In search of solutions regarding the sex education of people with intellectual disabilities in Poland - participatory action research

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ABSTRACT

Full and equal access to sex education for all citizens is ensured by international legal acts. Research shows, however, that people with intellectual disabilities (ID) receive neither support in understanding their sexual rights, nor access to sex education tailored to their needs. Sex education classes at a special school in Poland are not compulsory for students with ID, therefore they can be omitted from the curriculum. The research aims to learn the state of knowledge about human sexuality and to analyse the needs, barriers, and expectations of adult students with ID as regards their sex education. The methodology used included a qualitative approach (Participatory Action Research) using group interviews (FGI) with 24 ID students ages 18-24. The results of the study indicate that students taking part in the study possess fragmentary and incomplete knowledge about sexuality. They listed TV, the Internet, and friends as sources of information, leaving out school (teachers) and parents. However, their interest and willingness to talk was very high. A didactic tool for sex education was designed together with the student and is being used in schools.

KEYWORDS

Intellectual disability; sex education; participatory action research

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Introduction

Sexuality is not our choice; it is a natural part of our lives. It is a human right, regardless of gender, age, sexual orientation or disability, as confirmed by the Declaration of Sexual Rights (WAS 2014). Full and equal access to exercise human rights and freedoms on par with other citizens is ensured, among others, by the UN Convention on Rights of Persons with Disabilities, adopted by the General Assembly of the United Nations in 2006 (ratified in Poland in 2012). According to the assumptions of this international legal act, everyone has the right to sex education which supports the development of sexuality (UN 2006). Research shows, that people with intellectual disabilities (ID) rarely receive support in understanding their sexual rights, or access to reliable and tailored sex education (Adams 2015). Bernert (2011) and McGuire and Bayley (2011) show that people with ID experience resistance from their loved ones when exercising their sexual rights. Restrictive norms regarding sexual behaviour (e.g. in a family) apply only to people with ID, not parents or other family members without disabilities. Other barriers that researchers point out are the inability to openly discuss topics related to one's sexuality, lack of privacy, restrictive institutional regulations, overprotectiveness, and lack of sex education (Healy et al. 2009; Hollomotz 2011; Schaafsma et al. 2017). By limiting access to education and the opportunity to develop relationships with other people, it also deprives persons with ID of their right to self-realisation (Swango-Wilson 2008).

The sexuality of people with ID is still strongly mythologised. Stereotypes about this sphere of life create beliefs that fall on extreme ends of the spectrum: from infantilization (treating them as eternal children and being convinced of their asexuality) to demonisation (pointing out to hypersexuality and lack of ability to control over their own sexual needs) (Hollomotz 2011; Kijak 2013; Parchomiuk 2013; Gill 2015; Darragh et al. 2017). Researchers reveal that people with ID are interested in sexuality, although their knowledge in this area is insufficient (Leutar and Mihokovic 2007; Cuskelly and Gilmore 2007). The article aims to present own research concerning identifying the needs and expectations of people with ID (living in Poland) as concerns their sex education. For the authors, the starting point for the completed research project was the question: 'We teach people (with ID) many life skills; everything from cleaning their teeth to understanding public and private spaces. Why do we not routinely teach people to have healthy and intimate relationships?' (Alexander and Gomez 2017, 118).

The education system in Poland in sex education raises some doubts. Sex education classes in public schools (not in special schools) take place under the name 'Education for Family Life' (EFL). Each school year, 14 hours are allocated for implementing EFL classes (Journal of Laws from 2014, No. 395⁴). Unique solutions exist for special schools (especially for students with moderate and severe ID). The general education curriculum for them does not include such classes since it is a different educational system. These schools implement curriculum content not within specific lesson subjects (e.g. biology, physics), but during educational and revalidation classes. Each type of class for this group of students has designated teaching content in the curriculum. For example, one of them focus on two modules: 'I – the building of one's own identity' and 'I – will be an adult' (Journal of Laws from 2017, No. 356, item 5⁵). These modules provide the opportunity to

⁴ Notice of the Minister of National Education of 18 December 2013 on announcing a consolidated text of the Regulation of the Minister of National Education on the manner of school education and the scope of content concerning knowledge on human sexual life, principles of conscious and responsible parenthood, family values, life during the prenatal period and methods and means of conscious procreation contained in the core curriculum for general education (Journal of Laws of 2014, item 395).

⁵ Regulation of the Minister of National Education of 14 February 2017 on the core curriculum for pre-school education and the core curriculum for general education in primary schools, including for pupils with moderate and severe intellectual disability, and for general education in stage I sectoral vocational schools, general education in vocational schools for people

introduce sex education-related content into the classroom, however, doing so depends on the teacher in charge. Access to reliable knowledge remains in the hands of teachers who, due to a lack of legal obligation, may skip content relevant to the sexual development of students.

Traditionally, the sex education of people with ID included mainly controlling sexually related behaviours, providing only theoretical information about the dangers of sexual violence or sexual activity and even encouraged involuntary sterilisation (Aunos and Feldman 2002). Nowadays it is postulated that sex education should be treated much more broadly and include both knowledge and skills. It should not focus only on issues related to sex, pregnancy or sexually transmitted diseases, and should also cover parenting or issues related to sexual orientation (Walker-Hirsch 2007).

Research shows that people with ID have a lower level of sexual knowledge than peers from the general population (Jahoda and Pownall 2014). Comparative studies from the UK have also noted that they are less likely to engage in sexual activity than their peers in the 19–20 age group. However, once they have engaged in sexual activity, they are more likely to engage in dangerous sex than people in the general population, and girls with ID are more likely to become pregnant (Baines et al. 2018). Lack of sex education (Meer and Combrinck 2015) and deliberate disregarding of this topic in schools translates directly into the dangers posed by sexual violence. Analyses related to the frequency of sexual violence taking place show that among people with ID the rate of incidence is three to ten times higher for this violence than in the entire population and only 20% of these cases are detected (Abbott and Howarth 2005; Eastgate et al. 2011; Eastgate 2012).

Materials and methods

Design

The basis of the presented research is the participatory paradigm (Heron and Reason 1997). All attempts to explain the essence of disabilitymust be carried out with the active and conscious participation of people with disabilities so that the image of the phenomenon of disability is not created solely by the so-called able-bodied researchers, some of whom claim the right to define and describe that which is not their experience (McVilly and Dalton 2006). The answer to these stipulations is Participatory Action Research (PAR) (Garcia-Iriarte et al. 2009). PAR is a 'process in which members of an oppressed community or group actively collaborate in the identification of problems, collection of data and analysis of their situation to improve it' (Selener 1997, 11).

The research presented in the article is part of a six-month project. The theoretical goal of the presented qualitative researchwas to learn the state of knowledge about human sexuality and to analyse the needs, barriers, and expectations of adult students with ID in terms of their sex education at school. The practical goal of the undertaken actions was to create a didactic tool that would most tackle the actual needs and problems in sexuality. Specific questions guided the study:

- (1) How do people with ID conceptualise the idea of human sexuality? What makes up human sexuality according to the project participants?
- (2) Which topics related to human sexuality are the most relevant to people with ID?
- (3) What knowledge do people with ID have about human sexuality?
- (4) What needs regarding their sexuality (in terms of knowledge and skills) do people with ID indicate?
- (5) What should sex education involve according to people with ID?

The role of the project participants during each of the interviews was to create knowledge

with disabilities, and general education in post-secondary schools (Journal of Laws of 2017, item 356).

about issues relevant to them in human sexuality, becoming 'experts' and specialists in matters concerning them. The researchers' task was to moderate the discussion and to collect, organize and analyse the content, which was then used to create a dedicated didactic tool. Thanks to the issues identified by the students it was possible to create a tool directly tailored to their needs. In the later stages of the project, students also decided on the game mechanics, graphics and rules (which will not be described here).

Participants

The selection of participants for the study was deliberate (Creswell 2014). The criteria for selection were: aged over 18 years of age, interested and willing to be involved in the study, intellectual disability, able to understand questions and provide answers verbally and being a student of a chosen type of special school. We conducted the research over two months and included 24 adult students (11 men and 13 women) with a moderate (20 students) and severe (4 students) ID from four special vocational schools in Poland. The degree of intellectual disability of students is related to the school in which we conducted the research. However, because of the voluntary nature of participation, the project was mainly submitted by people whose level of cognitive functioning and social competence was relatively high. The age of the participants ranged from 18 to 24 years old. The research was planned under the ethics rules set out by the National Disability Authority (2009)⁶ and has been positively accepted by the funding organisation. Bearing in mind the role of gatekeepers, whose role is to protect the rights and interests of study participants, we had begun cooperation with the heads of selected institutions. Teachers cooperating with researchers provided information about the recruitment. Then there was an information meeting with all participants and individual interviews, during which they signed permissions to take part in the project. The consent form was prepared in an easy-to-read version. We informed the research participants about the purpose of the research and the entire project.

Procedure

Focus Group Interview (FGI) was the research method used in the project. FGI is a qualitative

research technique often used in research with people with ID (McCallion and McCarron 2004; Nind 2008). Themajor advantage of focused group interviews is the ability to observe natural social interactions between participants, which helps reconstruct deep-rooted ways of thinking and observe phenomena (Fatemeh 2004). It is recommended that a focus group of people with ID not be too large as it may hinder some participants from participating in the discussion (Fraser and Fraser 2000). Groups of 6 to 10 people are indicated, which further depends on the respondent's cognitive abilities and background, and the skills of the moderator (Andre-Barron, Strydom, and Hassiotis 2008). Conducive to research is also a situation in which the respondents know each other because it positively affects their spontaneity and honesty of speech (Krueger and Casey 2000).

Four homogeneous groups of students took part in the project, each comprising 6 people. We held eight meetings with each group (32 FGI interviews). Equal gender representation in each group was ensured. Each meeting lasted 60 minutes and took place in a school classroom. When organising the study, we used recommendations for focus group interviews with people with ID that had been developed by the National Federation of Voluntary Bodies Services (Doyle 2009). Because of the topics of the meetings being socially sensitive, we used projection techniques during each interview (Nind 2008). The techniques used include word associations, role-playing, stories and photography.

For each thematic category, there were prepared sets of photos (e.g. two people during a date, a mother with a child, condoms) or drawings (e.g. genital construction).

⁶ We decided to use the Irish guidelines because Poland lacks clear rules on this matter.

Also, the researchers prepared short scenarios of situations introducing the topic and encouraging discussion, e.g. meeting in a restaurant or babysitting. The course of each meeting (except the first one) was: the researchers presented to the participants the topic of the meeting and selected images (according to the keywords they pointed during the first meeting), asked about their associations with the topic and encouraged short scenarios. In the meantime, there was a discussion on each topic, during which the researchers also asked questions to check participants' knowledge. Students often spontaneously

uttered words that they associate with the subject, so they sometimes pointed out concepts they did not know the meaning of (heard them e.g. on TV), such as orgasm, gender change or erection. During the meetings, there were always two researchers, where one, apart from observing the group, also played a supporting role for the students.

Work with research participants began with an introductory group interview focused on the concept of human sexuality. During the brainstorming, the students' task was to indicate the words they associate with the concept of sexuality. Based on the results (Table 1), we could determine a preliminary dictionary of concepts regarding human sexuality that the students used.

Next, we conducted with each group 7 interviews based on selected categories. Students were offered the following topics (in parentheses there are thematic areas that each category covered):

- (1) Sexual identity (femininity and masculinity, sexual orientation, lack of acceptance);
- (2) Sexual awareness (body, intimate places, puberty, hygiene, STD);
- (3) Sexual/intimate behaviour (affection, showing affection, flirting, dating, jealousy,
- (6) quarrels);
- (4) Sexual relations (having sex, sexually transmitted diseases, contraception, responsibility,
- (7) impotence, pleasure);
- (5) Emotional relationships (closeness to another person, confession of love, partnership,
- (8) showing affection);
- (6) Sexual violence (rape, shame pornography, addiction, prohibition, Internet);
- (7) Parenthood (offspring, marriage, divorce, household duties, home, pregnancy).

Table 1. Keywords related to human sexuality suggested by the students during the first interview – creation of preliminary thematic categories.

HUMAN SEXUALITY			
LOVE	SEX	FAMILY, RELATIONSHIPS	THE BODY
 Being in a relationship Patience Responsibility Marriage Memories Family Lyrics 	 Pleasure Offspring Marriage Sexually Transmitted Diseases – HIV, AIDS, Syphilis) Affection Intimate places 	 Divorce Offspring Work Celebrating together Partnership, marriage Memories 	 Weight Parts of the body (buttocks, penis, vagina, breasts) Gender Puberty Femininity and masculinity

Data analysis

All the interviews were recorded and transcribed. The second researcher checked all transcriptions to confirm their correctness. Then, the collected data has been subjected to coding and categorisation (Gibbs 2008). The codes were assigned independently by two researchers and then compared with each other. Morgan (2006) shows that group interviews may be subject to the same analysis processes as individual interviews, provided that FGI analysis should take into account interactions within the group and the context that accompanies the interviews. According to Anderson's (1990) approach, there are two ways to report research using group interviews: a summary report of the key ideas arising in the interviews, or the use and presentation of verbatim data directly. These methods can be combined, and we have used both in our report.

Results

The results of the interviews were ordered according to pre-determined thematic categories. The student statements directly illustrate some conclusions.

Sexual identity

Students easily identified their gender by referring to themselves as a woman or a man. Most group members saw the moderator's request to determine their gender as a joke because it was obvious to them. Men relied on stereotypes of social role division more often: The task of a man is to support his family; A woman runs the home, looks after the children. They also considered it less likely for men to practise professions stereotypically perceived as being practiced by women, e.g. hairdresser, kindergarten teacher, make-up artist. When describing femininity and masculinity, respondents mainly described features of appearance: Women are pretty; They have overlong hair; They have nice nails, wears makeup; Men have short hair, have a beard. Women were also assigned character traits such as delicacy, openness, diligence, and humility; whereas they described men as strong, determined, and brave.

Students had no difficulty describing a heterosexual orientation. However, with a homosexual orientation, most students had problems explaining whom such a term

may apply to. They often claim that homosexuality is a disease and something forbidden. The discussion on this topic elicited potent emotions. After a lengthy conversation, the students indicated, that they did not know any persons with a homosexual orientation and would like to broaden their knowledge: *I want to know how it is; I do not know what this gay thing is all about.* In one group, a student also touched on transsexuality and asexuality, and gender reassignment: *I saw on TV that there was a woman, and then there was a man.* Even though such a concept was mentioned, none of the students in the group knew how to explain it. Students indicated that they would like to learn more about this topic.

During the discussion, students often pointed out that they do not know where they can find such information: *Nobody talks to us about it; How should I know, my mother says I should leave it be.* When listing sources of information and support, students most often mentioned friends, the Internet, television programmes and family (parents, grandparents).

Sexual awareness

Anatomical drawings and names of intimate body parts were embarrassing for the students, which they indicated with laughter or by the lowering of their heads and blushing. Most of the participants could name the external genitals presented in the drawings, but often they used vulgar terms to name them. Internal genital organs (e.g. uterus, oviduct, semen) were a bigger problem for them. Another issue raised during this meeting was Sexually Transmitted Diseases. They often mentioned STD as something to be feared. However, they could not explain how one gets infected with such a disease, which diseases fall into this category, or how to protect oneself against them. A similar situation arose concerning the process of impregnation and menstruation in women. Students were often familiar with the aforementioned concepts, but they could neither explain nor describe them, or associated them with myths, e.g. showing the belief that oral sex can lead to impregnation.

With personal hygiene and taking care of their own body, both men and women displayed a top level of knowledge: *Always have to shower; I change my underwear every day; I wash everywhere, my entire body.* They correctly identified what a gynaecologist does and indicate situations in which a woman should go see a gynaecologist. Women pointed out, however, that they do not know how to behave during a visit to the gynaecologist. Because most of the participants of the project had already undergone puberty, they could identify the changes that occurred in their body correctly (appearance of hair, voice change, change in body shape, etc.). However, students pointed out that when these changes were occurring, no one told themwhat was going on: *I asked what it was (regarding menstruation) but my mother just said it would pass.*

Sexual behaviour

There was an enormous interest in dating (preparing for a date, date planning, date behaviour). Students pointed to situations that seemed difficult to them, e.g. who pays for dinner, can a girl ask a boy out on a date, how to deal with jealousy. They talked a lot about the need to be with another person: *To have someone; To buy her gifts; To kiss and everything.* While roleplaying short scenes and during discussions regarding the photographs shown, students did not have major problems with naming emotions and feelings, or with correctly identifying their causes (e.g. jealousy, excitement, pleasure, falling in love). They described the reactions of their own body: *When I look at a pretty girl, I feel hot, I am sweaty and a little nervous; When B. is A.'s boyfriend now, I am angry with them, I am pissed; I'm nervous when I am to take her hand.* It was more difficult for them to describe the physical symptoms of sexual arousal in both men and women. Students had difficulty correctly describing what an erection is and what are the signs of arousal. Masturbation was also mentioned. Students did not use the word 'masturbation' but could correctly

describe and understood the activities associated with it. Most students indicated that it is an activity that should be done alone: So that nobody sees it.

Emotional relationships

Students talked about getting engaged with great fervour but they indicated that they probably can not get married and that it is something that remains only a dream: *Mother said they won't let us get married; Mrs. A. (the teacher) said that we should forget about it.* Getting

engaged, therefore, is more often a way to declare their love than an actual proposal of marriage. A paradox was noted in one group: I will have sex if I marry someone; Mrs. A. (the teacher) said that if I get married, it will be sex, but at the same time explicitly noting that getting

married is forbidden for them: Mrs. A. (the same teacher) says that there will be no wedding. The students show a great need to be in a relationship, to be with someone (in a physical and emotional context). Relationship aspects such as being responsible, caring for another person, loyalty, or solving problems together were mentioned less often. There were people in all groups who strove hard to have a partner while, with their behaviour, not respecting the rights of other people: I can kiss her when I want to and she will be my girlfriend; He will be my boyfriend because I want it that way. Basing on student statements, it has been determined that most of the relationships comprise school couples who do not meet outside of the confines of the school corridor and their contact is regulated by the teaching staff: Mrs. A. (the teacher) says that we can't hold hands because in a year the school will be over anyway and we won't be a couple anymore; I would like to take X. on a date, but I can't because my parents don't want to give me a lift.

Sexual violence

Most students recognise the authority of specialists and parents, even if it limits their freedom and intimacy. They believe that their parents or specialists (e.g. doctors) always may violate their intimacy (students in all groups concluded that at a physician's/parent's request they are required to undress, even when the purpose of the activity has not been explained). Respondents do not perceive there to be any threat from people they trust or who are socially recognised as an authority.

As perpetrators of sexual violence, the respondents always pointed to strangers. The concepts of rape and sexual harassment were very difficult for most students to explain and they could not point out when intercourse should be considered rape, even though everyone agreed that it was wrong. The surveyed students knew the norms of behaviour regarding the sexuality of others well, indicating that peeping, touching the intimate parts of another person's body without their permission, and posting nude pictures of another person on the Internet are all disallowed behaviours. However, they were not as adept at ascribing such rights to themselves, e.g. they did not perceive being watched or touched as something bad and which they may oppose.

Parenthood

Respondents in their statements often reinforced the traditional family structure that they were familiar with (a working father and a mother taking care of the home and the children). Some women opposed this by saying that the mother and the father should share household responsibilities equally and that women can not only work but even earn more than men: *Only a woman should look after everyone? Everyone has to.* Men also often pointed to the role of the father in the process of upbringing. Starting a family was a goal and a dream for many students. They often associated plans for the future were often with having one's own family and children: *I would like to have a big house, children, a dog; I will have a child and a husband.*

The students possessed the general knowledge that supporting a child is a tough task and requires financial resources. However, they could not indicate specific price ranges for items such as a baby stroller, baby clothes, toys, or baby food. Mostly, they correctly indicate the duration of pregnancy and its symptoms and describe how a woman should look after herself, but they showed less knowledge about the process of impregnation and the delivery of the baby. Women indicated that they would like to learn about labour because it is something they fear. They often associated childbirth only with a caesarean section: The child comes out after they cut the abdomen open. When it comes to new-born/infant care, most respondents did not have any difficulty explaining the cues. The respondents could indicate the causes of a baby crying and solutions to this problem (diaper change, hugging, feeding, singing a lullaby).

Discussion

According to the results, it can be concluded that the sexuality of young adults with ID does not differ from the sexuality of other people without disabilities in terms of the needs they show and the experiences described, as also shown by other researchers (Borawska-Charko, Rohleder, and Finlay 2017). When it does not manifest in the respondent's specific experiences, it becomes apparent in their needs and fantasies. A very important topic for the respondents was building a relationship with a partner and the need for intimacy and intimate relationship, which is also indicated by Leutar and Mihokovic (2007), Dukes and McGuire (2009) and Wheeler (2007). Despite sex education not being a compulsory part in the curriculum, the respondents displayed some knowledge of the topic. However, said knowledge was fragmentary and incomplete. Some statements were also false, e.g. about contraception. The obtained results are consistent with the meta-analysis data of 46 articles presenting research on the sexuality of people with ID (Borawska-Charko, Rohleder, and Finlay 2017). Also, Jahoda and Pownall (2014) stating that young people with ID express more wrong beliefs about sexuality than their peers from the general population. However, for people with ID, misconceptions are more difficult to refute because of barriers to accessing information (Löfgren-Mårtenson 2012). Besides, the results show that apart from knowledge, very important for the respondents are skills that they could use such as behaviour on dates, using contraception or visiting a gynaecologist.

The major sources of knowledge about human sexuality indicated by the respondents are the Internet, peers and television programs. Parents are also a source of information. The students most rarely pointed to teachers, which may be the basis for stating that sex education at school does not run properly. However, this is not in line with the actual needs of the respondents who want access to knowledge and want to develop their skills and be treated as sexually legitimate individuals. Gil-Llario et al. (2018) show that 89% of ID respondents want to talk about their sexuality more often, while up to 98% are interested in this topic. This is also indicated by other researchers (Frawley and Wilson 2016; Schaafsma et al. 2017). Many students in our research were ashamed to show interest in this topic in conversations with parents or teachers because, in their opinion, those people believe the respondents should not engage in sexual activities, as also confirmed by Bane et al. (2012). The respondents were afraid that without the support of the community, their relationships would fall apart because they would not meet after school. Several students expressed mainly negative views, repeating without reflection such statements as: Sex is bad, You mustn't talk about it, We don't talk about these things. Fitzgerald andWithers (2013) noted a similar correlation in their research, stating that being sexually active is understood by people with ID as something to be avoided, something 'dirty' and forbidden.

The alarming conclusion of the study concerns the area of sexual abuse. Firstly, students involved in the project rarely associated the possibility of experiencing harm with the people from their immediate surroundings. Secondly, students pointed out that even if they considered the event was potentially bad and could violate their intimacy, they most often indicated that they should handle the matter themselves

and lacked awareness of the possibility that they could inform someone about it. These results may be related to high sexual abuse rates and low levels of detection. As a result of subsequent meetings with the students (which, because of the length of the study, we will not present here), we created a board game about sexuality for schools. The game includes the same thematic categories and all issues mentioned during the meetings. Using games to support the development of people with ID is the latest trend and one worth tracking (Lanyi et al. 2011; Bronwen 2014; Terras et al. 2018). The tool created as part of the project probably cannot break all the barriers related to the conscious and equal pursuit of one's sexual rights for this cohort. Considering the respondents' increase in involvement and openness with each subsequent meeting, we can hope that the tool we created will give the players the skills to talk about their sexual needs and to start conversations with their guardians on topics not yet discussed.

Limitations

The research is not representative for all adults with ID in Poland. Lack of representativeness is determined by small sample size and testing only in 4 selected Polish schools. In this research project, non-verbal people who required alternative or supportive methods of communication, and people with mild and deep ID were excluded. Although research using the FGI method has brought many benefits to recognising the proposed topics, it was also noted that subsequent students repeated the views of the previous ones. When the first two students said homosexuality is a disease, the next few students repeated the same thing. Individual interviews would reduce this phenomenon. Many factors that are not included here influenced the level of knowledge about human sexuality in project participants, i.e. parents' attitudes towards sex education (Pownall, Jahoda, and Hastings 2012). Participation in the project was voluntary, therefore there is a risk that most students who volunteered came from homes where sexuality is not a taboo topic and they are not ashamed to talk about it.

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