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## Exploring sexual health in people with mild intellectual disabilities: A concept mapping study on the perspectives of relatives and support staff

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### ABSTRACT

**Background:** Sexual health includes physical, emotional, mental, and social wellbeing related to sexuality. Given people with mild intellectual disabilities' reliance on relatives and support staff, it is important to explore the latter's understanding of sexual health.

**Method:** Relatives ( $n=7$ ) and support staff ( $n=15$ ) of people with mild intellectual disabilities participated in a concept mapping procedure that included brainstorming, sorting and ranking activities. An expert group interpreted the results.

**Results:** Relatives and support staff identified aspects of sexual health of people with mild intellectual disabilities, including sexual preferences, sexual behaviour and support and education. While relatives prioritised relationships, support staff emphasised sexual identity.

**Conclusions:** The study highlights the necessity of adopting a comprehensive approach to sexual health for people with mild intellectual disabilities. This approach should consider developmental perspectives, incorporating support, education and a positive attitude towards their sexual health. Implications for research and practice are discussed.

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Mild intellectual disabilities; sexual health; support staff; relatives; concept mapping

Sexual health refers to a state of physical, emotional, mental, and social wellbeing related to sexuality (World Health Organization [WHO], 2015). It entails a positive attitude towards sexual relationships, ensuring pleasurable and safe sexual experiences free from coercion, discrimination, or violence (WHO, 2015). Despite increased attention on the sexual health of people with mild intellectual disabilities since the normalisation movement in the 1970s, being sexually healthy remains challenging for people with mild intellectual disabilities (Correa et al., 2022; Lam et al., 2019). For people with mild intellectual disabilities, sexual health encompasses their needs in relationships, sexual experiences, and sexual selfhood (De Wit et al., 2023). Living and working in specialised institutions or with relatives (Kahonde et al., 2020; Top, 2022), people with mild intellectual disabilities have fewer opportunities to meet their sexual needs than people without disabilities do (Carter et al., 2021; Jahoda & Pownall, 2014; Stoffelen et al., 2017).

Supporting the sexual health of people with mild intellectual disabilities is equivalent to a dilemma between promoting autonomy and providing protection (Bates et al., 2020). On the one hand relatives and

support staff recognise and encourage the sexual rights of people with mild intellectual disabilities, while on the other hand, they often hinder sexual experiences from concerns about sexual risks (Bay-Cheng et al., 2022; Lam et al., 2022). Recurrently, the personal attitudes of relatives and support staff determine the provided support and education provided (Leclerc & Morin, 2022). Relatives and support staff holding primarily supportive attitudes often focus on the physical and emotional needs of people with mild intellectual disabilities (Bates et al., 2021; Deffew et al., 2022). Restrictive attitudes have been found among relatives and support staff who perceive the sexual health of people with mild intellectual disabilities as abnormal, emphasising their support needs and vulnerability (Deffew et al., 2022; Frawley & O'Shea, 2020; Kahonde et al., 2020). Despite recognising the sexual rights and needs of people with mild intellectual disabilities (De Wit et al., 2022; Lam et al., 2019), relatives and support staff with more restrictive attitudes often hinder people with mild intellectual disabilities from gaining sexual experiences, due to concerns about privacy and sexual risks (Bay-Cheng et al., 2022; Lam et al., 2022).

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Although research comparing the attitudes of relatives and support staff towards the sexual health of people with mild intellectual disabilities is limited (Bates et al., 2021; Charitou et al., 2020), recent studies suggest that support staff may be relatively more accepting of their sexual rights (Correa et al., 2022), and more willing to discuss sexual matters with people with mild intellectual disabilities (Evans et al., 2009). Furthermore, most relatives believe that providing sex education should be the responsibility of support staff (Gürol et al., 2014; Neuman, 2021). However, a recent study reported that mothers consider sexual support a part of their parental role, even for their adult children with mild intellectual disabilities (Charitou et al., 2023). The existing research on the differences in attitudes between relatives and support staff remains inconclusive, necessitating further investigation.

Relatives and support staff are in need of support to prevent variations in sexual support and education resulting from different personal attitudes, as these might confound people with mild intellectual disabilities in what constitutes sexual health (Brown & McCann, 2019). Guidelines and training may aid in supporting relatives and support staff to address the sexual health needs of people with mild intellectual disabilities (Lam et al., 2022). The aim of this study was to explore the perceptions of relatives and support staff regarding the sexual health of people with mild intellectual disabilities in order to inform these guidelines, training, and future research.

## Method

### Design

A concept mapping procedure was selected as it allows researchers to explore and compare the perceptions of relatives and support staff on the complex concept of

sexual health for people with mild intellectual disabilities. This procedure allows for the integration of participants' perspectives into a visual representation, enhancing the comprehension and comparison of this complex concept between the two perspectives (Kane & Trochim, 2007). This approach has been successfully employed in various healthcare studies, including those focused on sexuality (Gausman et al., 2021) and intellectual disability (e.g., Kersten et al., 2023; Lokman et al., 2022; Nijs et al., 2022). In concept mapping, qualitative and quantitative research methods are integrated, allowing the participants to collectively develop an understanding of the research topic while incorporating individual input (Rosas & Kane, 2012).

### Participants

After ethical approval was provided by the Ethics Review Board of Tilburg University (RP612), relatives and support staff were recruited through purposive sampling. Selection criteria were predefined to ensure maximum variation in ideas within the research sample (Kane & Trochim, 2007), including both male and female perspectives, and different age groups. As sexuality during adolescence is influenced by hormonal and physical changes (Collins et al., 2009), only relatives and support staff with experience in supporting adults with mild intellectual disabilities were included. The relatives had to be involved in the support of a related adult with mild intellectual disabilities receiving support from an intellectual disability service provider, for example as a legal representative. Support staff had to provide direct support with at least two years of experience working with adults with mild intellectual disabilities. In total, 7 relatives (5 mothers, 1 aunt, and 1 father) and 15 support staff (9 women and 6 men) agreed to participate. Additional participant demographics are provided in Table 1.

**Table 1.** Characteristics of participants.

	Relatives	Support staff
Gender		
Male	1	6
Female	6	9
Age in years	55 (range 51–60)	37 (range 23–60)
Gender of child with mild intellectual disabilities		
Male	2	
Female <sup>a</sup>	5	
Age of child with mild intellectual disabilities	26 (range 18–39)	
Current work experience		
Residential		12
Community care		3
Previous work experience <sup>b</sup>		
Residential		14
Community care		8
Years of work experience with people with mild intellectual disabilities		12 (range 4–24)

<sup>a</sup>One daughter identified as male.

<sup>b</sup>Some participants had multiple previous work experiences.

## Procedure

Organisations providing residential and outpatient care and support for people with intellectual disabilities in the Netherlands and associated with the Academic Collaborative Centre Living with an intellectual disability (ACCL) were contacted to participate in the study. In the ACCL, the Tilburg University collaborates with 17 healthcare organisations for people with intellectual disabilities and the Dutch Self-Advocacy Federation and for people with intellectual disabilities (LFB) to develop scientific knowledge and to initiate care innovations. Five organisations agreed to participate, and contacts within their organisations (for instance a policymaker or a manager) provided a list of eligible participants based on selection criteria provided by the first author. The contacts approached the eligible participants and asked permission to receive an information letter and an informed consent form. Once all eligible participants had agreed to take part in the study, the first author provided them with the letter and consent form. Upon receipt of written informed consent, participants were invited to participate in a concept mapping procedure specific to relatives or support staff.

Noteworthy, the recruitment process was affected by the COVID-19 pandemic and associated healthcare regulations, initially resulting in a lower-than-desired number of participants – namely, 6 female relatives and 7 female support staff. To include a male perspective a second opportunity to participate as offered to relatives which eventually led to 1 father participating. For support staff, conducting a second online group meeting was deemed unfeasible due to high absence numbers and work stress. Instead, additional support staff were invited to participate in the sorting and rating task, as it could be done privately. This approach resulted in 8 additional participants, including 6 men.

After the recruitment process was complete, participants were invited to participate in a concept mapping procedure, consisting of four consecutive steps, including (1) brainstorming, (2) prioritising and clustering, (3) statistical analysis, and (4) interpretation (Kane & Trochim, 2007).

### Step 1. Brainstorming the statements

Separate online brainstorming sessions were conducted for relatives and support staff, adhering to COVID-19 regulations. The sessions utilised Microsoft Teams software for video conferencing and were recorded for future reference. An experienced male and female researcher facilitated all sessions. The first researcher served as the chairperson to encourage open discussion and brainstorming among participants. The second

researcher took on-screen notes capturing key points. Following a brief introduction outlining the aim of the study, participants were prompted to respond to the focus sentence: “Sexual health for people with mild intellectual disabilities consists of ...” The duration of the focus groups varied based on data saturation. Support staff sessions lasted approximately 75 minutes and relatives’ sessions were approximately 60 minutes for the first session and 35 minutes for the second session (with the father as participant). The brainstorming sessions resulted in a statements list for each participant group, which was edited to ensure clarity, combine overlapping ideas, eliminate duplication, and remove statements unrelated to the focus sentence.

### Step 2. Prioritising and sorting the statements

Next, each participant group (relatives and support staff) was invited to complete two computer-based assignments using Group Wisdom computer software (Lokman et al., 2022). The first assignment involved ranking the statements collected on a 5-point Likert scale, ranging from 1 (“Not important”) to 5 (“Very important”). In the second assignment, the participants were tasked with sorting the statements into piles based on their similar meanings. They were encouraged to create multiple sorting piles to avoid a binary inclusion and exclusion categorisation. Also, each sorting pile had to include a minimal of two statements, and a “Miscellaneous” pile was not allowed. The participants could label the sorting piles at any time, but they were prompted to review and label any unnamed piles upon completing the sorting task.

### Step 3. Statistical analysis

The researchers utilised Group Wisdom software to statistically analyse the data (Kersten et al., 2023; Lokman et al., 2022). A point map was generated positioning statements closer together when sorted frequently together in the second step of the procedure. Conversely, statements positioned further apart were assumed to have different meanings in their relation to sexual health. Through a hierarchical cluster analysis, multiple clusters were identified on each point map. Next, the relative importance of each cluster to the central concept was calculated. The results of the analysis yielded two visual concept maps depicting the respective understanding of relatives and support staff on the sexual health for people with mild intellectual disabilities.

### Step 4. Interpretation of the concept map

To confirm the concept mapping procedure (Kane & Trochim, 2007), the resulting concept maps were

presented sequentially during a meeting with additional expert participants conducted online using Microsoft Teams software. The expert group consisted of five female participants with relevant knowledge and experience based on completed education or training in a sexuality-related subject and at least two years of work experience: two mental health psychologists with expertise in the intellectual disability field and sexual support and education, a sexologist specialised in the intellectual disability field, and two experts who had experience with mild intellectual disabilities. All participating experts were approached through contacts of healthcare organisations related to the ACCL and permission sought to receive an information letter and informed consent form. These were provided to them by the first author after their permission had been obtained. Participants with a mild intellectual disability were offered an additional individual meeting during recruitment to explain the aim and procedure of the study. Prior to the meeting, the experts received a clustered statements list and were asked to label the clusters. During the meeting, the experts engaged in discussions and collectively determined the final labels for the clusters. The expert meeting was facilitated by two researchers, with the first researcher chairing to ensure a respectful and open exchange of ideas with input from all participants, and the second researcher noting the final labels live on screen within the concept map. Once all the clusters were labelled, the experts reviewed the labelled cluster maps to identify emerging dimensions.

## Results

In total, 161 statements on the sexual health of people with mild intellectual disabilities were collected, with 94 statements provided by relatives and 67 statements by support staff. (An overview of these statements is available in the online supplementary data file.) The statements by relatives were merged into nine clusters, while support staff generated eight clusters. An overview of the clusters, the number of statements in each cluster, and the average rating in the prioritising task for relatives and support staff are provided in Table 2. Concept maps were created for both sets of clusters, with Figure 1 displaying the concept map representing the perspectives of relatives and Figure 2 depicting the concept map for support staff. In the following sections, the resulting concept map for relatives and its clusters will be clarified first, followed by the concept map for support staff. All clusters will be discussed on ranking position with corresponding cluster numbers unless otherwise indicated.

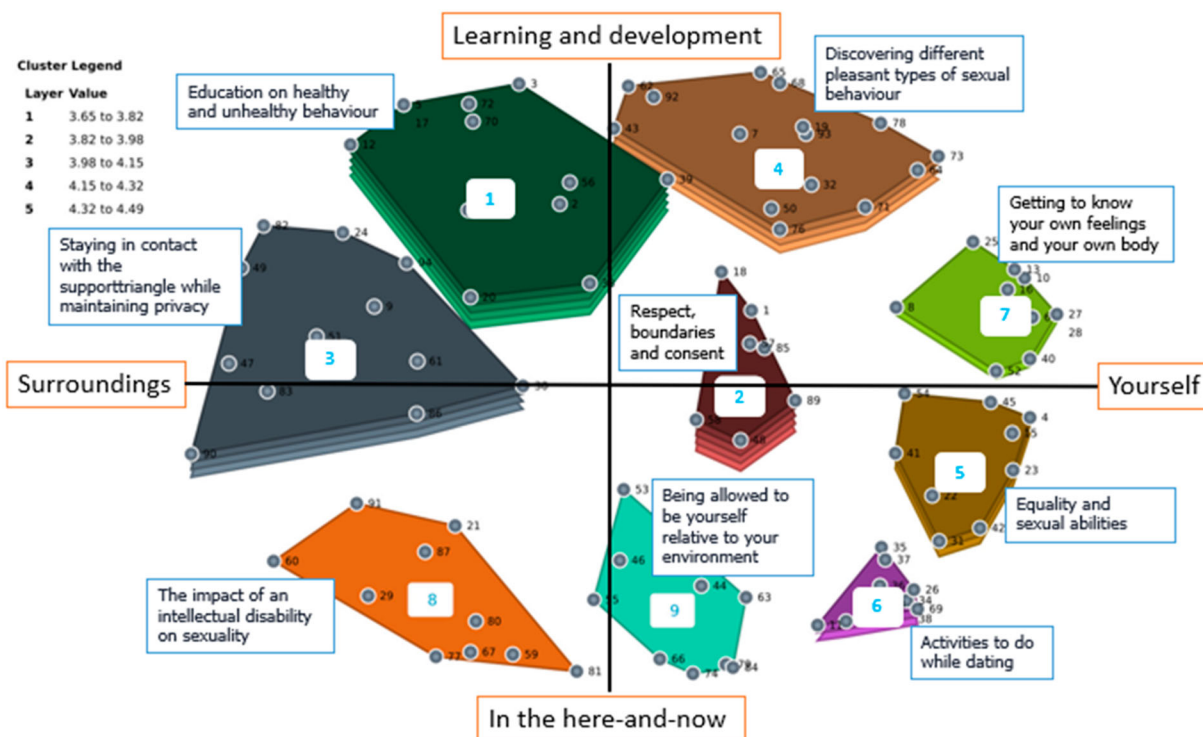
**Table 2.** Cluster labels, number of statements and average rating for relatives and support staff.

Cluster	Relatives	Support staff
1	Education on healthy and unhealthy behaviour (12; 4.49)	Discovering what you find pleasurable (20; 4.32)
2	Respect, boundaries, and consent (7; 4.33)	Feeling safe enough (5; 4.3)
3	Staying in contact with the support triangle while maintaining privacy (12; 4.31)	Accepting sexual behaviour (4; 4.24)
4	Discovering different pleasant types of sexual behaviour (15; 4.2)	Sexual support and education adjusted to individual needs (10; 4.19)
5	Equality and sexual possibilities (9; 4.02)	Developing and expressing your own gender identity (10; 4.16)
6	Activities to do while dating (10; 3.98)	Talking and openness about sexuality (12; 4.08)
7	Getting to know your own feelings and your own body (10; 3.88)	Sex education focused on the social area (5; 4.05)
8	The impact of an intellectual disability on sexuality (10; 3.78)	Accepting autonomy and experimentation (3; 3.74)
9	Being allowed to be yourself relative to your environment (9; 3.65)	–

## Relatives

According to relatives, the most important cluster related to the sexual health of people with mild intellectual disabilities was labelled “Education on healthy and unhealthy behaviour” (12 statements). This cluster emphasised the significance of sex education in understanding what constitutes healthy sexual behaviour, with specific statements highlighting examples of unhealthy sexual behaviours, such as “using objects not intended for sexuality,” “flashing yourself” and “not exercising your sexuality uninhibitedly” (Statements 17, 70, and 72). Relatives also emphasised the need to warn girls about the potential risk of “falling victim to sex traffickers” (Statement 33). Healthy sexual behaviours were associated with engaging in sexual activities at “suitable places for sexual behaviour” and the notion that “it remains safe for everybody and yourself” (Statements 3 and 75).

The second most important cluster identified by the relatives was labelled “Respect, boundaries and consent” (7 statements). This cluster emphasised the importance of understanding how to interact with potential partners. According to relatives, “both boys and girls can have bad experiences” (Statement 1), which concerned sexual abuse. To develop a healthy relationship, relatives considered “being asked what you want” to be important, as was “respecting that the other does not want to have sex,” and to “communicate your boundaries openly when it comes to sex” (Statements 57, 85 and 89). Furthermore, being “on the same page about how



*Note:* more layers indicate more importance.

**Figure 1.** Relatives' concept map on sexual health for people with mild intellectual disabilities.

*Note:* More layers indicate more importance.

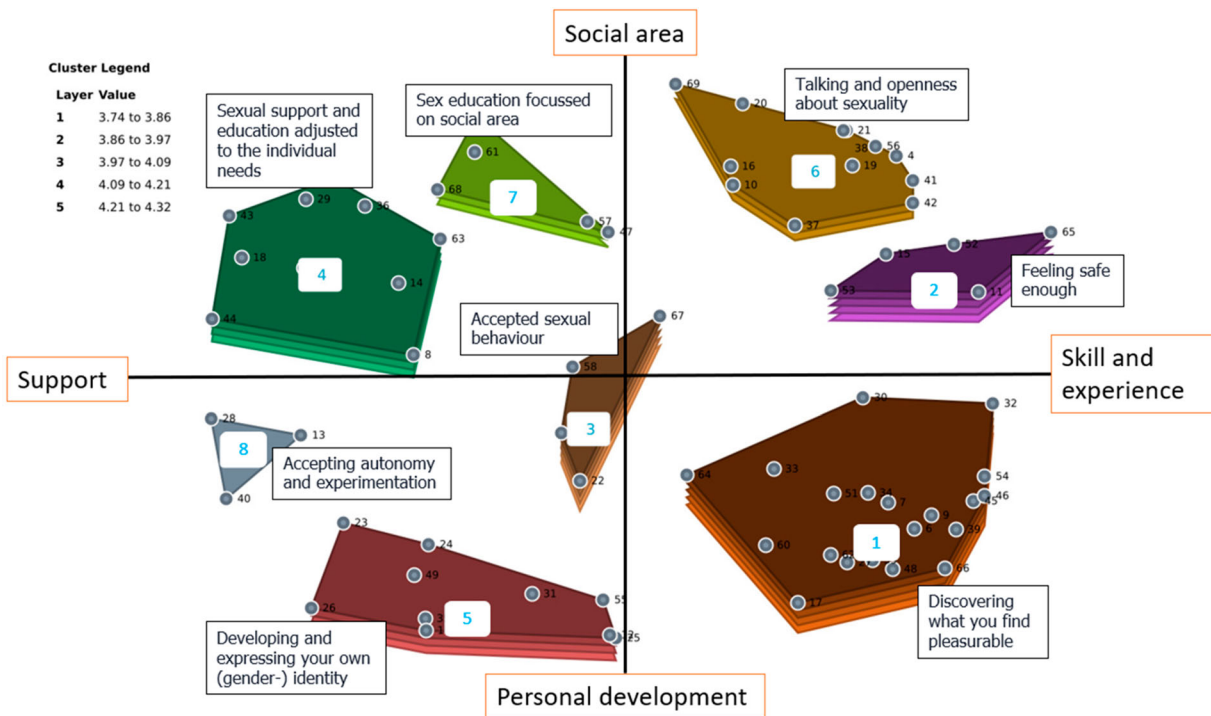
often you have sex" (Statement 58) within a relationship was considered important.

The third cluster was labelled "Staying in contact with the support triangle, while maintaining privacy" (12 statements) with statements focused on the necessary collaboration between people with mild intellectual disabilities, their relatives and the support staff to promote sexual health. The collaboration between these three groups was referred to as the "support triangle" (Statement 90). Relatives considered it important for people with mild intellectual disabilities to "discuss [sexuality] with parents and support staff" (Statement 82), although some issues might be considered more sensitive and so possibly "private" (Statement 9). Furthermore, some people with mild intellectual disabilities might "talk to someone who they trust or have a connection with" (Statement 83). Relatives also highlighted that to maintain a working relationship, "people with intellectual disabilities and support staff being together is not okay, because of the hierarchical order and care tasks" (Statement 49). This was considered to be worth mentioning, as people with mild intellectual disabilities "can feel attracted to young support staff without crossing the line" (Statement 24) and they should

"know the difference between support staff and potential partners" (Statement 86).

The fourth cluster was labelled "Discovering different pleasant types of sexual behaviour" (15 statements). This cluster described different forms of sexual behaviour and referred to sexual health as a developmental process. The sexual behaviours included "sex" (referring to sexual intercourse; in Statement 73), "making love to yourself" (Statement 78), and "calling upon a sex care worker" (Statement 93). Some relatives described how sexual behaviour "starts with sexual self-exploration: what does my vagina or penis look like" (Statement 68), while "learning the boundaries for how far you can go in your behaviour" (Statement 32). Relatives mentioned how people with mild intellectual disabilities learn valuable skills during this developmental process, including "recognising when you are approached sexually" (Statement 76) and "knowing what you can and cannot do about your sexual arousal" (Statement 92).

The cluster labelled "Equality and sexual abilities" (9 statements) ranked fifth and highlighted the equal sexual abilities of individuals with mild intellectual disabilities in comparison to those without disabilities, according to relatives. The statements included, "the journey of discovery is the same process for everybody"



*Note:* more layers indicate more importance.

**Figure 2.** Support staff's concept map on sexual health for people with mild intellectual disabilities.

*Note:* More layers indicate more importance.

(Statement 23) and “it is okay to look [at women], as every man would do” (Statement 41). Equality was also considered an important aspect to strive for within relationships. To do so, one should be able to “stand up for yourself within a relationship,” “be allowed to determine what feels right or wrong for yourself” and “before you have sex, you should have gained trust in each other” (Statements 22, 54 and 56).

In cluster 6, labelled “Activities to do while dating” (10 statements), relatives provided insights into the activities and conditions that they considered important during the dating process. In this cluster, relatives mentioned various behaviours, such as “sharing a dinner,” “walking hand in hand” and “watching a romantic movie” (Statements 11, 38 and 69). In addition, they mentioned several conditions they considered helpful for dating, such as “a girlfriend who lives somewhere in the neighbourhood” (Statement 14).

Cluster 7 was labelled “Getting to know your own feelings and your own body” (10 statements) and focused on the development of the individual’s sexual self. According to relatives, people with mild intellectual disabilities should “first discover for yourself what you like,” to have “watched yourself in the mirror” and to “learn to experience sexual sensations when you touch

your own body with your own hands” (Statements 10, 13 and 28). Some relatives noted that this “journey of discovery can take longer because of a slow start due to the intellectual disability” (Statement 6). For people with mild intellectual disabilities, it is important to learn “what they are allowed to see and say” and to “understand your own feelings” (Statements 16 and 52).

The barriers individuals with mild intellectual disabilities face concerning their sexual health were described in label 8 “The impact of an intellectual disability on sexuality” (10 statements). These barriers included the risk of “not recognising the intellectual disability” (Statement 29) while dating, as it could lead to disappointment. Other barriers were related to social skills, such as “it can be more difficult to connect with peers,” as well as the difficulty to “verbally express your interest in another” (Statements 60 and 87). Additionally, some relatives stated how love and relationships could be sought for other reasons than those of people without disabilities. For example, relatives stated that “love can have a different meaning for people with mild intellectual disabilities” and that someone might “crave for a girlfriend as a buddy” (Statements 59 and 77). To cope with these barriers, a suggestion was to “search on a dating site with support

for people with mild intellectual disabilities” (Statement 81).

The least important cluster for the sexual health of people with mild intellectual disabilities was Cluster 9, labelled “To be yourself related to your environment” (9 statements). This cluster reflected the perception of relatives regarding the desires of people with mild intellectual disabilities to align with social norms. For example, relatives perceived people with mild intellectual disabilities as wanting “the same things as anybody else” (Statement 53), including “a girlfriend to fit in with everybody else” (Statement 79). In addition, they mentioned desires through which people with mild intellectual disabilities attempted to fit in, including “wanting to be able to flirt with each other,” “to be able to attend a party with their girlfriend” and “to be happy with their relationship” (Statements 44, 74 and 84).

The above-mentioned clusters were distributed over two dimensions relating to the sexual health of people with mild intellectual disabilities according to relatives. On the left side of the *x*-axis, Clusters 1 and 3 were focused on the “surroundings,” highlighting the importance of support, education and the necessary collaborative relationship between individuals with mild intellectual disabilities, their relatives and support staff. On the right side of the *x*-axis, the statements related to “oneself,” and included Clusters 2, 5, 6 and 9 exploring different aspects of relationships from the perspective of people with mild intellectual disabilities, including dating, equality with others and behaviour within relationships. Above the *y*-axis, Clusters 4 and 7 addressed “learning and development,” encompassing the sexual development of people with mild intellectual disabilities regarding their sexual feelings and behaviour. Finally, below the *y*-axis, Cluster 8 discussed the sexual health of individuals with mild intellectual disabilities “in the here and now,” focusing on the barriers they face while dating and seeking relationships.

### Support staff

The top-ranked cluster regarding sexual health of people with mild intellectual disabilities according to support staff, was labelled “Discovering what you find pleasurable” (20 statements). The statements in this cluster described positive aspects of sexual health development, including sexual behaviours, personal identity, and confidence. Sexual behaviours included “figuring out if you enjoy a touch,” “having sexual pleasure” and “becoming aware of what you like” (Statements 7, 51 and 59). Additionally, related to keeping sexual behaviours pleasurable, included statements reflected on the importance of “learn[ing] what your boundaries are”

(Statement 46) and “not crossing boundaries” (Statement 60). Other statements referred to discovering one’s personal identity and feeling confident with oneself, such as “becoming aware of who you are,” “having a good self-image,” “feeling comfortable with yourself” and “having self-confidence” (Statements 17, 39, 54 and 66).

The second cluster emphasised the importance of “Feeling safe enough” (5 statements). The statements in this cluster described how people with mild intellectual disabilities need to feel sufficiently secure in their relationship with support staff to have a conversation about their sexual feelings. This was expressed in statements such as “to express yourself safely,” “feeling safe enough to talk about sexuality” and “daring to talk about it” (Statements 11, 52 and 65). To promote these feelings of safety, it was suggested that support staff should provide “support with compassion” (Statement 15).

The importance of open conversations on sexual health between support staff and people with mild intellectual disabilities was further described in Cluster 6, labelled “Talking and openness about sexuality” (12 statements). The statements in this cluster described the conditions for an open conversation on this topic. According to support staff, “sexuality is not a taboo subject” but a “familiar subject” (Statements 20 and 42), which can also “be fun to talk about” (Statement 41). Furthermore, people with mild intellectual disabilities should be able to have “a normal conversation with support staff,” “with parents,” “with peers and other people” (Statements), or with “someone who they feel comfortable with” (Statement 19, 21, 38 and 56). The final condition mentioned was that people with mild intellectual disabilities should “have the vocabulary to be able to talk about sexuality” (Statement 69).

The third-ranked cluster was labelled “Accepted sexual behaviour” (4 statements) and described the conditions for accepting sexual behaviours according to support staff. It emphasised that people with mild intellectual disabilities should “have sexual contact voluntarily” (Statement 50) and “should continuously learn what behaviour should not be displayed publicly” (Statement 67). Likewise, it was suggested that “sexuality does not have to be secretive” (Statement 58) and that support staff should also “allow [people with mild intellectual disabilities] to enjoy sexual services” (i.e., paid sex with sex care workers within a care provider context; Statement 22).

Cluster 4 was labelled “Sexual support and education adjusted to individual needs” (10 statements). Included statements described important topics and conditions for successful sexual support and education, such as



being designed to “prevent negative sexual experience” and “prevent having children” (Statements 8 and 29). Likewise, included statements suggested that support and education should “focus on safe sex” and “sexually transmitted infection (STI) prevention” (Statements 3 and 43). Other important topics included “options to experience sexuality in a way that people with mild intellectual disabilities can cope with, ranging from sexual relations to alternatives such as justifiable pornographic movies, magazines, sex care and prostitutes” (Statement 44). According to support staff, sexual support and education should also be adjusted to individual needs by being “continuous” and “well-timed” (Statements 5 and 36).

The significance of sex education was further described in Cluster 7, labelled “Sex education focused on the social area” (5 statements). This cluster complemented the topics addressed in Cluster 4 by emphasising the goals of sexual support and education from a social perspective. The statements described what people with mild intellectual disabilities should learn to engage in healthy sexual behaviours within a social context. This included “continuously learning what thoughts should not be shared with others,” “to know what to expect from others in social surroundings and what the boundaries are,” and to have “sufficient sexual knowledge through full sex education” (Statements 57, 61 and 68).

The fifth-ranked cluster was labelled “Developing and expressing your own gender identity” (10 statements) and discussed the importance for people with mild intellectual disabilities to explore their sexual feelings and gender identity. The statements on discovering their identity mostly related to sexual expressions, such as “transgender feelings,” “non-binary and homosexuality” and “different sexual desires, such as fetishes” (Statements 1, 26 and 55). Support staff also described how people with mild intellectual disabilities should be able to express their sexual and gender identity. This was expressed in statements such as “express your self-image,” “be allowed to have multiple sexual partners” and “experience your arousal with your preferences, for example with raincoats, shoes and feet” (Statements 12, 24 and 31).

Cluster 8 was considered the least important by support staff and labelled “Accepting autonomy and experimentation” (3 statements). The cluster focused on the possibilities for people with mild intellectual disabilities to exercise autonomy in their sexual health. This included statements about people with mild intellectual disabilities having “a choice to organise their life according to their desire to have children” (Statement 13) and “being allowed to have sexual contact with other people

with intellectual disabilities under support” (Statement 28). Furthermore, this autonomy included having “room for sexual experimentation” (Statement 40).

The resulting dimensions on the  $x$ - and  $y$ -axes were interpreted by the experts. Below the  $y$ -axis, Clusters 1 and 5 represented “Personal development,” addressing sexual identity, feelings, and behaviours for people with mild intellectual disabilities. Above the  $y$ -axis, Clusters 4 and 7 represented the “Social area,” emphasising the importance of sexual support and education in learning social norms. The right side of the  $x$ -axis, labelled “Skill and experience,” included Clusters 2 and 6, which highlighted the need for open conversations between support staff and individuals with mild intellectual disabilities to foster growth in sexual skills and experience. Finally, the left side of the  $x$ -axis was labelled “Support,” as it described conditions that support the sexual self-determination of people with mild intellectual disabilities in Clusters 3 and 8.

## Discussion

To inform future guidelines, training and research, a concept mapping study was conducted to investigate aspects of sexual health of individuals with mild intellectual disabilities based on the perspectives of relatives and support staff. Participants generated statements which were used to create concept maps for each group. The maps were then separately prioritised and clustered. While the clusters were ranked in order of importance, it is relevant to note that the participants considered even the lowest-ranked clusters significant for the sexual health of people with mild intellectual disabilities.

The concept maps from both relatives and support staff revealed mostly similar dimensions, including “developing sexual behaviour and feelings,” “the working relationship between people with mild intellectual disabilities, their relatives and support staff,” and “the need for sexual support and education.” Relatives also emphasised “relationships” in their concept of sexual health, where support staff included more sexual identity-related statements, for example, referring to transgender identity and sexual fetishes. These differences in perspectives might be related to the generally older age of participating parents, as having older age is often related to more conservative attitudes on sexual health (Deffew et al., 2022). Furthermore, these differences might result from the personal or professional relationship with people with mild intellectual disabilities (Correa et al., 2021). Unlike previous studies (Correa et al., 2022), there was no clear distinction between relatives and support staff regarding their level of

restrictiveness or supportiveness concerning sexual health. This study made three key findings that will be discussed in detail below, highlighting the similarities and differences between the perspectives of relatives and support staff.

First, both relatives and support staff were found to recognise the significance of sexual development – including sexual feelings and behaviours – for the sexual health of people with mild intellectual disabilities. Relatives stated that the sexual development of people with mild intellectual disabilities is similar to that of those without disabilities, albeit with possible delays, aligning with previous research (Kijak, 2013). Moreover, the study reaffirmed previous findings (Charitou et al., 2023; Neuman, 2021) highlighting the continued importance of a developmental perspective throughout adulthood. This finding might extend the WHO's definition of sexual health, which describes it as a state rather than a process (WHO, 2015). Future research and the provision of sexual support and education for people with mild intellectual disabilities should incorporate a developmental perspective into the concept of sexual health.

In addition to the developmental aspect, both relatives and support staff in our study mentioned a wide range of sexual feelings and behaviours, including arousal, kissing, touching, masturbation and intercourse, which is consistent with previous studies (de Wit et al., 2021; Medina-Rico et al., 2018). Participants in the current study also reported the involvement of sex care workers, and the exploration of personal fetishes, which had not been previously reported to our knowledge. These findings indicate that according to relatives and support staff, a broad range of sexual behaviours can be considered healthy for people with mild intellectual disabilities. Moreover, both relatives and support staff appeared to associate pleasurable sexual behaviours with understanding one's sexual preferences and boundaries, which aligns with previous studies on the sexual health of adolescents without disabilities (Boislard et al., 2016). Therefore, future research is recommended to explore the importance of sexual experiences for the sexual health of people with mild intellectual disabilities and its practical implications.

Secondly, in our study, relatives ranked relationships as the least important aspect of sexual health for individuals with mild intellectual disabilities, while support staff did not mention relationships as a separate cluster at all. However, recent research suggests that people with mild intellectual disabilities themselves consider relationships as the most important aspect of their sexual health (De Wit et al., 2023). Earlier studies found that relatives and support staff tend to underestimate

the importance of relationships for people with mild intellectual disabilities and to question their romantic interests (Charitou et al., 2023; Retznik et al., 2022). Underestimating the importance of relationships may result in inadequate sexual support and education for people with mild intellectual disabilities (Retznik et al., 2022). Given the importance of tailoring sexual support and education to individual needs (De Wit et al., 2022; Neuman, 2021), it is crucial for relatives and support staff in practice to prioritise relationships.

Finally, both relatives and support staff emphasised the importance of sexual support and education in promoting sexual health for people with mild intellectual disabilities. They underlined the need to acquire knowledge about healthy and unhealthy sexual behaviours, including personal boundaries and appropriate sexual behaviour. Support staff particularly emphasised the prevention of negative experiences (i.e., safe sex and STI prevention) and having children. This focus on sexual risks aligns with previous research on sex education (Azzopardi-Lane, 2022; Hole et al., 2022). However, an overemphasis on sexual risk has been associated with more restrictive forms of support (Lam et al., 2019). This contradicts the positive attitude towards sexual health that is required to promote sexual health (Parchomiuk, 2021).

Furthermore, in the current study, both relatives and support staff highlighted the importance of the working relationship between individuals with intellectual disabilities, their relatives and support staff. Relatives believed that the three parties involved should cooperate, consistent with previous studies (Lam et al., 2019). However, other studies show contradictory results regarding whether to involve (Brown et al., 2020) or exclude relatives (Neuman, 2021). The support staff stressed the importance of supporting sexual autonomy, allowing individuals to make decisions about their sexual expression and their sexual partners. Previous studies have shown that sexual autonomy can improve through open discussions about sexual health with adolescents without disabilities (Riley & McDermott, 2018). This may also be applicable to people with mild intellectual disabilities (Skuban-Eiseler, 2022). Indeed, in the current study, both relatives and support staff stressed the importance of open discussions about sexual health, with relatives emphasising the need to balance openness with privacy. These findings have important implications for practice, as guidelines and training should promote open discussions of sexual health and a positive attitude, while respecting privacy.

In considering the perspectives from relatives and support staff on the important aspects of sexual health

for people with intellectual disabilities, some limitations should be addressed. Firstly, the participating relatives were limited to those using care from a single healthcare organisation. Secondly, the initial brainstorming sessions only included female participants in both participant groups. To address this, a second brainstorming session was organised for relatives, with one father attending. For support staff, this was addressed by recruiting both male and female participants for the computer-based rating and sorting task. Nevertheless, the research predominantly consisted of women within the study population, reflecting the demographic of the individuals under investigation, including relatives and support staff. This may have influenced the findings, resulting in a predominantly female perspective. Thirdly, the expert meeting did not include input from an experienced researcher, which could have provided a more comprehensive outlook on the discussion of the concept maps. Finally, in the brainstorming session, both relatives and support staff referred to sexual behaviour and relationships. From these statements, it remains unclear if the participants assumed that people with mild intellectual disabilities would only have relations with other people with (mild) intellectual disabilities, or if it also included people without disabilities. It is recommended to replicate the study in diverse cultural and international settings while addressing these limitations.

This study provides valuable insights for practice and research. In practice, it is important to view sexual health in a developmental perspective, for which people with mild intellectual disabilities need the possibility to have sexual experiences. According to the participants, this experiential learning adds to developing one's sexual preferences, their boundaries, and the skills to adhere to them, that is, promoting sexual autonomy. Moreover, the results of the study indicate that relatives and support staff are to collaborate with people with mild intellectual disabilities to promote their sexual health. A positive attitude is deemed conditional for this working relationship to promote an open dialogue.

In research, in line with the perspectives of people with mild intellectual disabilities on their sexual health (De Wit et al., 2023), relatives and support staff emphasised the importance of recognising a wide range of sexual feelings and behaviours in people with mild intellectual disabilities, viewing sexual health as a developmental process similar to that of people without disabilities, albeit with potential delays. They also emphasised the need for a positive attitude towards sexual health, while balancing the promotion of sexual experiences with the protection from sexual risks. As such, the study underscored the significance of sexual

support and education, open discussions and the inclusion of sexual experiences and relationships in promoting sexual health in people with mild intellectual disabilities. However, recent reviews have indicated that restrictive measures from relatives and support staff are still prevalent (e.g., Lam et al., 2019). Therefore, further research is needed to determine how to provide sexual support and education that promotes optimal sexual health for people with mild intellectual disabilities.

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### Data availability statement

The data that support the findings of this study are openly available in Dataverse at <https://doi.org/10.34894/AS4NLG>.

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