Views on Sex Using the Nominal Group Technique to Explore Sexuality and Physical Intimacy in Individuals with Intellectual Disabilities

J. M. T. Stoffelen^{1,2,3} · D. Schaafsma^{1,4} · G. Kok^{1,2} · L. M. G. Curfs¹

Published online: 11 December 2018
© The Author(s) 2018

Abstract

Individuals with an intellectual disability (ID) have sexual feelings, are sexually active and have ideas about sexuality. There is limited information available about the ideas and experiences regarding sexual expression, interests and knowledge of sexual rights in this population. This study aims to identify the ideas, expressions, barriers to sexuality, experienced by people with IDs, using the Nominal Group Technique (NGT). The NGT was used to explore the views of people with mild ID on sexual needs and issues. NGT is a structured and specific form of focus group research. It is a ‘single-question’ technique that combines quantitative and qualitative methods of data collection for relatively small groups. NGT involves four steps: silent generation of ideas, round robin recording of ideas, clarification of ideas, and ranking of ideas. It was an inclusive research project: people with an ID were involved in the design, planning, performance, and analysis of the study. In total 39 people with mild IDs were able to explore their experiences and ideas on sexuality. They were able to answer questions like: What are their needs? What are their problems? They were capable of expressing their views, needs and barriers on sexuality and sexual rights. The most important items were the relationship between two people (47%), sex and sex related subjects as sex education (23%), and feeling safe and comfortable (10%). People with mild IDs are capable of expressing their views on sexuality and sexual rights. The participants stated that they need support in achieving these rights. The nominal group technique appears to be an appropriate methodology on sensitive issues as sexuality and sexual rights.

Keywords Sexuality · Sex · Sexual rights · Intellectual disability · Learning disability · Inclusive · Research · Methodology · The Netherlands

✉ J. M. T. Stoffelen
Joke.stoffelen@maastrichtuniversity.nl

¹ Governor Kremers Centre, Maastricht University, Maastricht, The Netherlands

² Psychology and Neuroscience, Work and Social Psychology, Applied Social Psychology, Maastricht University, Maastricht, The Netherlands

³ Zorgbelang Gelderland-Utrecht, Arnhem, The Netherlands

⁴ Fontys University of Applied Sciences, Eindhoven, The Netherlands

Introduction

Sexuality and Sexual Rights

Sexuality is an essential human capability: “Having the opportunity for sexual satisfaction and choices about reproduction” [29]. The World Association for Sexual Health (WAS) promotes sexual health by developing sexual rights for all. The WAS [60] has specified a number of sexual health rights, including the right to privacy, the right to sexual health, the right to marriage and to start a family, the right to decide on the number of children, the right to information and education, the right to freedom of opinion and expression, and the right to protection of these rights. Sexuality should be a positive part of the human experience and human life [47]. These rights apply to all people, including people with disabilities [43]. People with an intellectual disability (ID), like everyone else, have sexual feelings, needs, and desires. According to the American Association on Intellectual and Developmental Disabilities, ‘These sexual rights and needs must be affirmed, defended, and respected’ (in ‘Position Statement Sexuality’ [1]). People with mild IDs have the right to make independent decisions about with whom, how and when they want to have sex. In this respect, they have the right to dignity, respect, privacy, confidentiality and freedom. See “Appendix” (Table 2) for the definitions of sex, sexuality, sexual health and sexual rights.

People with an Intellectual Disability

Of the global population, 1.04% has an ID [21]. Just as the population of people with an ID is very diverse [8], so too are they diverse in terms of sexual desires and sexual experiences. ID, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; [4]), is characterised by a substantial impairment in both cognitive functioning (an IQ of below 70) and adaptive behaviour, originating in the developmental period (before age 18). Impairments can impact a range of skills, including conceptual skills (such as reading and writing, understanding money, time, and numbers), social skills (such as interpersonal relationships, self-confidence, obeying rules and laws, avoiding victimization) and practical adaptive skills (including activities of daily living, dealing with money, healthcare, and safety). The definitions of ID are not unequivocal. The conceptual framework is also subject to change [39, 40].

Sexual Rights in Practice

People with ID experience barriers in realising their sexual rights in practice: they are extra vulnerable to sexual abuse; they have a lack of knowledge and skills; they are dependent on others; they are unable to talk openly with their parents or caregivers about their sexual relationships; and they have limited information.

The World Association for Sexual Health (WAS) designed *The Millennium Development Goals* [59]. Promoting sexual health is a key role because ‘Individuals and communities who experience sexual wellbeing are better positioned to contribute to be eradication of individual and societal poverty’. The WAS declared sexual rights from the point of view that ‘sexuality is an integral part of the personality of every human being.’ Watson et al.

[58] analysed sexual rights in relation to people with ID. Based on a literature review, they concluded that these rights have not been fully acknowledged or confirmed. People with ID are not given the respect and support that is required.

Sexual Abuse

For people with an ID, sexual abuse remains a serious problem [3, 9, 16, 33, 45, 54]. Over-protection, segregation, and a lack of skills among the residents themselves, make these people especially vulnerable to sexual abuse [17]. Even studies examining the sexuality of people with an ID, not specifically focusing on abuse, have reported incidents of sexual abuse in this group [36, 45]. Reiter et al. [33] found that young people with an ID are more often abused than young people without a disability. They are more likely to be forced to do things they do not want to do. Approximately 40% of the respondents with ID has been subjected to sexual abuse [33].

A Lack of Knowledge and Skills

A lack of knowledge about sexuality and sexual rights makes people with an ID especially vulnerable [28, 30]. People with an ID receive less sex education. As a result, they usually have less knowledge about topics such as pregnancy, safe sex, reproduction, masturbation, and sexual diversity than their peers without an ID [15, 18, 19, 22, 24, 28, 37]. A lack of knowledge and skills concerning sexuality, can result in being less capable of recognizing risky situations, which in turn increases the risk of sexual abuse [35].

Dependence on Others

Another important factor is the dependence on others for care and support. In their daily lives, individuals with ID have to deal with many professional carers [20, 48]. This support relationship is characterised not only by dependence, but also by a difference in power. This kind of relationship makes a person with an ID even more vulnerable, especially if someone has malicious intentions. The dependency is related to a lack of empowerment. For many people with an ID, it is difficult to take action if they experience something unpleasant, which is partly because they are not always taken seriously [41, p. 19]. Bernert [6] and McGuire and Bayley [26] found that people with an ID experience resistance from their immediate surroundings when exercising their sexual rights. Family members and caregivers apply different norms to people with an ID than they do to themselves or to people without a disability [7, 49, 62]. Training and support can enable family members and caregivers to talk about sexuality of people with an ID and to discuss this topic with them [3, 10, 45].

Limited Information

People with ID also have little access to information about their rights due to the inaccessible language used in the human rights documents. Stories and personal biographies in understandable language can enable people with ID to understand these rights and exercise them in their daily lives [2]. Training and support can help people with ID, family members, and carers to talk about the sensitive topic of sexuality [3, 10, 45].

Source of Information Considerations

When studying the sexuality of people with ID, proxies are often queried instead of the actual subjects. These proxies are often family members, staff from support institutions and caregivers. However, this should be done cautiously. It is difficult to predict the extent to which the responses of the proxies would match the responses of the subjects if they were questioned themselves [38]. People with an ID are in fact fully capable of discussing their views and experiences on ‘difficult’ topics [13, 42, 51–53]. They are also capable of discussing the research itself with the researchers [25, 57]. More research about sexuality is needed in which people with an ID are questioned directly, instead of their proxies. To support people with ID effectively, knowledge about their needs and wishes regarding sexuality is essential [12, 23].

Inclusive Research

Participative research with people with an ID, is a new step to achieve empowerment of people with ID. Walmsley and Johnson [57] refer to the history in which people with IDs were seen as people who ‘had nothing to say that was of value to researchers’ and were ‘passive beneficiaries’. They refer to [5] and their publication which represent the voices of people with IDs. More than 200 people with an ID disability talked about their experiences and their stories through drawings, poems, and other contributions. This caused a ‘paradigm shift’. Since then, people with IDs are involved in scientific research. Unfortunately, inclusive research on sexuality is scarce. They examined with people with an ID the societal barriers that lead to safer sexual lives.

A Method: The Nominal Group Technique

One method that can be used to study the opinions of people with an ID is the Nominal Group Technique (NGT). Previous research [11, 34, 52] has shown that NGT is an effective and acceptable method for determining and collecting the ideas and views of people with an ID. NGT is a structured and specific form of focus group research; it was first used at the end of the 1960s and was developed further by Van de Ven and Delbecq in [55]. The authors advocate this method when researchers want to determine the views of ‘users’ themselves in their own language, and want to minimise the influence of the researcher. The method is also suitable to use in determining the consensus in groups where the members are not of equal standing or have a relationship of authority, and in groups where participants find it difficult to express their individual views or are incapable of doing so [31, 32, 44]. The method is widely used in health-care studies; see [14] for a review of the relevant literature. NGT is a ‘single-question’ technique that combines quantitative and qualitative methods of data collection for relatively small groups [27] and has a number of basic steps: (1) generating individual ideas; (2) collecting the ideas; (3) presenting and clarifying the ideas; and (4) selecting and ranking the ideas.

Aim

In this study, a structured method (NGT) was used to hold discussions with people with an ID. Our aim was to acquire insight into what people in the target group believe is important, with respect to sexuality and their sexual rights. We addressed the following research question: *What do people with a mild ID believe is important with respect to their sexual rights?* We wanted to know how they experience their sexual rights in their daily lives. What are their wishes? What are their constraints? What kind of support do they need?

Method

The study design describes the research set-up; the membership of the advisory group; the components of the study with which the advisory members were involved; how the participants were recruited and how they were informed about the study. In addition, attention is paid to the methodology, ethics and the analysis.

Advisory Group

An advisory group was established for this study. This group consisted of four participants from LFB Zuidoost (a Self-Advocacy Group in the Netherlands) and their coaches. Their involvement in the study included a number of elements and tasks: involved and providing advice on the research design; the story line; the drawings; supporting group meetings; collaborating on the ‘interim step’ of the NGT method; devising a follow-up; and the analysis. The collaboration on the ‘interim step’ of the NGT method consisted of selecting ideas from each group and preparing a voting form. The co-researchers were guarding the principles of inclusive research: the issue must matter to people with an ID; the research must represent their views and experiences; people were treated with respect by the researchers [57].

Participants

In total, 39 people participated in the study, which included 14 women and 25 men. The average age was 44 years (with a range from 23 to 70 years). Researchers did not inquire after the level of social, emotional or intellectual function, nor the ethnicity of the participants. The participants in the research project were recruited from the *Onderling Sterk* groups in the Netherlands. *Onderling Sterk* groups are *self-advocacy* groups. There are no criteria for participation in these groups. The majority of people who join the *Onderling Sterk* groups function at the level of mild ID.

The participants were divided into six groups. The NGT method consists two group meetings. Some participants attended the first group meeting, but not the second one, and vice versa. In total, 35 participants attended the first meeting and 39 participants attended the second meeting. The meetings were facilitated by coaches and members

of the advisory group. Between the two meetings, the researchers and members of the advisory group met six times, see ‘Between the meetings’.

Informed Consent

The staff of LFB Zuidoost had contact with the groups beforehand; the participants were verbally informed about the study. In addition, they received an informational folder about the study in advance. The dates for the two meetings were coordinated in mutual consultation. As a result, people who were not interested in the study were given the opportunity to indicate this and were not present on the planned dates. At the beginning of each meeting, the participants were informed about the aim, the rules, and procedures with the aid of a PowerPoint presentation. In this way, the participants were informed multiple times about the study. The informed consent procedure was based on a procedure developed by Thomas and Kroes [50], see also [37]. Topics in this procedure were: goal of the meetings; confidentiality; voluntariness; support. All participants signed a statement of consent. Following the two meetings, all participants received a certificate of participation, a report on the method and the outcomes of the meetings in which they had participated.

Ethics

The study was presented to, and received the approval of the Ethics Review Committee of the Faculty of Psychology and Neuroscience, Maastricht University. To support the participants, a qualified and experienced confidential counsellor was available. However, none of the participants used of this option.

Nominal Group Technique

To introduce the topic and the research question to the participants, an illustrated storyline was used. As a result, the research question was placed in a context and should be better understandable by the participants [56]. The storyline was devised together with the advisory group, and an artist was commissioned to make the necessary drawings. The storyline consisted of eight drawings which told the story of Sanne and Tom, occasionally supported with a few words such as ‘in love, together, dreams.’ With the final drawing, the research question was presented to the participants: ‘What do Sanne and Tom need?’

First Meeting

Step 0 Introduction

At the beginning of every meeting, the participants were welcomed and informed about the aim of the research and the method used. After this, the storyline was shown and the research question was presented (Fig. 1).

Step 1 Generating individual ideas

The participants were invited to write down their individual ideas and experiences in silence. It was emphasised that all ideas and experiences are good and no limitation was placed on the number of ideas. A few participants were unable to write or could only write with difficulty and were aided in noting down their ideas by the coaches or members of the advisory group. The facilitators could encourage the

Fig. 1 Examples of drawings of the storyline

participants, but could not make any suggestions. As a result, bias due to the influence of third parties was reduced as much as possible.

Step 2 Collecting the ideas

All ideas were collected and compiled on a flip chart. The participants, or one of the facilitators, read the ideas aloud. There was room for the addition of new ideas, and these were also collected. No opportunity to discuss the ideas was provided at this time; the aim was just to collect as many ideas and experiences as possible.

Step 3 Presenting the ideas

The participants read out loud their ideas on the flip chart. The other participants could ask for clarification. The purpose of this step was to make sure the idea was clear to everyone. For example, one of the participants had written ‘talk about it’. Following clarification, it became clear that the idea was to ‘talk about what’s on your mind with a caregiver’. Another participant wrote: ‘don’t sleep with each other right away’. After discussing this idea, it turned out that the idea was to: ‘not sleep with each other right away, but date each other for a while first and get to know each other’.

Between the Meetings

Between the two meetings, the researchers and members of the advisory group met. The flip charts with all the ideas and additions were compiled into a single list. Difficult words were converted into easily understandable language. This resulted in a group list of ideas.

Second Meeting

Step 4 Selecting and ranking the ideas

At the beginning of the second meeting, all participants were again informed about the aim and method used, and about the storyline of Sanne and Tom and the ‘single question’: ‘What do Sanne and Tom need?’ Participants received the group list of ideas on a large sheet of paper, which was then discussed by the entire group. The participants received a pen and a pair of scissors and were asked to cut out the five ideas which they thought were the most important. During the first two group meetings, the participants received all group ideas on separate cards (see [34, 52]). However, the participants were overwhelmed by the amount of cards, so this aspect of the method was changed. Providing a single sheet of ideas which they could cross out or cut out, enabled them to have a better overview.

The participants were invited to evaluate these five most important ideas by rating them from 1 to 5. Five points for the most valuable idea, and one point for the least important idea. For this purpose, five voting boxes were made in declining sizes, where the largest voting box displayed the numeral 5, and the smallest displayed the numeral 1. “This is just like Eurovision Song Contest,” said one of the participants. After the voting, the voting boxes were opened, the votes were counted and written on the flip chart. It became clear to all participants which ideas they found important and valued most highly as a group. This was discussed by the entire group.

Analysis

All the participants’ ideas were collected per group and compiled into a single summary list: the group list. The participants ranked the five best ideas by assigning a ranking of 1–5 for each idea. This resulted in a group idea score which had received the highest ranking. All the ideas from the group lists and the highest ranked ideas from the individual groups were entered separately and analysed with NVivo8 and discussed with the co-researchers with an ID. In order to compare the value of the ideas of the groups we calculated the factor of each group. In this way we could calculate the percentages of each idea.

Results

First, we pay attention to the results of working with the NGT-methodology. Then we pay attention to the content. The 39 participants in the study were capable of expressing their views and answering the question ‘What do Sanne and Tom need?’ Seven participants (of the 39 participants) were aided in noting down their ideas by facilitators. In total 198 ideas were submitted by the participants during session 1. And 140 ideas left to be valued in session 2. A total of 867 points were given to all 140 ideas. The participants were divided into six groups. Each individual listed 3–5 ideas on average. When compiling a group list, similar ideas were combined. The six group lists consisted of 15–58 ideas each. The outcomes are displayed beside the description of the meeting process.

Working with NGT

The participants used various strategies to answer the question about the needs of Sanne and Tom. Some of them got to work immediately, went off by themselves and wrote down many ideas. Others found it more difficult to write something down; they contacted others to find out what was meant to be done or to come up with ideas. They were supported by the facilitators who went through the question with them again, and encouraged them to formulate their ideas.

The atmosphere was pleasant in all the meetings. During the introduction of the study, there was initially some shyness and joking. When the story of Sanne and Tom was shown, however, many people responded seriously and began to talk spontaneously about their own experiences,

That also happened to me. I also went for a walk in the park with my girlfriend.
(man, 29 years)

Most participants got to work in a very focused and serious fashion. Some of them also had a need to immediately say aloud what they had written down. Because working in silence was advantageous, they were asked to wait before they told their story. This did not cause any problems. With only a few exceptions, the participants enjoyed presenting their ideas to each other. They also thought it was exciting to talk in a group about such a sensitive topic.

This is the first time I have told you about this. My brother knows about it. My caregiver knows about it. And now you know about it too. (man, 48 years)

Most of the participants responded respectfully to each other's stories and ideas, and encouraged each other to describe them clearly, "That's right!", "I think you mean..." or "I always call that ..."

While selecting the five most important ideas, the participants were generally somewhat noisier. They indicated the difficulty in making a choice, and the need for time to do so. They thought very seriously about what was really important to them.

This is hard, but I decided against my 'red car of love' after all, even though I really liked it. No... that's too bad, but that's the way it goes! (man, 29 years)

The evaluation showed that the participants appreciated the meetings: "Is it really done? Are you going to come back?" They stated that, at the meetings, they were rather tense initially, "This is something you don't talk easily about." When the meeting ended, they indicated their satisfaction: "It was fun!" Participants indicated that they appreciated being able to talk seriously about sexuality.

Results NGT Meetings

The 39 participants had ideas about what Sanne and Tom needed, and discussed these ideas with each other in six groups.

Relationship

The participants gave the highest ranking (47%) to the relationship between two people, for example: ‘it must come from both sides’, ‘being happy together’, ‘accepting each other’, ‘being together’, ‘accepting each other as you are’. This high rating means that the participants considered the relationship between two people of great value. Participants told about their experiences with relationships.

I have been married. But it did not go well anymore. My wife did nothing at all and I had to do everything. After work I had to do all the cooking and cleaning. I got a depression... We divorced... after many years, and after trying everything. (man, 59 years)

A participant talked about his relationship and the involvement of everyone with this relationship:

She listens to her family-members. And they don't like me. We argue about that. I ask her: with whom are you dating? With your family or with me? I have a disability and her family find that difficult. But I am who I am. (man, 36 years)

Some participants felt sad because of the missed opportunities in their lives.

I was dating a girl from the laundry. And then my father found out. He said: ‘She is not the right girl for you.’ So, I broke with her. Yes, I did. Otherwise I would have been married now. And perhaps had a couple of children. Sometimes I think back and then I regret. (man, 56 years)

Sex and Sex Related Issues

In addition, participants indicated that sex and issues related to sex as sex education and lovemaking, were important (23%). For example, ‘*kissing*’, ‘*sex education*’, ‘embarrassed to talk about it’, ‘fear of pregnancy’, and ‘safe sex’.

I never dared to do anything. I was so afraid to get children. My family has scared me. It's now too late to get children. If I was young, I would not listen anymore to my family. (woman, 64 years)

Why aint there a booklet about what's normal and what not?... I didn't know that sex with my bother wasn't normal. Later I heard that is not normal. That you don't do that with your brother. But how could I know?... How it's supposed to be? And how it doesn't belong. I would like to have that. Then I read about it. And then I know how it should be. How you get children. And all about sex. And what's up with sex. And what you should do and don't... I would like to know that. And accept your own body. I think that is very important. I'm having trouble with that. I find it difficult. (woman, 39 years)

Feeling Safe and Comfortable

A ranking of 10% was given by the participants to feeling safe and comfortable. The ideas they had given were, for example: ‘having your own room that can be locked’, ‘not being ashamed of your body’, ‘indicate boundaries’. Many participants live

together with other people with a disability in a group home. Despite the fact that each has its own room, each ones' privacy is not always respected. Monitoring your privacy becomes even more difficult when it comes to sensitive subjects as relationships, sexuality or using contraceptives. Not all conversations with care staff take place at one's room or at the group office. Group members hear or sometimes know what's going on.

I talk with care staff at my room. Nowhere else... (woman, 36 years)

In their daily lives people with IDs are dependent on others, no matter how independent they live.

We have a bathroom in the hallway. If you go there, go on your bathrobe. A roommate always walks naked through the hallway. And he never locks up the door. I do not like that. (woman, 41 years)

Participants talked about negative experiences. One participant told about his experience with stalking:

...My brother has taken action and I never had any more contact with my friend. I was so relieved. I could breathe again. I was so glad I have told my brother. My brother is my best friend. He helps me when I need him! (man, 48 years)

I think back of the unpleasant things that happened. I had a friend and he wanted me to do things I did not want. I do not really want to remember this. (women, 34 years)

This participant talked with her coach about it in a separated room. After a while she decided to write her ideas on paper during the first meeting.

Other ideas got a low ranking: ideas about children 5%, family and friends 4%, choosing with whom you live 4%, income and money 4%, and support 3%.

Discussion

People with an ID are capable of stating what they think is important when it comes to sexuality and their sexual rights. Important aspects for them include the relationship between two people, sex related items as sex education and lovemaking, and feeling safe and comfortable. This corresponds to a number of the sexual rights that have been defined [61], such as the right to a voluntary sexual relationship; the right to bodily integrity; the right to pursue a satisfying, a safe and a pleasurable sex life; the right to choose your own partner; the right to education, information and protection. The outcomes indicate that more values and aspects are important for people with IDs: quality of life; empowerment; communication; social skills; and a good home. The key issues are not only about the physical aspects of sexuality, but also the emotional and psychological aspects, and capabilities. It is in line with the plea of [37] for sex education which includes the improvement of sexually-related skills as well.

The present study confirms that people with an ID are fully capable of discussing their views and experiences on sensitive topics [13, 42], [51–53]. They are also capable of discussing the study itself with the researchers [25, 57]. The outcomes of the study conducted by Watson et al. [58]—that the sexual rights of people with an ID are not fully acknowledged and confirmed, and that they need support—are consistent with the outcomes of the present study, in which people frequently used terms such as 'respect', 'acceptance' and 'being honest'. The fact that the realisation of these rights is not naturally, and that people experience constraints

and concerns, is shown through the responses in which terms such as ‘fear’ and ‘shame’ were used. With one of the groups, a follow-up meeting was held during which the participants indicated that they wished to have support from their caregiver or family. Other studies have also shown that people with an ID indicate that they need support when it comes to sexuality [3, 17, 37, 45]. This calls for a support plan that pays attention to sexuality and sexual health [46].

The presentation of the results include data that are not strictly NGT findings (see ‘Working with NGT’). It provides notion how working with the NGT methodology affects people. The atmosphere, the active method, and telling their stories to each other, works inviting for people with IDs.

In the present study, the topic of sexual abuse was also addressed. For example, three participants indicated that they had experiences with sexual abuse. Relative to a total of 39 participants, this appears to be a substantially lower rate of sexual abuse than generally indicated by research on this topic [3, 9, 16, 33, 45, 54]. A possible reason is that the design of the present study did not focus on sexual abuse. Consequently, these meetings did not lend themselves very well to discussing these specific experiences.

Limitations

The participants were recruited from ‘self-advocacy’ groups. These participant groups were heterogeneous: more men than women; difference in age; difference in verbal abilities. Hol-lomotz [17] concluded that these groups contribute to the development of a positive identity, and to improving people’s self-confidence and assertiveness. The outcomes therefore cannot simply be attributed to the ‘target group’ of all people with an ID. This is not only because this group is extremely heterogeneous, but also because the people who are active in ‘self-advocacy’ groups are not representative of the general population. People with an impaired functional level who live in an intramural setting are rarely active in such groups.

To determine a valid group consensus and group ideas, a minimum group size is desirable. Stewart et al. [44] referred to a group size of 8–12 individuals in focus groups. Van de Ven and Delbecq [55] concluded that a group size of 5–8 individuals is acceptable with the nominal groups. In the present study, the group size ranged from 3–14 individuals. Further research into the ideal size for the specific target group of people with an ID is needed.

Interaction between the participants themselves and with the facilitators in focus groups can have undesirable effects on the outcomes [44]. This is why one of the rules of the present study was working in silence. During the first part of the meetings, this aspect was emphasised and the participants worked quietly; during the second part of the meetings, it was sometimes substantially noisier. The participants found it difficult to choose, and apparently needed to make this known to each other, and to seek support for their choices. It helped them to talk to each other about these choices.

And finally, there was a difference in literacy skills among the participants. Facilitators helped seven participants (of the 39 participants) to write down their ideas. Despite the instruction to the facilitators to influence people as little as possible, there will be bias.

Conclusion

It is of great importance to understand the views of people with an ID on sexuality and sexual rights. Therefore, it is essential to ask these people directly about their ideas and opinions. All service providers should seek proactively the views of their service users. Only when supporters listen carefully to the wishes and needs of people, they are capable to provide good care. Not just about sexuality, but about all sorts of items. Talking seriously with people with IDs about life issues, shows engagement. The present study has shown that they are capable of expressing their views about such a sensitive topic. The nominal group technique appears to be a suitable method for this purpose. People indicate that they need support to realise these rights. More attention should be paid to this aspect in the institutional support plan and the daily support activities. The NGT is suitable for inclusive research with people with an ID.

Compliance with Ethical Standards

Conflict of interest All authors declare that he/she has no conflict of interest.

Ethical Approval The study was presented to and received the approval of the Ethics Review Committee of the Faculty of Psychology and Neuroscience, Maastricht University. To support the participants, a qualified and experienced confidential counsellor was available. However, none of the participants made use of this option.

Informed Consent The staff of LFB Zuidoost (a Self-Advocacy Group in the Netherlands) had contact with the groups (of participants) beforehand; the participants were informed about the study verbally. In addition, they received an informational folder about the study in advance. The dates for the two meetings were coordinated in mutual consultation. As a result, people who were not interested in the study were given the opportunity to indicate this and were not present on the planned dates. At the beginning of each meeting, the participants were informed about the aim, the rules and procedures with the aid of a PowerPoint presentation. In this way, the participants were informed multiple times about the study. The informed consent procedure was based on a procedure developed by Thomas and Kroes [50], see also [37]. Topics in this procedure were: goal of the meetings, confidentiality, voluntariness, support. All participants signed a statement of consent. Following the two meetings, all participants received a certificate of participation and a report on the method and the outcomes of the meetings in which they had participated.

Open Access This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

Appendix

See Tables 1 and 2.

Table 1 Results of the six groups

Top 3 of the most highly rated ideas from each group (with total score)

Group 1 (4 participants)

1. Living circumstances (11 points)
2. Accept your one body (10 points)
3. Living together (9 points)

Group 2 (first meeting, 11 participants; second meeting, 14 participants)

1. Mutual trust (25 points)
2. Respect (23 points)
3. Setting limits (14 points)
 - Sex (14 points)
 - Accepting each other as they are (14 points)

Group 3 (first meeting, 4 participants; second meeting, 6 participants)

1. Income (20 points)
2. Mutual trust (13 points)
 - Being happy together (13 points)
 - Feelings must come from both sides. Both of you have to want it (13 points)
3. A private home (11 points)

Group 4 (3 participants)

1. No family interference (9 points)
2. Fear of pregnancy (8 points)
3. Your own room that can be locked (5 points)
 - Embarrassed to talk about it (5 points)
 - Sex is a big taboo if you are disabled (5 points)
 - Money and work (5 points)

Group 5 (first meeting, 6 participants; second meeting, 5 participants)

1. Being there for each other in sickness and health (10 points)
2. Loving each other (10 points)
3. Having a good connection with each other (5 points)
 - Keeping their friends (5 points)
 - Being honest with each other (5 points)
 - Understanding each other (5 points)
 - Contraceptives (5 points)
 - Time to get to know each other and see if they are compatible (5 points)
 - Setting limits (5 points)
 - It has to come from both sides (5 points)
 - It's about what's inside, not how you look on the outside (5 points)
 - Being faithful to each other (5 points)

Group 6 (7 participants)

1. It has to come from both sides (20 points)
 2. Living together (15 points)
 3. Being together (13 points)
-

Table 2 Definitions

The WAS has, after consultation with the WHO, formulated the following definitions on the terms ‘sex’, ‘sexuality’, ‘sexual health’ and ‘sexual rights’

Sex

Sex refers to the biological characteristics which define humans as female or male. [These sets of biological characteristics are not mutually exclusive as there are individuals who possess both, but these characteristics tend to differentiate humans as males and females. In general use in many languages, the term sex is often used to mean “sexual activity”, but for technical purposes in the context of sexuality and sexual health discussions, the above definition is preferred.]

Sexuality

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.

Sexual health

Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

Sexual rights

Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus documents. These include the right of all persons, free of coercion, discrimination and violence, to:

- The highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services;
- Seek, receive and impart information in relation to sexuality;
- Sexuality education;
- Respect for bodily integrity;
- Choice of partner;
- Decide to be sexually active or not;
- Consensual sexual relations;
- Consensual marriage;
- Decide whether or not, and when to have children;
- And pursue a satisfying, safe and pleasurable sexual life.’ (WAS, n.d.)

References

1. AAIDD: Sexuality. Position Statement of AAIDD and the Arc. AAIDD, Washington (2008)
2. Abbott, D. (2013). Nudge, nudge, wink, wink: Love, sex and gay men with intellectual disabilities—a helping hand or a human right? *J. Intellect. Disabil. Res.* **57**, 1079–1087. <https://doi.org/10.1111/j.1365-2788.2012.01642.x>
3. Abbott, D., Howarth, J.: *Secret Loves, Hidden Lives? Exploring ISSUes for People with Learning Difficulties Who are Gay, Lesbian or Bisexual*. The Policy Press, Bristol (2005)
4. American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn. American Psychiatric Association, Arlington (2013)
5. Atkinson, D., Williams, F.: *Know Me as I Am: An Anthology of Prose, Poetry and Art by People with Learning Disabilities*. Hodder and Stoughton, Sevenoaks (1990)

6. Bernert, D.: Sexuality and disability in the lives of women with intellectual disabilities. *Sex. Disabil.* **29**, 129–141 (2011)
7. Christian, L., Stinson, J., Dotson, L.A.: Staff values regarding the sexual expression of women with development disabilities. *Sex. Disabil.* **19**(4), 283–292 (2002)
8. Chiurazzi, P., Pirozzi, F.: Advances in understanding—genetic basis of intellectual disability. *F1000 Res. Fac. Rev.* (2016). <https://doi.org/10.12688/f1000research.7134.1>
9. Eastgate, G., Van Driel, M.L., Lennox, N., Scheermeyer, E.: Women with intellectual disabilities. A study of sexuality, sexual abuse and protection skills. *Aust. Fam. Physician* **40**(4), 226–229 (2011)
10. Evans, D.S., McGuire, B.E., Healy, E., Carley, S.N.: Sexuality and personal relationship for people with an intellectual disability. Part II: staff and family carer perspectives. *J. Intellect. Disabil. Res.* **53**, (11), 913–921 (2009)
11. Friedman, C., Arnold, C.K., Owen, A.L., Sandman, L.: “Remember our voices are our tools:” sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sex. Disabil.* **32**, 515–532 (2014). <https://doi.org/10.1007/s11195-014-9377-1>
12. Galea, J., Butler, J., Iancono, T., Leighon, D.: The assessment of sexual knowledge in people with intellectual disability. *J. Intellect. Dev. Disabil.* **29**(4), 350–365 (2004)
13. Goodley, D.: Empowerment, self-advocacy and resilience. *J. Intellect. Disabil.* **9**, 333–344 (2005)
14. Harvey, N., Holmes, C.A.: Nominal group technique: an effective method for obtaining group consensus. *Int. J. Nurs. Pract.* **18**, 188–194 (2012)
15. Healy, E., McGuire, B.E., Evans, D.S., Carley, S.N.: Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *J. Intellect. Disabil. Res.* **53**(11), 905–912 (2009)
16. Hickson, L., Khemka, I., Golden, H., Chatzistyli, A.: Profiles of women who have mental retardation with and without a documented history of abuse. *Am. J. Ment. Retard.* **113**(2), 133–142 (2008)
17. Hollomotz, A.: *Learning Difficulties and Sexual Vulnerability. A Social Approach*. Jessica Kingsley Publishers, London (2011)
18. Lesseliers, J.: A right to sexuality? *Br. J. Learn. Disabil.* **27**, 137–140 (1999)
19. Leutar, Z., Mihoković, M.: Level of knowledge about sexuality of people with mental disabilities. *Sex. Disabil.* **25**, 93–109 (2007). <https://doi.org/10.1007/s11195-007-9046-8>
20. Löfgren-Mårtenson, L.: ‘May I?’ About sexuality and love in the new generation with intellectual disabilities. *Sex. Disabil.* **22**, 197–207 (2004). <https://doi.org/10.1023/B:SEDI.0000039062.73691.cb>
21. Maulik, P.K., Mascarenhas, M.N., Mathers, C.D., Dua, T., Saxena, S.: Prevalence of intellectual disability. *Res. Dev. Disabil.* **32**(2), 419–436 (2011). <https://doi.org/10.1016/j.ridd.2010.12.018>
22. McCabe, M.P.: Sexual knowledge, experience and feelings among people with disability. *Sex. Disabil.* **17**, 157–170 (1999). <https://doi.org/10.1023/A:1021476418440>
23. McCarthy, M.: *Sexuality and Women with Learning Disabilities*. Jessica Kingsley Publishers, London (2001)
24. McCarthy, M.: Contraception and women with intellectual disabilities. *J. Appl. Res. Intellect. Disabil.* **22**, 363–369 (2009). <https://doi.org/10.1111/j.1468-3148.2008.00464.x>
25. McDonald, K.E., Kidney, C.A.: What is right? Ethics in intellectual disabilities research. *J. Policy Pract. Intellect. Disabil.* **9**(1), 27–39 (2012)
26. McGuire, B.E., Bayley, A.A.: Relationships, sexuality and decision-making capacity in people with an intellectual disability. *Curr. Opin. Psychiatry* **24**, 398–402 (2011). <https://doi.org/10.1097/YCO.0b013e328349bbcb>
27. Moore, C.: *Group Techniques for Ideas Building*. Sage Publications, London (1987)
28. Murphy, G.H., O’Callaghan, A.: Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychol. Med.* **34**, 1347–1357 (2004)
29. Nussbaum, M.C.: *Mogelijkheden scheppen. Een nieuwe benadering van de menselijke ontwikkeling. [Creating Capabilities. The Human Development Approach]*. Ambo/Anthos uitgevers, Amsterdam (2014)
30. O’Callaghan, A.C., Murphy, G.H.: Sexual relationships in adults with intellectual disabilities: understanding the law. *J. Intellect. Disabil. Res.* **51**(3), 197–206 (2007)
31. Porter, J.: Be careful how you ask! using focus groups and nominal group technique to explore the barriers to learning. *Int. J. Res. Method Educ.* **36**(1), 33–51 (2013). <https://doi.org/10.1080/1743727X.2012.675554>
32. Porter, J.: Methodological issues in collecting children’s view part 2: using nominal group technique to explore children’s views of the difficulties encountered in school. *Procedia Soc Behav. Sci* **47**, 1627–1631 (2012)
33. Reiter, S., Bryen, D.N., Shachar, I.: Adolescents with intellectual disabilities as victims of abuse. *J. Intellect. Disabil.* **11**(4), 371–387 (2007)

34. Roeden, J.M., Maaskant, M.M., Curfs, L.M.G.: The views of clients with mild intellectual disabilities regarding their working relationships with caregivers. *J. Appl. Res. Intellect. Disabil.* **24**, 398–406 (2011)
35. Schaafsma, D.: *Sexuality and Intellectual Disability: Implications for Sex Education*. Universitaire Pers Maastricht, Maastricht (2013)
36. Schaafsma, D., Stoffelen, J.M.T., Kok, G., Curfs, L.M.G.: Exploring the development of existing sex education programs for people with intellectual disabilities: an intervention mapping approach. *J. Appl. Res. Intellect. Disabil.* **26**, 157–166 (2013). <https://doi.org/10.1111/jar.12017>
37. Schaafsma, D., Kok, G., Stoffelen, J.M.T., Curfs, L.M.G.: People with intellectual disabilities talk about sexuality: implications for the development of sex education. *Sex. Disabil.* **35**, 21–38 (2017). <https://doi.org/10.1007/s11195-016-9466-4>
38. Schalock, R.L., Felce, D.: Quality of life and subjective well-being: conceptual and measurement issues. In: Emerson, E., Hatton, C., Thompson, T., Parmenter, T.R. (eds.) *The International Handbook of Applied Research in Intellectual Disabilities*, pp. 261–281. Wiley, Chichester (2004)
39. Schalock, R.L., Borthwick-Duffy, S.A., Bradley, V.J., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., Yeager, M.H.: *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th ed. of AAIDD Definition Manual). American Association on Intellectual and Developmental Disabilities, Washington (2010)
40. Schalock, R., Luckasson, R., Bradley, V., Buntinx, W., Lachapelle, Y., Shogren, K.A., Wehmeyer, M.L.: *User's Guide to Accompany the 11th Edition of Intellectual Disability: Definition, Classification, and Systems of Supports. Applications for Clinicians, Educators, Organizations Providing Supports, Policymakers, Family members and Advocates, and Health Care Professionals*. AAIDD, Washington (2012)
41. Scharlo, S., Ebbers, S., Spijker, M.: *SOS Snelle opvang bij seksueel misbruik van mensen met een verstandelijke beperking [SOS Rapid Care for Sexual Abuse of People with Intellectual Disabilities]*. Bohn, Stafleu, Van Loghum, Houten (2014)
42. Schoeters, L., Schelfhout, P., Roets, G., Van Hove, G., Townson, L., Chapman, R., Buchanan, I.: Partnership working between university researchers and self-advocacy organizations: 'a way forward for inclusion?' In England and 'five feathers make a fine bird' in Flanders. *J. Intellect. Disabil.* **9**, 345–356 (2005)
43. Stainton, T., Clare, I.C.H.: Human rights and intellectual disabilities: an emergent theoretical paradigm? *J. Intellect. Disabil. Res.* **56**(11), 1011–1013 (2012)
44. Stewart, D.W., Shamdasani, P.N., Rook, D.W.: *Focus Groups. Theory and Practice*. Sage Publications, London (2007)
45. Stoffelen, J., Kok, G., Hospers, H., Curfs, L.M.G.: Homosexuality among people with a mild intellectual disability: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *J. Intellect. Disabil. Res.* **57**(3), 257–267 (2013). <https://doi.org/10.1111/j.1365-2788.2011.01532.x>
46. Stoffelen, J.M.T., Herps, M.A., Buntinx, W.H.E., Schaafsma, D., Kok, G., Curfs, L.M.G.: Sexuality and individual support plans for people with intellectual disabilities. *J. Intellect. Disabil. Res.* **61**(12), 1117–1129 (2017). <https://doi.org/10.1111/jir.12428>
47. Stoffelen, J.M.T., Schaafsma, D., Kok, G., Curfs, L.M.G.: Chapter seven—sexual health of people with an intellectual disability. *Int. Rev. Res. Dev. Disabil.* **52**, 201–237 (2017). <https://doi.org/10.1016/bs.irrdd.2017.07.004>
48. Stoffelen, J.M.T., Schaafsma, D., Kok, G., Curfs, L.M.G.: Women who love an explorative study on the lived experiences of lesbian and bisexual women with a mild intellectual disability in the Netherlands. *Sex. Disabil.* (2018). <https://doi.org/10.1007/s11195-018-9519-y>
49. Swango-Wilson, A.: Caregiver perception of sexual behaviours of individuals with intellectual disabilities. *Sex. Disabil.* **26**, 75–81 (2008)
50. Thomas, G., Kroese, B.S.: An investigation of students with mild learning disabilities reactions to participation in sexuality research. *Br. J. Learn. Disabil.* **33**, 113–119 (2005). <https://doi.org/10.1111/j.1468-3156.2005.00336.x>
51. Tuffrey-Wijne, I., Davies, J.: This is my story: i've got cancer. 'The Veronica project': an ethnographic study of the experience of people with learning disabilities who have cancer. *Br. J. Learn. Disabil.* **35**, 7–11 (2006)
52. Tuffrey-Wijne, I., Bernal, J., Butler, G., Hollins, S., Curfs, L.: Using nominal group technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *J. Adv. Nurs.* **58**, 80–89 (2007)
53. Tuffrey-Wijne, I.: *How to Break Bad News to People with Intellectual Disabilities. A Guide for Carers and Professionals*. Jessica Kingsley Publishers, London (2012)

54. Van Berlo, W., De Haas, S., Van Oosten, N., Van Dijk, L., Brants, L., Tonnon, S., Storms, O.: Beperkt weerbaar. Een onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking [Limited Defences. A Study on the Sexual Abuse of People with a Physical, Sensory or Intellectual Disability]. Rutgers WPF & Movisie, Utrecht (2011)
55. Van de Ven, A.H., Delbecq, A.L.: The nominal group as research instrument for exploratory health studies. *Am. J. Public Health* **62**(3), 337–342 (1972). <https://doi.org/10.2105/AJPH.62.3.337>
56. Veen, Van: Onderzoek naar informatieoverdracht via stripverhalen aan mensen met een verstandelijke beperking [Study on Information Transfer Through Comics to People with Intellectual Disabilities]. LSR & LFB, Utrecht (2011)
57. Walmsley, J., Jonhson, K.: Inclusive Research with People with Learning Disabilities. Past, Present and Futures. Jessica Kingsley Publishers, London (2003)
58. Watson, S.L., Venema, T., Molloy, W., Reich, M.: Sexual rights and individuals who have a developmental disability. In: Griffiths, D.M., Richards, D., Fedoroff, P., Watson, S.L. (eds.) *Ethical Dilemmas: Sexuality and Developmental Disability*, pp. 19–53. NADD Press, New York (2002)
59. World Association for Sexual Health: Sexual Health for the Millennium. A Declaration and Technical Document. World Association for Sexual Health, Minneapolis (2008)
60. World Association for Sexual Health: Declaration of Sexual Rights (2014)
61. World Health Organization: Sexual Health, Human Rights and the Law. WHO, Geneva (2015)
62. Yool, L., Langdon, P.E., Garner, K.: The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities. *Sex. Disabil.* **21**(2), 137–151 (2003)

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.