



# Thoughts, Attitudes and Experiences of Parents of Children with Disabilities in the Republic of North Macedonia About Comprehensive Sexuality Education

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## Abstract

When it comes to sexuality education, people with disabilities are often left out of the conversation. Many believe that these people are asexual, sexually inactive, that they do not need sexual education, that they cannot and should not have sexual relations and cannot/should not have love relationships and start a family. The main purpose of the research is to determinate thoughts, attitudes, knowledge and personal experience of the parents of children with disabilities regarding comprehensive sexuality education of their children. The data were collected through a survey of 54 respondents, parents of persons/children with disabilities from different regions in the Republic of N. Macedonia. Data were analyzed using the SPSS program and Chi square and Fisher exact test. From the data, it can be concluded that the majority of parents covered by this research are not familiar with the most appropriate age at which sexual education should begin. Around 57% of parents completely agreed with the statement that sex education should be part of the educational program in schools and only 38.9% of parents believe that their child should study all subjects. Children with disabilities need developmentally appropriate sex education to stay safe and healthy and to achieve self-determination.

**Keywords** Disabilities · Comprehensive sex education · Attitudes · Parents · North Macedonia

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## Introduction

In “The International Technical Guide to Sexuality Education” created by UNESCO, UNAIDS, UNFPA, UNICEF, UN WOMEN and WHO *comprehensive sex education* is defined as “a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. Aims to provide children and young people with knowledge, skills, attitudes and values that will encourage them to realize their health, well-being and dignity; to build social and sexual relationships based on respect; to consider how their choices affect their well-being and the well-being of others; and, to understand and ensure the defense of their rights throughout their lives” [1].

The International Planned Parenthood Federation points out that there is no single definition of comprehensive sex education and that they explain it as a holistic, developmentally and age appropriate, culturally and contextually relevant and scientifically accurate learning process, grounded in a vision of human rights, gender equality, positivism towards sex relationships that aim to:

- Encourage children and young people to maintain their rights and the rights of others and to contribute to the achievement of an equal, diverse, compassionate and just society;
- Enable children and young people to make decisions about their health and have access to key sexual and reproductive health services;
- Increase the abilities of children and young people to engage in equal, happy, healthy, fulfilling and consensual relationships and experiences; [2].

All people are born as sexual beings and have to develop their sexual potential in some way. Sexuality education helps prepare young people for life, especially for building and maintaining fulfilling relationships, and contributes to their positive personal development and self-determination. The need for sex education has arisen due to several developmental stages in the last decade. This includes the rapid spread of new media, specifically the internet and mobile phones, the emergence and spread of HIV/AIDS, the growing concern about sexual abuse of children and adolescents, and changing attitudes towards sexuality and changing sexual behavior among young people. This calls for effective strategies to enable young people to deal with their sexuality in a safe and satisfying way [3]. Foremost, sexual education is a basic right of every person. The right to sexuality education is a universal human right, including the right to education and health, and is enshrined in numerous international agreements, such as the Convention on the Rights of the Child, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, as well as the Convention on the Rights of Persons with Disabilities.

Historically, people with disabilities have often been seen as asexual or sexually inactive, so sex education has generally been seen as unnecessary and even harmful for them. Already existing education for young people with disabilities often presents sex as dangerous and the sexuality of people with disabilities as problematic. Traditionally, the sexual life of people with disabilities was actively ignored and socially stigmatized. This topic was constantly ignored because it was considered a taboo topic. Additionally, sexuality as a form of pleasure and expression of love is still not recognized for people with disabilities. Also, some socio-cultural beliefs have contributed to barriers that prevent people with disabilities from exploring their sexuality [4]. All young people with disabilities are sexual

beings and have the same right to enjoy their sexuality within the highest standards of health, including pleasurable and safe sexual experiences, free from coercion and violence, and to have access to quality sexuality education and services for sexual and reproductive health [1].

Due to the lack of knowledge related to sexuality and sexual health, persons with disabilities are at high risk of sexual violence and exploitation, unwanted pregnancies and sexually transmitted infections [5]. According to the University of Michigan, it is estimated that as many as 40% of women with disabilities experience sexual assault or physical violence in their lifetimes and that more than 90% of all people with developmental disabilities will experience sexual assault. Some children with disabilities may be vulnerable to sexual violence due to daily dependence on others for their intimate care, increased exposure to numerous caregivers, inadequate social skills and poor judgments, inability to seek help or report violence, as well as lack of strategies to defend oneself against violence [6]. In a study conducted in the Republic of N. Macedonia out of a total of 213 examinees with different types of disabilities aged 10 and over, 23.72% were forced to watch various sexual acts or pornographic materials, 10.56% were forced to perform sexual acts themselves, and 14.42% were forced to take off their clothes [7].

Previous studies have shown that parental attitudes are highly significant predictors of the sexual and emotional functioning of persons with disabilities. Initiating conversations about sexuality and sexual behavior can be difficult for parents of preteens and adolescents, especially parents of children with intellectual disabilities, primarily because sexuality may not be a priority in the face of other time-consuming educational efforts and interventions or may be delayed by parents' reluctance to see their children with special needs as sexual beings. However, sexuality education should begin at birth when parents bathe, diaper, stroke, hold, and cuddle their baby and continues as toddlers and preschoolers when parents dress, toilet-train, and teach their child about his or her body. Early sexuality education can foster independence and prevent victimization of children with disabilities [8].

## Methods

The study is modern and quantitative, in which the methods of comparative and descriptive analysis were applied, as well as the method of generalization, in order to determine the thoughts, attitudes and experiences of parents of children with disabilities for comprehensive sexual education.

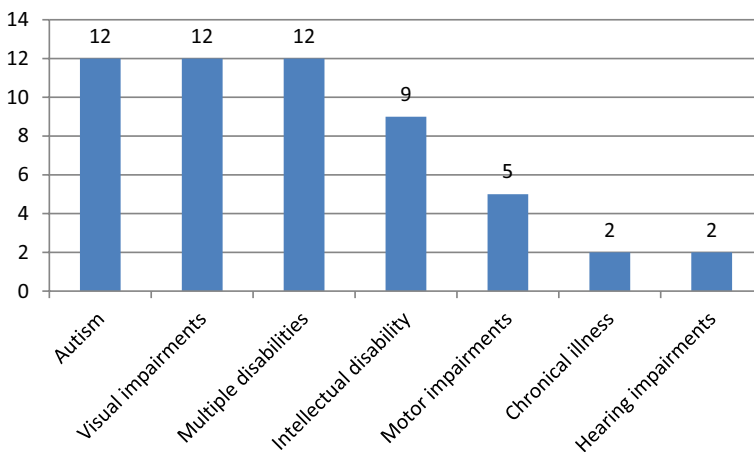
Wanting to determine the attitude of parents regarding what is the most appropriate age to start comprehensive sexuality education, what topics comprehensive sexuality education should cover, which people should realize, as well as the challenges they face related to the sexual behavior of their children, we applied the survey technique. For the survey of 54 parents of children with disabilities, a survey questionnaire consisting of a total of 32 questions was used. Of these, 7 questions are about demographic data, and the remaining 25 questions are directly related to the topic. Out of those 25 questions, 5 are open type and 20 are closed type. After first analyzing the literature and existing information on this topic in the territory of the Republic of Macedonia, we created a questionnaire for the needs of the research. Then we piloted the questionnaire on a small group of examinees, parents of students with disabilities, in order to see the shortcomings. After we finalized it, we applied it. The age of the respondents varies from 32 to 65 years, with the arithmetic mean of 45.87 years, and regarding gender 46 (85.2%) are mothers, 6 respondents (11.1%) are

fathers, and foster mothers and foster fathers are equally represented by 1 respondent each (1.9%). We obtained the research sample by applying the "snowball" method. We actually contacted the first respondents as parents of visually impaired students (5) at the Institute for the Rehabilitation of Visually Impaired Children and Youth "Dimitar Vlahov" from Skopje and parents of students with intellectual disabilities and autism (9) in a primary school with a resource center "Dr. Zlatan Sremec" from Skopje. The rest of the respondents were contacts of the first, members of the different parents associations and thus widened the network, conducting online surveys, as a result of movement restrictions due to the COVID-19 pandemic. The main criterion for inclusion in the research was to be parents/guardians of a child with a disability over the age of 6, who is included in the educational system.

According to the demographic data and in correlation to the degree of education of the examinees, it can be noted that almost the largest number of respondents, i.e. 26 respondents (48.1%) have a higher education, 21 respondents (38.9%) were with finished secondary education, 5 respondents (9.3%) have an associated degree of education and only 2 respondents (3.7%) pointed out that they have primary education. Regarding the type of the disability of the children of examinees (Fig. 1), 12 respondents (22.2%) answered that they have children with an autistic spectrum disorder and children with impaired vision, 9 respondents (16.7%) pointed out that their child has an intellectual disability, 5 respondents (9.3%) pointed out that their child has a motor disorders and with equal representation, i.e. 2 respondents each (3.7%) answered that they are parents of a child with hearing impairment and a chronic disease. The youngest age of the respondents' children is 6 years, and the oldest is 40 years, the arithmetic mean is 15.79 years, and the majority of the respondents' children, i.e. 33 (61.1%) are male, while the remaining 21 (38.9%) are female children.

Our main hypothesis claims that the majority of parents of children with disabilities would have a negative attitude towards the realization of comprehensive sexuality education for their children.

After the data were collected, they were analyzed, grouped and presented tabular and graphically. The data were presented as a percentage and through call frequency. To



**Fig. 1** Types of disabilities of the children of examinees

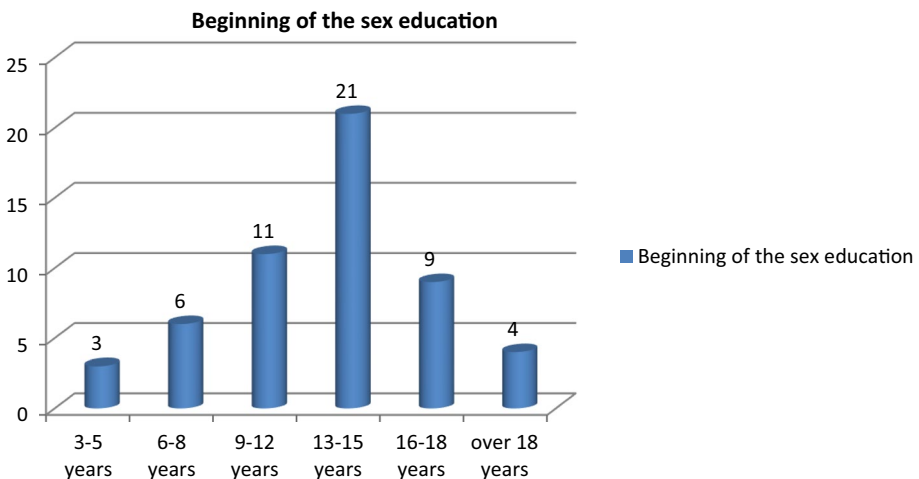
analyze the data and make a comparison in order to determine the relationship between the obtained data from the different groups of respondents, we used computer processing of the data with the standard statistical program SPSS for Windows XP, applying the  $\chi^2$  test and Fisher's exact test. The chi square test was used to determine the correlation between the variables and to test the hypotheses, and for those questions where the frequency of answers was lower, given the respondents' freedom of response, the Fisher exact test was used for greater precision. Values with  $p$  lower than 0.005 were considered statistically significant.

## Results

We will try to summarize the large amount of information obtained from 32 questions in a short presentation of the most relevant answers by the respondents.

To the question "At what age do you think it is most appropriate to start sex education?" It can be noted that the majority of respondents, i.e. 21 out of a total of 54 respondents (38.9%), believe that the most suitable time to start sexual education is between 13 and 15 years of age. Fewer, i.e. 11 respondents (20.4%) believe that sex education should start between 9 and 12 years of age, 9 respondents (16.7%) believe that it should start between 16 and 18 years of age and 6 respondents (11.1%) believe that the same should start between 6 and 8 years of age. Only 4 respondents (7.4%) believe that the most appropriate time to start sex education is after 18 years of age, and the smallest number of respondents, i.e. only 3 respondents (5.6%), believe that sex education should start from the youngest age, between 3 and 5 years old (Fig. 2).

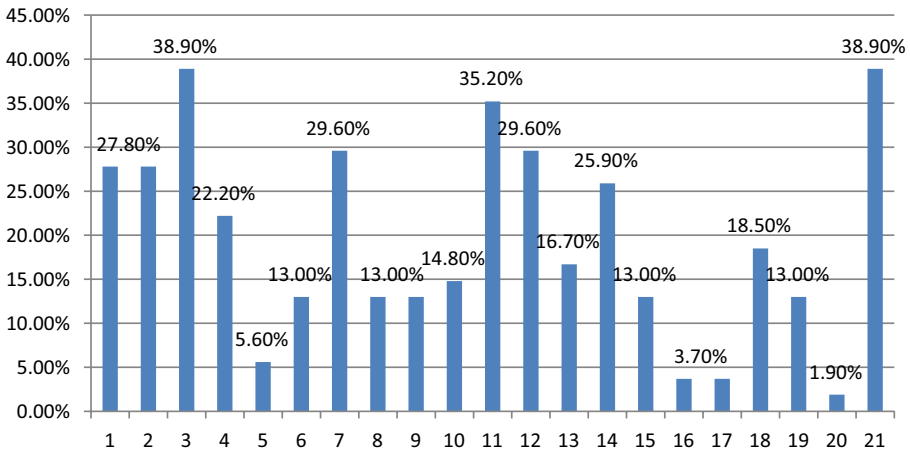
Regarding the second question, "Should sexuality education be part of the education curriculum itself?" most of the respondents, 31 (57.4%) believe that sexual education should be part of the educational program in the schools themselves, and in the same direction, on the third question "If there is a regular subject for comprehensive sexual education in the schools themselves, which of the following topics do you think should be part of that subject?", the respondents were able to give more different answers, more exactly to round



**Fig. 2** Attitudes about the optimal time to start sex education

up all those topics that they consider should be taught as part of the comprehensive sexual education (CSE) subject from the list of 19 offered topics (Fig. 3). From the data, it can be concluded that only 38.9% of parents believe that all the topics should be included in the comprehensive sexuality education in school. The least number of parents, 3.70% of all examinees agree on the topics “Gender stereotypes and gender equality” as well as “Gender determination”.

In terms of who should work on these topics with the children with disabilities, the largest percentage of respondents, as many as 43 out of 54 respondents (79.6%) believe that the mother should work on these topics, slightly less, that is, 40 out of 54 respondents (74.1%) rounded that teachers and special educators should work in the schools themselves. The third most common answer is that the father should work on these topics with the child and this was stated by 34 respondents (63.0%) of the total number of respondents. Thirty respondents (55.6%) stated that psychologists should work on these topics, 22 respondents (40.7%) circled special educators in day care centers, and 17 respondents (31.5%) circled the options of doctors and social workers. Six respondents (11.1%) believe that the brother or sister should work on these topics, three respondents (5.6%) each belief that peers and other family members should work on these topics in addition to those listed and only one respondent (1.9%) thinks that none of the above should work with their child on topics related to sex education. The parents were also asked to indicate who is currently working on these topics with the child, with 75.9% indicating the mother as the person who



- 1. Intimate parts of the body
- 2. Public and private space
- 3. Changes that occur during puberty
- 4. Menstrual cycle
- 5. Wet dreams
- 6. Masturbation
- 7. Appropriate and inappropriate touch
- 8. Giving consent for sexual relations
- 9. Types of relationships
- 10. Sexual relations
- 11. Sexually transmitted infections
- 12. Contraception
- 13. Pregnancy
- 14. Sexual violence
- 15. Safe use of online tools
- 16. Gender stereotypes and gender equality
- 17. Gender determination
- 18. Sexual and human rights
- 19. Sexual diversity and discrimination
- 20. None of these topics
- 21. All listed topics

Fig. 3 Topics of the CSE

is currently talking about sex education topics, and 31.5% indicating the father. Forty-six percent of parents pointed out that they openly talk with their child about sexuality education topics, and around 26% of examinees disagreed with this statement. On the question “Within which subject comprehensive sexuality education should be studied if it is not a specially designed subject”, 38 respondents (70.4%) chose the subjects of biology and psychology, less than them, that is, 20 respondents (37.0%) chose the subject of sociology and 9 respondents (16.7%) chose the natural sciences as optimal subject.

When comparing the answers received regarding the gender of the person working with the person with a disability on the topics related to comprehensive sexual education and the gender of the person with a disability, it can be noted that there is a statistically significant difference, i.e. ( $p < 0.05$ ). From Table 1, it can be noted that in relation to parents of male children, a small proportion of them, that is, only 6 (11.1%) consider it important that the person who works with their child should be of the same gender. The majority of parents of male children, i.e. 26 (48.1%) do not care if the person who works with their child is male or female. While this is not the case with the parents of female children. The greater number of parents of female children, i.e. 12 (22.2%) believe that the person who should work on these topics with their child should be female, while only 8 parents (14.8%) do not care if the person is male or female. In terms of challenges faced by parents in correlation with sex education, it can be noted that a very small portion of the respondents did not face any problems until now, while a certain part of the respondents have not discussed these topics until now and still consider that sex education should start at an older age. However, most of the respondents faced some kind of problem and many of them needed help from the professional staff. In line with the results can be concluded that parents need more information, training and professional help, in order to receive certain guidelines on how to work with their children on these topics and overcome certain challenges they face.

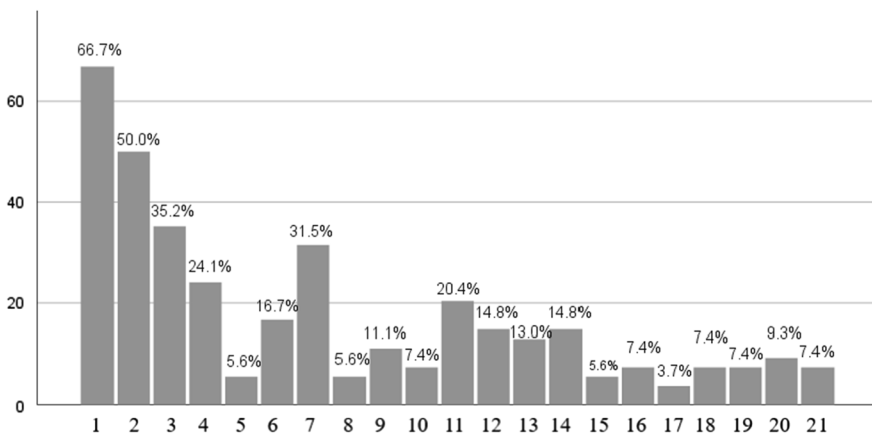
Regarding “The importance of comprehensive sexuality education for their children with disabilities”, it can be noted that the largest number of respondents consider that sexuality education is of great importance for their child, out of a total of 54 respondents, 34 (63.0%) completely agree with the statement, 15 respondents (27.8%) partially agree, only 2 respondents (3.7%) stated that they have no opinion. Guided by the importance of sexual education, parents were asked “Do their children have enough knowledge in the field of comprehensive sexuality education?”, and the largest number of respondents answered that they partly agree with the statement, i.e. 17 respondents (31.5%), while 7 respondents (13.0%) completely agree with this statement. Eleven respondents (20.04%) do not have an opinion on this topic, 12 respondents (22.2%) partially disagree with this statement and 7 respondents (13.0%) disagree with it at all and consider that their child does not have sufficient knowledge of the topics included in sexuality education.

Parents were also asked to indicate which sex education topics they discuss with their children, so out of the total number of respondents, 5 (9.3%) pointed out that they had

**Table 1** Gender differences regarding the gender of the CSE teacher

	Gender of the examinee						$\chi^2$	df	P
	Male		Female		It is not important				
	N	%	N	%	N	%			
Boy	6	11.1%	1	1.9%	26	48.1%	20.767	2	0.000
Girl	1	1.9%	12	22.2%	8	14.8%			

not discussed any of the offered topics with their child, while 4 (7.4%) out of a total of 54 respondents pointed out that they had discussed all the topics that were offered as answers. The remaining 45 respondents chose specific topics (Fig. 4), out of the 19 offered, 36 respondents (66.7%) pointed out that they had discussed with their child the topic "Intimate parts of the body", after them 27 respondents (50%) pointed out that they had discussed the topic "Public and private space", 19 respondents (35.2%) mentioned the topic "Changes that occur during puberty", 13 (24.1%) mentioned the topic "Menstrual cycle", only 3 respondents (5.6%) mentioned the topic "Wet dreams", and 9 respondents (16.7%) the topic "Masturbation". Seventeen respondents (31.5%) pointed out that they had discussed with their child the topic "Appropriate and inappropriate touches", only 3 respondents (5.6%) covered the topic "Giving consent for sexual relations", and also some respondents, i.e. 6 (11.1%) chose the topic "Types of relationships". Only 4 respondents (7.4%) pointed out that they had discussed the topic "Sexual relations". A slightly larger number of respondents, i.e. 11 (20.4%) mentioned the topic "Sexually transmitted infections", then 8 respondents (14.8%) circled the topic "Contraception (Method of protection against pregnancy and sexually transmitted infections)", 7 respondents (13.0%) circled the topic "Pregnancy", while 8 respondents (14.8%) pointed out that they had discussed the topic "Sexual violence". Only 3 respondents (5.6%) have discussed the topic "Safe use of online tools", 4 (7.4%) circled the topic "Gender stereotypes and gender equality", and only 2 respondents (3.7%) emphasized that they have discussed the topic "Gender Determination". The same number of respondents, i.e. 4 respondents each (7.4%) pointed out that they had discussed



1. Intimate parts of the body 2. Public and private space 3. Changes that occur during puberty 4. Menstrual cycle  
 5. Wet dreams 6. Masturbation 7. Appropriate and inappropriate touch 8. Giving consent for sexual relations 9.  
 Types of relationships 10. Sexual relations 11. Sexually transmitted infections 12. Contraception 13. Pregnancy  
 14. Sexual violence 15. Safe use of online tools 16. Gender stereotypes and gender equality 17. Gender  
 determination 18. Sexual and human rights 19. Sexual diversity and discrimination 20. None of these topics 21.  
 All listed topics

**Fig. 4** Topics discussed with the parents



the topics "Sexual and human rights" and "Sexual diversity and discrimination". One respondent, who concluded that she had not discussed any of the topics, stated in the questionnaire itself that her child is still small.

To the next related question, "How do they feel during a conversation about sex education with their children?", 26 respondents (48.14%) point out that they feel normal when talking about these topics with their child, 20 respondents (37.03%) feel uncomfortable, shy, confused during such conversations and a third group of respondents, 8 (14.8%) feel that they are not professional enough on this topic. Regarding the challenges that parents faced when talking about sexual education topics, 8 parents (14.8%) indicated that they had no challenge, another 8 (14.8%) pointed out a feeling of shame, part of 20 respondents (37.03%) pointed out that they do not know how to explain to their children and that they are not sure how much their children understand them, so in that direction they pointed the need for cooperation with experts and additional education. To the question "Who has helped them so far, where do they get information about sexual education of their children?" Three out of 54 respondents (5.6%) did not answer this question, even half of the respondents, ie 27 respondents (50.0%) pointed out that they have not received any information on this topic until now. Few respondents, i.e. 7 (13.0%) pointed out that they got the information from training sessions, while 8 (14.8%) stated that they got it from seminars. Only 4 respondents (7.4%) pointed out that they receive information from special educators and only 2 (3.7%) pointed out that they receive it from teachers in regular schools. The remaining 15 parents (27.8%) pointed out that they receive help and information about how to teach their child about topics related to sex education from other parents of a child with a disability.

Another topic that parents responded to was "The sexual behavior of their children", so in that direction, the majority of respondents indicate that their child has normal, acceptable sexual behavior, or 17 respondents "Completely agree" with this statement and the same number "Do not have opinion" (31.5%), 10 respondents (18.5%) indicated that they partially agree with this statement, only 4 respondents (7.4%) answered that they partially disagree with the statement and only 5 (9.3%) disagree at all with the statement that their child has appropriate sexual behavior. When asked "what are your biggest fears and challenges regarding your child's sexuality and sexual behavior?" 10 respondents (18.51%) did not answer this question, 1 respondent answered that he does not know what his/her fears are, 15 respondents (27.7%) pointed out that they have no fears on this topic, of which one respondent points out: "I have no fears, because my child is constantly under my supervision". In addition, two respondents (3.70%) pointed out that they have no fears because their children are small and it is still early. The remaining 26 respondents (48.14%) had fears about various aspects of their child's sexuality. Seven of the respondents (12.96%) associate their fears with their children's intimate relationships and sexual relations, but also with the possibility of their sexual inactivity. One respondent (1.85%) pointed out that he is afraid of sexually transmitted diseases, 2 respondents (3.70%) pointed out the fear of sexual relations as an act and the need of their children for it. Two respondents (3.70%) expressed their concern about whether their child would be sexually active, so one stated that he was afraid of his child's sexual inactivity, while the other stated: "Will he have sexual intercourse at all, knowing that he has a disability?". One respondent (1.85%) highlighted the challenge of the first girlfriend, while another respondent is worried about whether his child will find a suitable partner. Eight respondents (14.8%) are most afraid of sexual abuses of their child or any kind of victim. These are some of their statements:

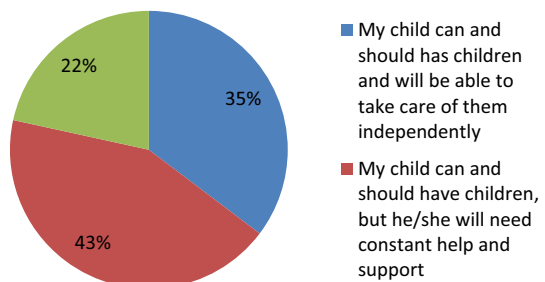
- "Inappropriate behavior of others towards my child and his reaction"

- "I'm afraid she can be easily abused"
- "He wouldn't tell me about sexual harassment or something worse if something happened to him"
- "Not to be a victim of sexual violence by stronger people."
- "The biggest fear for me is that someone could sexually exploit my child, because I don't know how much my child understands that he should give consent for intimacy"

In terms of partner relationships, 13 respondents (24.1%) agree with the statement: "I think it's okay for my child to have a crush, but not for it to grow into a relationship." Almost half of the respondents, i.e. 26 (48.1%) pointed out that they agree with the statement "I think that my child can and should have a love relationship". A very small number of respondents, i.e. only 5 (9.3%) pointed out that they agree with the statement: "I think it is okay, if my child wants and feels that way, to have a relationship with a person of the same sex." 25 (46.3%) parents agreed with the statement: "I think it's okay, if my child wants and feels that way, to have a relationship with a person with the same disability as his/her." With the statement: "I think it's okay, if my child wants and feels that way, to have a relationship with a person who has a different disability than his/her own." 22 respondents (40.7%) agreed. Half of the respondents, 27 (50.0%) agreed with the last statement: "I think it is okay, if my child wants and feels that way, to have a relationship with a person who does not have a disability." Regarding their children's sexual relations, 51.9% of parents agreed that their children should have sexual relations at an appropriate age, in contrast to 18.5% who did not agree at all. Only 3 respondents (5.6%) pointed out that they agree with the statement: "I think that my child, if he does not have or cannot have sexual relations with a partner, it is okay to have sexual relations with sex workers."

Examining the attitude of parents about their children's offspring, it can be noted that the majority of respondents believe that their child can and should have children, 18 respondents (33.3%) agree with the statement: "My child can and should have children and will be able to take care of them independently", 22 respondents (40.7%) agreed with the statement: "My child can and should have children, but he/she will need constant help and support". The remaining 11 respondents (20.4%) agreed with the statement: "My child cannot and should not have children" (Fig. 5).

**Fig. 5** Attitude of parents about their children's offspring



## Discussion

Historically, for individuals with disabilities, there has been a fear that by providing sexuality education, their sexuality, which, presumably, would have otherwise remained dormant, will somehow be awakened. The attitudes of parents and staff members about the sexuality of an individual with a disability tend to determine the amount of education he or she receives. Forward-thinking parents and staff are more likely to provide quality sexuality education, while those who are less liberal and believe that providing this education will lead to harm, fail to do so [9]. In our research, all respondents agree that sex education is of great importance for their children, while in 75.9% of children, the mother is the one who works on these topics with the child. From the analysis of the results itself, it can be concluded that the general hypothesis “That the majority of parents of children with disabilities will have a negative attitude towards the implementation of comprehensive sexual education for their children” is rejected, considering the fact that 57.4% of parents completely agreed with the statement that sexual education should be part of the educational program in the schools themselves.

Stein, Kohut and Dillenburger in 2017 in their research found that parents of children with intellectual disabilities are less likely to believe their children will have consensual or non-consensual sex before age 18 than parents of children without IDD, but favor sexuality education for their children, with parents preferring to provide it themselves, with the assistance of or through preparation by workshop with a professional [10]. Pownall et al. [11] interviewed mothers of typically developing children and children with developmental disabilities and determined that mothers were somewhat reluctant to initiate conversations about sexuality when their children had developmental disabilities, and, when they did so, it was with less detail than the conversations of mothers with typically developing children. From the data obtained in our research, it can be concluded that the majority of parents have not discussed all or most of the topics of comprehensive sex education with their children. Most of them discussed more general topics such as intimate parts of the body, private and public space, etc., and only 7.4% of respondents pointed out that they had discussed all the topics included in CSE with their children. When comparing the results with research done in Macedonia in 2009 on the topic "Sex education of persons with disabilities", where 30 parents of children with disabilities were included as part of the respondents, it can be seen that some of their answers coincide with the answers of the respondents covered in this research. The largest number of respondents included in the 2009 survey answered that they are uncomfortable when they have to talk with their child about sexual development and sexual behavior, 8 parents answered that they are very uncomfortable, 7 answered that they talk about that topic as normally as any other, and 4 parents answered that they don't care [12]. Zarrilli in 2021, in his study, obtained similar results to our research data, the content area with the highest approval rating among parents of children with disabilities was human development at 97.56% and the lowest approval rate was for gender identity and sexuality orientation at 73.17% [13].

Kamaludin with coworkers explored the challenges mothers encountered while educating their children with intellectual disability about sexuality, and they identified four significant hurdles to delivering SE: (1) paucity of knowledge impedes the role, (2) perceived SE is less necessary, (3) communication barrier, and (4) family value and Adat (culture-norm). In correlation to our findings, we can conclude that although a large part of parents (23) feel normal and comfortable when talking about these topics with their children, twenty two parents feel unprofessional, uncomfortable, and ashamed, have problems when talking

about sexuality topics with their children. Some of them themselves point out that they need professional help. This highlights the need for mutual cooperation between parents and professionals, in order for parents to receive help and support and to be able to pass on information to their children more easily [14]. The conclusion of our research that parents need more information and education about the topics of sex education in order to know how to position themselves with their child in conversation and education, correlates with the results of a survey conducted in Ontario, Canada, on the topic "Experience on sexuality education among health professionals, parents and adolescents with physical disabilities in Southwestern Ontario". Parents pointed out that they feel inadequately prepared to provide sex education and believe that someone else's responsibility is to convey this information to young people with disabilities, not theirs [15]. Likewise, parents of children with an autistic spectrum disorder, in the USA in 2012 involved in research on the topic "Parental views regarding communication about sexuality in the families of children with an autistic spectrum disorder", emphasized a huge desire for communication with their children and sexuality professionals, but also certain concerns regarding such discussions. The majority of parents indicated that they would feel comfortable talking to their children with ASD about sexuality, but questioned their child's ability to understand the information, citing this as a barrier to discussions. In addition to this, parents further pointed out that despite the fact that many professionals are actively involved in their children's lives, they felt isolated in terms of receiving information or preparations on how to address their child's sexuality. Parents emphasized that professionals did not have the initiative to guide children's sexual maturation, unless some aspect of sexuality presented itself as a behavioral problem [16]. Eyres [17] also emphasized the need of parents for cooperation and professional help for support when implementing comprehensive sex education for children with disabilities. According to Michielsen and Brockshmidt, there are seven barriers to sexuality education for children and young people with disabilities, including the social misperception of people with disabilities as asexual and in need of protection which, combined with limited support for educators, resulted in non-comprehensive and normative sexuality education. Educators seem inclined to redirect responsibility for sexuality education to others, and diversity among children and young people with disabilities, as well as cultural and religious diversity, makes it difficult to define a general approach. The need for additional training of parents regarding the topics of sexuality education has been elaborated in numerous studies and papers, and a large part of them emphasized the positive impact of trainings. Frank and Sandman [18] in their study found that the sexuality education training and workshops for parents reduce the negative attitudes of parents regarding the sexuality of their children and increases their self-efficacy discussing sexuality topics. Kok and Akyüz, in their study on the impact of training programs on the implementation of sexual education by parents, point out that in addition to the great theoretical knowledge of parents, a significant improvement is observed in the practical implementation of sexual education of their children with disabilities after the completion of the training [19].

From the analysis of the data, we can conclude that the majority of parents disagree that it is okay for their child to have a relationship with a person of the same sex, a large proportion of the parents disagree with the fact that their children should have sexual relations, especially if they are not in a serious relationship. Only 9.3% pointed out that they agree with the statement: "I think that my child can and should have sexual relations when he is in a relationship that is not very serious." Most of the parents who agreed with the statement, "My child can and should have children and will be able to take care of them independently", are parents of visually impaired children (15.7%). "My child cannot and should not have children", was chosen only by parents of children with ASD, IP, Combined

disabilities and chronic illness. Aunos and Feldman in 2022 found out that despite the ban on involuntary sterilization, it appears that many parents and teachers of persons with intellectual disabilities still support it as a form of contraception, especially for persons with severe intellectual disabilities. Likewise, attitudes towards parenting by persons with intellectual disabilities remain negative, and these attitudes may adversely affect the provision of competency-enhancing support and services for parents with intellectual disabilities and their children [20]. From the results of our research, it can be pointed out that a large number of parents disagree that their children should have sexual relations, especially if they are not in a serious relationship. This finding is supported by the results shown in the work of Tamas and colleagues, where they pointed out that the parents of persons with intellectual disabilities often worry that their children might fall victim to sexual abuse and are therefore rather restrictive when it comes to allowing them to have sexual experiences [21].

## Conclusion

Comprehensive sexuality education aims to provide accurate information about all facets of human sexuality, helps develop relationships and other interpersonal skills, and helps learners to develop skills to navigate relationships in ways that are fulfilling and safe.

In general, within public education settings, people with disabilities are often excluded from sexuality education and unfortunately, this lack of education increases, rather than decreases, their vulnerability to sexual abuse and exploitation. Lack of knowledge and competence, the diversity of children's disabilities, and the influence of social-cultural values in daily life contribute to the complexity of an already challenging situation for the parents of children/persons with disabilities. The role of parents is very important in providing sexual education to their children, to support them primarily in getting to know their body parts, understanding their sexual development stages, appropriate modes of sexual behavior as well as their attitude towards the opposite sex.

The results we obtained, although they indicate that the majority of the parents included in the research consider that sex education is of great importance for their child, they still face a series of prejudices, regarding the topics that should be addressed, the people who should be involved and the institutions where it should be implemented. This study emphasizes the need for future interventions to overcome the barriers at each obstacle level to ensure that the comprehensive sex education of persons with disabilities can be implemented successfully in all developmental stages and all life circumstances.

## Strengths and Limitations

Although comprehensive sexual education has been talked about for a long time, still under the influence of the stigmatization of persons with disabilities, studies on the attitudes of parents of persons with disabilities regarding comprehensive sexual education of their children are relatively few. An analysis of the existing literature and a comparison of the data from other researches and studies with the data from our research has been made, however, the relatively small number of respondents involved will be cited as a limitation of our study.

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## Declarations

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