Group, *Focus Group 1*).

The women suggested the idea of forming groups of mothers or future mothers with intellectual disabilities; these would serve as a meeting place for women who had questions about maternity, or needed support, and where women who already were mothers could give advice based on their own experiences.

> *LUA: I think that this subject should be talked about with mothers with a disability, because they can give you advice and you can get a bit prepared, and the families too, they also end up supporting the person* (Morning Group, *Focus Group 7*).

Adapted and specific training

The second most frequent demand was for training specifically adapted to meet the needs of mothers or future mothers with intellectual disabilities. This sub-theme arose in seven of the focus groups and was mentioned by five participants. All agreed that it would be useful to have specific courses before, during and after pregnancy. They also mentioned the importance of training in how to ask professionals for support or advice.

> *LUA: Before you're pregnant, so that you know something... To learn how to look after the child, I'd be very interested in courses.*
>
> *LLUM: Workshops, yes. For example, they tell you "you should do this or that..."* (Morning Group, *Focus Group 9*).

Resources for mothers and families

In five of the focus groups, six participants shared their ideas on the resources they would like to have available to them. There is a direct link between one of the desired resources and one of the barriers mentioned above, namely, the difficulty in finding somewhere to live independently with their partner and children. Furthermore, the women explained that group homes for people with a disability are often not suitable for living with a partner and children. They called for homes that were prepared for such contexts, or, at the very least, group homes with bedrooms that couples could share.

Another resource the women wanted was access to psychological support. They felt that this should be free, and adapted to the needs of the women who already were, or wished to become, mothers.

> *LUA: I agree that there should also be a psychologist to deal with things, like if you want to be a mother with a disability* (Morning Group, *Focus Group 8*).

They also noted the benefits of a service providing specific guidance on maternity. As the family network is important to the women, and they recognized the need for external help, this service would have a professional to mediate between them and their families; the professional would also find suitable resources for them.

Change of paradigm

Lastly, seven of the participants alluded to the need for social, institutional and legal change to ensure that their rights were recognized and respected. Such a change would involve breaking a number of the barriers they expected to face, including that preventing them from sharing a home, prejudice regarding their capacity to be mothers, the uncertainty they feel and external intervention. The women were convinced that these aims could be met through street demonstrations to make their demands more specific to politicians and society in general, leading to more research into the opinions of women with intellectual disabilities and greater media coverage. They also highlighted the importance of having access to legal advice adapted to their circumstances, which would help them denounce situations where their right to be mothers was discriminated against.

> *HELENA: The law should be changed, and there should be more government departments to support us* (Morning Group, *Focus Group 4*).

The women emphasized the importance of raising awareness regarding the motherhood of people with intellectual disabilities, since this could eliminate the stigma associated with it. They stressed that a greater understanding of their lives could be a driving force in changing the attitudes of those around them and society in general.

> *HELENA: I wanted to say that there's a play which would be good if you could see, because it's the story of a woman with intellectual disabilities who wants to be a mother and she comes up against obstacles in her family. It's a play that would open they eyes of many parents and other people.* (Morning Group, *Focus Group 1*).

Support

Lastly, the support for maternity that they received, expected to receive or wished for was discussed by five of the women in six of the focus groups. Within this theme, the results have been divided into two sub-themes: *sources of support* and *need for support*.

Sources of support

Five of the participants identified a number of sources of support in five of the focus groups. The family was the most frequent source, with the women underlining the particular importance of the role of their mothers, and, in one case, the mother-in-law. They mentioned the importance of parents, although no participant specifically referred to their father's support.

Five of the women felt that motherhood could be very complex without the support of a partner, since the mother would have to work twice as hard.

> *HELENA: And, really important, is having the support of your husband. If he doesn't support you, then that's bad* (Morning Group, *Focus Group 7*).

As sources of external support, they referred to friends and therapeutic psychologists.

> *ANA: If you feel comfortable, tell them, if not, then go to the psychologist, if you can't explain things to your mother or family, you can see a psychologist* (Morning Group, *Focus Group 1*).

Other sources of support named were information found on the Internet, and in books and internet tutorials.

Need for support

Five of the women identified the support of those around them as being vital. However, they also agreed that they would be able to manage as mothers or future mothers if this support was lacking, even though this implied a great effort on their part.

> *LULÚ: I'll tell you something, the day you get pregnant, the moment you get pregnant, you'll find the strength… to raise the baby* (Morning Group, *Focus Group 7*).

The participants agreed that support for mothers with intellectual disabilities was lacking, stressing the fact that no association or service exists to advise them on maternity.

Discussion

Despite the many barriers, motherhood and the desire to become a mother play an important role in the identity and well-being of the participants in our study, similarly to women who have participated in other research on this topic in high-income English-speaking countries (Carter et al., 2021; Conder et al., 2011). They believe motherhood would give them a new role, strengthen their resilience and bring them into contact with other people in their environment

(Starke, 2011). As happened in Kaspar and Kroese's (2017) study conducted in the UK, participants in this study identified emotional attachment, practical skills, financial knowledge, affection and support as important factors in good mothering. The women interviewed believed that everyone has the right, but not the obligation, to decide whether to become a mother, and that those around them should not interfere with this decision. People with intellectual disabilities often suffer from a lack of autonomy; their infantilization by parents and carers results in women within this group having restricted choices regarding their bodies and relationships, sometimes leading to decisions being made that are against the individual's wishes (Carter et al., 2021). Although the participants in this research do feel free to take their own decisions, they have had to fight against the opinions of those around them to a certain degree. With regard to motherhood, it should be noted that many women face different barriers such as economic precariousness or lack of preparation, regardless of whether they have a diagnosis of intellectual disability or not. However, the intersectional discrimination experienced by women with intellectual disabilities means that this group must face not only the usual challenges that motherhood presents, but also the misunderstanding and stigma associated with disability, making these barriers greater and resulting in a greater need for support.

Previous research from Western countries has found evidence of stigma with regard to women with intellectual disabilities and motherhood, and the attitudes of their family and professionals may contribute to this (Carter et al., 2022; Kaspar & Kroese, 2017; Potvin et al., 2019; Sheerin et al., 2013; Starke, 2011; Strnadová et al., 2019). Five of the participants in this study described how people they knew, and especially their parents, opposed their decision or wish to have a child, using the argument that they might not be able to care for their children. While only one participant was considering concealing a potential future pregnancy from her family due to her fear that they might object, a previous study conducted in Sweden (Höglund & Larsson, 2013) highlighted the significance of such apprehension in making decisions about motherhood. The women in our study knew that motherhood was not something they could take for granted, and fear of their families' reaction made them want to demonstrate their worth as mothers or future mothers. They felt they needed to prove their ability to be competent mothers to their families and the relevant authorities (Malouf, et al., 2017b). They also shared the belief that the diagnosis of a disability did not mean they would be bad mothers, and expressed their opposition to prejudices against mothers with intellectual disabilities. However, some women did suggest that degree of disability could have an influence on motherhood. Such statements show that women with intellectual disabilities themselves are not free from internalized prejudice, a finding that coincides with that of Kaspar and Kroese (2017) in the UK.

Negative attitudes were not the only barriers identified, however. Objective barriers also exist, including the problems women with intellectual disabilities face in accessing living conditions that facilitate motherhood and child-raising. The study participants highlighted the challenge of finding somewhere to establish as their own home and live with their future family, a matter not formerly addressed in existing research. This study was carried out in Spain, where housing is a widespread problem exacerbated by the absence of social and economic policies that address the accommodation needs of the most vulnerable individuals.

The women also felt that their experience of motherhood or their wish to become mothers was viewed more harshly compared to women without an intellectual disability. This made them feel judged and supervised (Malouf et al., 2017b). The women reported a lack of information and training regarding motherhood, this finding being consistent with those of prior research conducted in New Zealand (Carter et al., 2021). Additionally, they said that there was a lack of resources tailored to the needs of mothers and expectant mothers (Carter et al., 2022; Mayes & Llewellyn, 2012; Sheerin et al., 2013; Starke, 2011). A recurrent subject in research into mothers with intellectual disabilities is that they often face the possibility of losing custody (MacLeod et al., 2022), although this was not identified as a barrier in the present study, probably due to the fact that many of the participants were not mothers.

Despite the aforementioned barriers, academic research indicates that with adequate support women with intellectual disabilities can be successful mothers (Malouf et al., 2017a; Traustadóttir & Sigurjnsdttir, 2008). The participants in this study identified the family as their primary source of support, together with their partner, friends and psychologists. This finding closely coincides with those of previous studies from Australia, the United Kingdom, the Czech Republic and Iceland (Carter et al., 2022; Kaspar & Kroese, 2017; Malouf et al., 2017a; Malouf et al., 2017b; Strnadová et al., 2019; Traustadóttir & Sigurjnsdttir, 2008). However, both the family and professionals can also act as a barrier at times. To overcome this, the women suggested the possibility of engaging a mediator in their dealings with family members and other stakeholders. Further suggestions that emerged from the focus groups included forming support groups for mothers with intellectual disabilities, tailored psychological services for their motherhood-specific needs, assistance in locating accommodation suitable for their family and the provision of adapted pre- and and postnatal courses. These suggestions are consistent with a significant number of research findings from high-income English-speaking countries (Conder et al., 2011; Kaspar & Kroese, 2017; Malouf et al., 2017b), which recommend actions of positive value. Proposals regarding the need for support mention the need to also offer support for decision-making. The CRPD reaffirms the right to decision-making of persons with intellectual disabilities (United Nations, 2006). Equally, this article defends the need for women with intellectual disabilities to have access to a support and information service regarding decision-making on motherhood, and all that this entails. Conder et al. (2011) came to the same conclusion, pointing out that allowing people with intellectual disabilities to make informed decisions about motherhood can increase the percentage of parents with intellectual disabilities who raise their children successfully.

The study participants called for specific healthcare, family planning and social services for women with disabilities; these would be distinct from those available to the general population and provide important support to mothers and expectant mothers with intellectual disabilities. Research conducted in Canada and the UK leads us to suggest that a positive relationship is often developed between mothers with intellectual disabilities and the professionals who assist them (Aunos et al., 2008; Jamieson et al., 2016; Potvin et al., 2019). Such support best involves the use of easy-read information or audio-visual materials (Aunos et al., 2008; Malouf et al., 2017a; Malouf et al., 2017b; Starke, 2010).

This study recommends the adoption of three main strategies to improve support for women with intellectual disabilities: the creation of specific new services; the adaptation of existing services; and the active promotion of all such services to increase their visibility among women with intellectual disabilities and those around them.

Finally, this study provides evidence of the need for implementation of social and political actions deriving from the recent paradigm shift in relation to barriers faced by these women with respect to motherhood. Our research shows that structural and profound changes are needed to break down the barriers that women face to be able to become mothers and, ultimately, to be able to make decisions about their own lives. Implementing decision-making support processes that help women position themselves in relation to motherhood and seek help to be able to develop this facet of their lives is one of the strategies that would improve their lives in general, and in particular their potential motherhood. Transforming social services funding model towards one based on direct payments or personalized budgets would also grant them decision-making power and the possibility of allocating resources or support to their desired life objectives. In respect of this, adopting the Citizenships paradigm would be a favouring factor in the development of complex personal projects such as motherhood.

In recent years, the self-advocacy movement has helped normalize the maternity of these women in certain countries such as the UK (Malouf et al., 2017b), while a study conducted in Canada has shown that positive interactions with people with disabilities can reduce prejudice (Potvin et al., 2019). In accordance with that advocated by Mayes et al (2006) in Australia, the participants call for their experiences to be heard and recognition of their role as experts in the development of policies and resources surrounding their own motherhood.

Conclusion

The aim of this study was to explore perspectives on motherhood among women with intellectual disabilities in order to identify the barriers they anticipate encountering, the demands they make, and the support they expect to receive during such a significant period of their lives, whether they are currently mothers or wish to be so in the future. Previous research, confirmed by our study, has shown that the motherhood of these women is highly regulated by those they interact with. The environment in which women with intellectual disabilities find themselves may help or hinder the process, depending on the attitudes of those around them towards their motherhood. Participants in our study emphasized the importance of raising awareness about their rights and the barriers they have to face among their acquaintances and creating specific support resources for current and futures mothers with intellectual disabilities.

One limitation of our study is that, while some of the nine participants in the focus groups were mothers and others were not, their experiences may not be representative of all women with intellectual disabilities. Equally, the experiences of this group of women are marked by their socio-cultural context and may differ greatly from those of other women with the same diagnosis. That being said, however, there was no aim for this research to be all-encompassing. The smaller sample size and the work carried out with the women over a long period allowed for a more in-depth understanding of participants' experiences and viewpoints. The present study therefore serves as a first exploration of this issue in the context of Spain, while the results have resonated with those of previous studies conducted in other countries, demonstrating that some of the challenges faced by these women when it comes to motherhood are transferable to other contexts.

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14. Discussion and Conclusions

This research demonstrates how the lives and affective-sexual relationships of people with intellectual disabilities are shaped by ableism and prejudices derived from societal beliefs about people with intellectual disabilities. Furthermore, it has enabled a more in-depth examination of the perceptions of participants with disabilities on dimensions that align with the majority of previous research. The research presented in this Compendium offers a synthesis of the barriers, supports and demands experienced by people with intellectual disabilities in relation to their affective-sexual relationships and motherhood. In the case of women with intellectual disabilities, a group that is doubly disadvantaged due to their combined status as a woman and a person with intellectual disabilities, investigating their views and needs can contribute to improving their lives and empowering them.

The systematic literature review in **article 1** provides information about the needs, experiences and knowledge of adult women with intellectual disabilities from diverse global contexts. The results of this study demonstrate the current state of knowledge on the topic of interest, namely the affective-sexual relationships of adult women with intellectual disabilities. It has been determined that further research in this field is imperative. Furthermore, the study offers insights into the knowledge, beliefs, and attitudes of individuals with intellectual disabilities regarding sex and sexuality. The extracted results can inform the provision of assistance, support and education in the field of affective-sexual relationships, in particular for families and professionals. In addition, four main implications can be drawn. Firstly, there is a clear requirement for ongoing affective-sexual education that extends beyond the confines of the education system (Brkić-Jovanović et al., 2021; Friedman, 2023; McClelland et al., 2012). The second conclusion is that there is a need to create spaces for dissident forms of sexuality and gender within this affective-sexual education (Schaafsma et al., 2013). Thirdly, the importance of the creation and distribution of accessible information on issues related to affective-sexual relations is highlighted (Friedman, 2023). Finally, it is recommended that the training of family members and professionals be enhanced, as their opinions and attitudes influence the opportunities that women with intellectual disabilities will have (McCarthy et al., 2017; Tomsa et al., 2021).

Article 2, developed with the Advisory Committee, proposes to analyse and make changes in different areas of the life of people with intellectual disabilities, especially regarding sexuality. It is based on the premise that barriers and supports affect their affective-sexual relationships. This is due to the fact that the participants indicate that they do not receive sufficient support from professionals and perceive families and support services as conditioning factors of their sexuality. Furthermore, they highlight the difficulty in forming friendships and denounce the prejudices of society, among other issues (O'Shea & Frawley, 2020, Azzopardi et al, 2019). The testimonies of the participants highlight the necessity to challenge traditional perceptions about the sexuality of individuals with intellectual disabilities (Scott et al., 2014). This requires the promotion of policies, services and professionals that provide support that guarantees the fulfilment of their rights (Puyaltó et al., 2019). At the professional level, the necessity of establishing trusting relationships with families and services in order to provide personalised support and appropriate and accessible sexuality education is emphasised (Rushbrooke et al., 2014). Furthermore, given the challenges in establishing diverse support networks, the promotion of healthy affective-sexual relationships is proposed through the creation of opportunities for interaction in inclusive environments to strengthen personal support networks that accompany these individuals in their affective-sexual relationships.

The interviews described in **Article 3** have allowed for the development of a list of valued and considered necessary supports based on the women's accounts. The aforementioned strategies are designed to address the sexual health needs and rights of individuals with intellectual disabilities through a range of approaches. Firstly, it is imperative that comprehensive sexuality education programmes are made available which are tailored to the diverse needs and abilities of the population in question (De Wit et al., 2022; Hole et al., 2021; Löfgren-Mårtenson, 2013). Furthermore, research based on the experiences of individuals with intellectual disabilities is required to inform the development of specific interventions and policies. It is imperative that specific resources, including accessible materials, be developed to assist individuals in fully expressing their sexuality. It is similarly important to raise awareness and combat stereotypes in society, as this can foster more inclusive environments (De Wit et al., 2022). Finally, the promotion of positive representations of individuals with disabilities in the context of sexuality is essential to enhance autonomy and self-esteem (Kulick & Rydström, 2015).

Article 4 presents the results of research on the perspectives of a group of women with intellectual disabilities on motherhood. The results are structured along four main axes: barriers, perceptions, requests and support. The women rejected the stigma attached to motherhood and asserted their right to choose whether or not to become mothers. The obstacles that were identified were the difficulties in accessing housing, as well as the lack of resources, information and training that were adapted to their needs (Kaspar & Kroese, 2017). In response to the barriers identified, the establishment of collaborative networks between mothers with intellectual disabilities is proposed as a means of mutual support and empowerment. It is also evident that there is a need for support in securing adequate housing, as a stable and supportive environment is fundamental to the well-being of mothers and their children. Furthermore, it is crucial to emphasise the significance of access to comprehensive prenatal and postnatal education and training that is tailored to their specific needs (Carter et al. 2022, Mayes & Llewellyn 2012, Sheerin et al. 2013, Starke 2011). It is imperative that the voices of women with intellectual disabilities be heard and that their representation in decision-making processes be ensured. It is essential that the perspectives, concerns and experiences of women with intellectual disabilities are recognised and integrated into policy formulation, service delivery and programme development. This recognition and inclusion are essential not only to promote the empowerment of women with intellectual disabilities, but also to foster a more inclusive and equitable society in which their rights and needs are upheld and respected (Conder et al. 2011, Kaspar & Kroese 2017, Malouf et al. 2017b).

In conclusion, to highlight the potential limitations of the studies conducted. It is important to note that the experiences and views expressed by the participants may not be representative of all people with intellectual disabilities. This is due to the limited sample size and the lack of representation of transgender people, as well as those people with intellectual disabilities who have more extensive and pervasive support needs. Furthermore, it is possible that the experiences and opinions may have been influenced by the socio-cultural context of the women participants. Nevertheless, the objective of this research was not to encompass a multitude of perspectives but rather to gain a deeper understanding of the experiences of a specific group of individuals with intellectual disabilities. This study has enabled the identification of results that are consistent with those of previous research, as well as the identification of aspects that have not previously been mentioned in the literature.

Additionally, while the aforementioned studies emphasize the necessity for professional assistance in improving the affective-sexual relationships of women with intellectual disabilities, it is essential to consider the potential implications of increased professional involvement in decision-making processes for individuals with intellectual disabilities. This is particularly relevant in the context of people with disabilities, where the distinction between the private and public spheres is often not clearly defined. Such external involvement has the potential to impact their autonomy and privacy, as others may be able to exert influence or control over significant aspects of their personal lives (Shildrick, 2009).

In view of potential future research, it is crucial to emphasise the significance of continued investigation into the affective-sexual relationships of individuals with intellectual disabilities. This should be conducted in an inclusive manner, with a particular focus on incorporating the voices and experiences of this group. It is of the utmost importance that research in this field prioritises the understanding of the perspectives and needs of women with intellectual disabilities, acknowledging their specific characteristics and challenges in the context of affective-sexual relationships. One potential course of action would be to expand the study sample to include a larger and more diverse range of participants. This could entail including women of varying ages, ethnic backgrounds, levels of disability, and geographical locations. For instance, an investigation of the experiences of women with intellectual disabilities residing in rural areas could yield insights into the challenges they may face in accessing services and support. Another area of interest could be to examine how the experiences and perspectives on affective-sexual relationships of women with intellectual disabilities have evolved over time and between different generations. This could entail a comparison of the experiences of younger women with intellectual disabilities with those of older generations, with a view to elucidating the impact of factors such as advances in disability awareness, policy changes and technological advances on their sexuality and relationships. Based on the findings of the doctoral thesis, work could be done on the design and evaluation of sex education training programmes specifically aimed at women with intellectual disabilities. Furthermore, it is important to recognise the significance of considering the intersection of intellectual disability with other dimensions, such as gender identity or sexual orientation. It is therefore recommended that future research should explore the experiences and opinions of LGTBIQ+ people with intellectual disabilities, with a view to identifying the ways in which these identities intersect and shape their experiences in the field of affective-sexual relationships.

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