

# The Sexual Education of Children with Intellectual Disability

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## Abstract

The main objective of this research was to investigate the views of parents of children with and without intellectual disabilities in the sexual education of young people with intellectual disabilities. Our survey included 306 parents of children without intellectual disabilities and 304 parents of children with intellectual disabilities. Their views were investigated using a questionnaire created for research purposes based on Greek and international bibliography. The analysis of the data showed that the parents of both groups agree that the sexual education of all young people with and without intellectual disabilities is necessary and will offer the quality of life of the families that raise people with intellectual disabilities. They also think they have the skills and it's their responsibility to talk first of themselves about sex education to their children. They agree that sex education will offer a lot of respect for the human rights of disabled young people and they feel they should enjoy the same rights as their peers without disabilities.

**Keywords:** Intellectual disabilities, Parents, Sexual Rights, Sexual Education,

## Introduction

In Greece, the question of the sexual education of people with intellectual disabilities has clearly taken on a few researchers, despite its importance. The road that remains in our country until sexual education becomes an act is long. In recent years, of course, in the subject of sex education, a great deal has been devised about the concept of sexual education, its models of introduction and teaching, its content, methodology, and effectiveness [4, 6].

Previously, [28] focused on the experiences and difficulties faced by parents in raising their children with mental disabilities. In this study, respondents were consulted about sexual issues only on three questions. Whether or not the child will be in special education and what criteria will support this decision, the difficulties of accessing children in the special school due to distance or lack of means of transportation and the frustration experienced by parents and children with special needs from parent's children of co-educational regular schools.

In a study [6] on the sexual education of autistic young people, it was found that only 3% of the parents who took part welcomed the conclusion of sexual relations among young people with intellectual disabilities. (a) They, therefore, refuse to complete their sexual relations with their children; (b) As regards clothing, they try to dress them in a way that does not raise sexual desires for their children; (c) The majority of parents discard the solution of the house of tolerance, although ultimately adopted at higher rates; (d) most of the male parents agree with the completion of the sexual relations of their boys with intellectual disabilities. In similar earlier research by Grunewald and Liner (1981), it has been shown that people with intellectual disabilities seem to have little or no sexual relations because they are afraid of sexual intercourse or have in mind that such relationships are forbidden. Nevertheless, there is always a desire to participate in a more active sex life in men or couples with intellectual disabilities, which is more intense in men than in women [11]. In another research, [6] reports that only 8% of parents agree to marry people with intellectual disabilities under very restrictive conditions. All the parents of his research, however, converge in the failure of such a marriage. But will

and desire for marital life are present especially in people with moderate intellectual disabilities. The primary reason is the abandonment of their previous social isolation. In a very old survey, [2] reports that marriage is a sign of regularity and gives a place of free man within the community. In a Greek study [11], the sexual behavior of Greek adults with Down syndrome was examined. The sample consisted of parents, relatives, and professionals. (N = 56) as a team that trains and educates young people with Down syndrome. Teachers and teachers were used as a control group (N = 55). Data were collected at 21 questions questionnaire. The results showed that Downward Adult Greek adults, like other adults, have the opportunity to express views on their sexual behavior when they are provided with appropriate conditions by the community and adults who are taught basic knowledge and experiences for individuals with Down syndrome get a positive view of these. Rechargers in Greece [2], investigated the information and sexual activity of adolescent boys with special needs and in particular the way and frequency of sexual information and life of adolescent boys with intellectual disabilities. We studied 110 boys aged 15-18 years with intellectual disabilities (intelligence index 40-70) and with normal genital development and secondary sex characteristics. The study was based on an interview with parents (and as much as possible about children) about masturbation, sexual intercourse of young people and the sexual information of young people at the initiative of parents or questions themselves.

The same questions were raised in the control group. It was found that 59% of young people are masturbating, for 16% there were indications of masturbation and 6% had sexual contacts, which were achieved by the parent or relative guidance. No child asked to be informed, and few parents did (informally ignorant) efforts to inform them. The control team found that 100% were masturbating and 61% had sex. The research concluded that the sexual information of teen boys has been virtually non-existent and their sexual activity very poor. Coordination of efforts is needed to make progress on this issue, which is fundamental to the psychosomatic health and right of all people. Furthermore, researchers investigated the attitudes of ordinary people to the sexuality of people with intellectual

disabilities in Greece [12]. The survey was conducted in Athens, Patras, and Agrinio, and 311 people of the general population took part. It was found that the participants generally expressed positive attitudes towards the sexual education of young people with intellectual disabilities in addition to some areas such as homosexuality and the acquisition of children. Research into the attitudes towards the sexuality of people with intellectual disabilities is limited due to the lack of a weighted assessment body that will allow a direct comparison of surveys [11]. This kind of measurement would allow researchers to make comparisons about attitudes to the sexual education of people with and without intellectual disabilities [11]. Other researchers [7], investigated the attitudes and perceptions of the educational staff of Special Education Schools regarding the introduction and teaching of sex education in school and sexual education in pupils with intellectual disabilities. The sample consisted of 196 people (teachers and support staff), and the results showed a high degree of necessity to apply sex education to school and the role of the persons involved in this education, the high degree of necessity of sexual education in people with intellectual disabilities and the important role of the family and the school in this issue has emerged.

Sexual education in the countries of the Europe, America, and Australia is quite developed and organized. These countries have developed enough education programs for several years, but which have not been evaluated over the years. Sexual education for all young people is considered very important [37]. It includes education in social skills, individual self-determination, respect for others, right and socially acceptable behavior, giving and accepting love, tenderness, and respect for the opposite sex. As for people with intellectual disabilities, the emergence of the normalization movement for their inclusion in the social environment that they belonged to had the same precondition for respecting their human rights that were ignored in the past. Sexual education, therefore, is undoubtedly the right of people with intellectual disabilities.

It was therefore considered, as a natural consequence, that they should receive the same training provided to their peers without intellectual disabilities. Even more so, when there is a

high rate of sexual abuse in people with intellectual disabilities and the only way to avoid it, is proper sexual education [21]. The views of parents and specialists involved in their education agree that they need to receive sexual education from an early age so that they can grow up to manage their feelings and needs and also to develop skills and knowledge on issues protection against sexual abuse, health, hygiene, and undesirable pregnancy. Parents themselves argue that a strict manipulation capable of suppressing any sexual expression is capable of protecting their children and admits to a large extent that they are unable to provide sufficient information or would prefer that another body take over this task [22].

In the literature, there are studies and programs of sexual education developed and implemented by other countries, sexual education programs for young people with intellectual disabilities are implemented [34, 23]. So one might wonder why a similar program does not apply in Greece. Perhaps, it should be noted here that these issues are related to the particular cultural characteristics [4, 6, 8, 12], which concern the culture of every people and thus it is difficult to generalize to different cultures. Almost all European countries have experience in sexual education. This experience may be a good resource for the study and needs of our country of the problems faced by autistic young people with regard to their sex education in relation to the views of parents with and without children with intellectual disabilities. In particular, what is observed with regard to sexual education is a lack of educational policy, an absence of programs, unscientific teachers and school staff [4, 6, 12].

Important parameters influencing and shaping the relationships of members of a family are the characteristics of the personality of each member, as well as the importance the family gives to personal, social and other values. Inside a family system, individuals are linked to each other, with strong, long-lasting and mutual ties, which may vary in intensity but last throughout the family's life [8]. Views on the value and effectiveness of the family as a social system vary. However, it is sure to be the primary physical placement of every person's exercise to develop interpersonal relationships. It is the framework through which each child learns to adhere to rules and order, to respect

persons and things, to experience and to shape himself, to develop skills that will help him later to find his place in society [1].

## Method

### Participants

Participants were total 614 and from them, 308 had children with intellectual disabilities from 6 to 23 years old and 306 had children with typical development from 6 to 18 years old. Children and young people with intellectual disabilities attended educational structures in general or special education, according to the Greek law for the education of children with special needs

### Research questions

Based on what has been mentioned above, this research focuses on the following research questions:

Parents of children with and without intellectual disabilities

- 1) Consider the provision of sexual education to their children a human right
- 2) Consider the sexual education of young people with intellectual disabilities in school age to be important
- 3) Have the ability to properly prepare their children for the socio-sexual aspects of life?
- 4) Are responsible for the sexual education of their children

### Data collection tool

In order to be able to collect data for the present research, a specific questionnaire invented which consisted of 3 parts (1st) Demographic features of the parents outlining their social profile as age, marital status, occupation, educational level and place of residence (2nd) Parents' views on sexual education for young people with intellectual disabilities about their concern on sexual education of young people in general [15, 16], if they are willing to take the responsibility to talk to their children

about sex education or if they prefer someone else to do so [26, 27, 40] and their views on the sexual rights of young people with intellectual disabilities grouped in eight pillars on (1) the creation and family upbringing of children with intellectual disabilities [45, 40] (2) the usefulness of sexual education [47, 48] (3) the most important areas of sexual education [40] (4) the areas of hygiene and protection [46, 50] (5) the young people's interpersonal relations with a intellectual disabilities [22, 23] (6) the human rights of young people with intellectual disabilities [46, 50] (7) the prevention of disease transmission and exploitation through [38, 40] and the prevention of unwanted pregnancy [43, 45] and (3rd) Parents participation in the implementation of sexual education as the most appropriate age at which sexual intercourse begins educating young people with intellectual disabilities [50] which is the most appropriate person to undertake sexual education of young people with intellectual disabilities [47] the purpose and content of sexual education programs [43, 44] in what ways can parents teach sexual education [13, 46], the characteristics that parents need to have to teach children with intellectual disabilities [6, 47] points to emphasize sexual education [1] the different way that each family faces the issues sexual education [50, 39, 41] the issues of sexual education that the same parents consider more important to teach [33, 27] whether they consider puberty the most appropriate age to talk about sexual education for their children [7, 11, 16] the reasons why there is no sexual education for young people with intellectual disabilities in Greece [40, 13, 23]. The questions are of the Likert type [51] in which the respondent is asked to declare the degree of agreement or disagreement on a five-point graded scale (1 = totally disagree, 2 = disagree, 3 = neither disagree nor agree, 4 = agree and 5 = totally agree) or there were five options from which respondents should choose one, or Yes/ No options.

### Data analysis

Psychometric Properties of the Measurement Scale of Parenting of Children with and without Intellectual disabilities on Sexual Education of Young People with intellectual disabilities

Cronbach's internal consistency (reliability) score for the total

scale of 25 questions was calculated at  $\alpha = 0.811$  and considered satisfactory [35, 36]. By convention, the ratio of 0.60 [35, 36] or 0.70 and above [35] is considered satisfactory. Thus, in the case of the particular measuring tool, the overall scale of the 25 questions was considered to be sufficiently reliable in terms of internal consistency. In order to demonstrate the internal coherence of the total scale and the individual factorial axes, the respective discrimination indices were calculated.

The total scale discrimination indices were satisfactory with a median of 0.38. Conventional median bid index values  $> 0.20$  are considered sufficient [35]. The credibility of the factorial axes was evaluated on the basis of CCR (Composite Construct Reliability) [36].

Analysis in Main Components highlighted nine factors (F1-F9, the questions that make up these factors have a good degree of correlation with each other) that interpret a total of 64.8% of the total dispersion.

## Results

Table 1: Positive results of sexuality education

	I ab- solutely dis- agree	rather disagree	do not agree or not agree	rather agree	strongly agree
	N	N	N	N	N
Parents of children with I.D.	0	0	4	47	255
Parents of typical children	0	0	5	44	259
Total	0	0	9	91	514

"Parents of children with and without intellectual disabilities in a very large proportion of 84.1% and 83.3% believe that sex education will have a positive effect on the lives of their mentally disabled children. And have the capacity to properly prepare their own children for the socio-sexual aspects of life." Parents of children without intellectual disability and parents of children with intellectual disabilities replied "I totally agree" to a large extent on all the questions.

Table 2: Human rights

	I abso- lutely dis- agree	rather disagree	do not agree or not agree	rather agree	strong- ly agree
	N	N	N	N	N
Parents of chil- dren with I.D.	2	2	8	65	228
Parents of typical children	2	2	8	66	229
Total	4	4	16	131	457

In a very high percentage, parents of both groups (eg 74.6% and 74.8%) believe that sex education is a basic quality human right. In this question, however, we see a fairly high percentage of around 22% not responding in the affirmative.

Table 3: Getting Sexual Training

	l abso- lutely dis- agree	r ather disagree	do not agree or not agree	r ather agee	strongly agree
	N	N	N	N	N
Parents of chil- dren with I.D.	1	1	4	60	240
Parents of typical children	1	1	5	62	239
Total	2	2	9	122	479

The parents of both groups at a very high rate (77.6% and 78.4%) agree that children with intellectual disabilities should receive sex education

Table 4: Ease of discussion

	l ab- solutely disagree	r ather dis- agree	do not a g r e e or not agree	r ather agee	strongly agree
	N	N	N	N	N
P a r - ents of children with I.D.	13	59	41	103	90
Parents of typi- cal chil- dren	21	54	48	104	81
Total	34	113	89	207	171

By contrast, only 1 in 4 parents, e.g. thinks it's easy to talk to their children about sex education. The percentage of parents were. is 29%, ie 1 in the three parents think they can talk to their

children about sex education

Table 5: the difficulty of discussion

	l ab- solutely disagree	r ather disagree	do not a g r e e or not agree	r ather agee	strong- ly agree
	N	N	N	N	N
P a r - ents of children with I.D.	22	157	52	51	24
Parents of typical children	41	130	61	48	28
Total	63	287	113	99	52

Parents of non-disabled children, at a rate of 42.2%, feel they have no difficulty in discussing with their children about sex education. At a rate of 51.3%, the parents of children with intellectual disabilities consider that they will have difficulty in making such conversations with their children.

Table 6: Liability of the discussion

	l ab- solutely disagree	r ather disagree	do not a g r e e or not agree	r ather agee	strong- ly agree
	N	N	N	N	N
P a r - ents of children with I.D.	31	155	43	50	27
Parents of typical children	42	133	47	56	30
Total	73	288	90	106	57

Nearly half of parents (50%) with children with intellectual disabilities completely disagree that it is the responsibility of others to talk about sex education to their children because they would obviously want to be the ones responsible for the sexual education of their children. A similar and a slightly higher percentage is the percentage of parents with children without disabilities (43%) who feel that others have to deal with the sexual education of their children.

## Discussion

Investigators refer to a lack of discussion about sex education and disability and argue that the social relations between people with and without intellectual disabilities, the symbolic notion of disability, and the psychological impact of experiencing multiple barriers to sexual expression and the development of sexual relations among people with intellectual disabilities [10, 13, 14].

According to the findings of our research, both parent groups, for example, and so on to a very large extent, consider that the sexual education of all young people with and without intellectual disabilities will have positive effects on the quality of their family life. From the data we have, we find that in 1988 the percentage of adolescents who were pregnant in Greece was about 10.3% in all pregnancies, the annual number of abortions exceeds the medical organizations of Northern Greece (AUTH, 2002), and there was an announcement that spoke about 40,000 abortions per year in young people aged up to 16 years. The above elements, therefore, support the need for parents to consider the sexual education of all young people as very important. After all, many problems that have to do with the sexuality and sexual behavior of young people are the results of parents' ignorance. For example, according to the Hellenic Institute of Sexology (1995), many parents, in order to overcome their fears about the erotic preferences of their sons, force them to have early erotic experiences.

Most of the research on the sexual education of people with intellectual disabilities has been examined only from the medical perspective. [18, 16]. According to this theory, disability is still considered a "defect" and the suppression or questioning of the sexuality of people with intellectual disabilities as an

inevitable part of it. The sexuality of people with intellectual disabilities is considered as something abusive, and should be treated, treated and controlled [23, 24, 27] argues that medical science-based "research" examines sexual education issues by focusing on the difficulties only created by disability, and considers emotional and romantic relationships among young people with intellectual disabilities to be impossible and undesirable.

The results of the study [13, 14] show a more modern concept of sexual education since the parents who participated in their research seemed to believe how young people with intellectual disabilities need sexual education as well as young people without intellectual disabilities. However, there will always be parents who will not encourage the provision of sexual education to their children with intellectual disabilities, fear of possible negative effects on their lives [28]. From the fact that there are no differences in the views of the two parent groups in our research, it is concluded that the sexuality of young people with intellectual disabilities is recognized and this can be seen as an indication that the interviewed parents are willing to work to eliminate various negative stereotypes developed in the past for sex education [16, 18, 21].

In our survey, parents showed a desire to be these original sexuality instructors for their children. So almost half from both teams disagree with the prospect to take other sexual education of their children, apparently because they want to raise their children according to their own family and moral values. Investigators also stated that parents are the best sexual instructors for all young people [9, 13]. So, in our research, we see this fact confirmed, that is, families want to play a very important role in the early sexual education of their children. Also has been shown that in the Netherlands, where many families consider it as an important responsibility to talk openly with their children about sex and sexuality, this fact contributes to greater cultural honesty about sex and sexuality and improved sexual health among all young people [13, 14]. The responses of both parent groups and confirm similar results from other studies, according to which, the parents want to be the first ones who have the responsibility to talk to their children about

sex education [37].

Furthermore, in our research, one-third of the parents and the two groups do not find it easy to talk about sex education to their children. These low rates are in agreement with a previous study by [33], where they reported that parents of autistic children might not feel comfortable discussing sexuality with their children because they think they could give their child the wrong impression they are promoting sexual activity. Sex education issues are usually hard for some parents, and some even find it particularly difficult to talk about the sexual needs of their child [23, 24]. Investigators report in their research that parents of children with intellectual disabilities do not recognize or consider their children's need for sexual education and often keep the contact of young men and women with intellectual disabilities limited from the fear of sexual abuse and unwanted pregnancy [17, 18]

In contrast, another survey, which looked at the level of comfort of parents to speak to their children about sexuality, reported that 83% of parents with children with and without disabilities felt comfortable in discussing these issues [30, 31]. However, in the same study, 48% of autistic young people who were also included in the survey reported that their parents had a little talk about sexual assault [31]. However urges all parents to learn and teach their children about sex education from an early age [32]. Parents, of course, often find themselves comfortable talking and giving information, but they do not do it, probably or because they do not know how or because they tend to see their child as an eternal child. In particular, this is the case with the parents of children with intellectual disabilities. Another reason may be their uncertainty as to time, place and way of presenting their children with the information they want [29].

## Conclusion

In conclusion, the parents of both groups express very clearly their positive view of the need for sexual education of all young people with and without intellectual disabilities, but only one in three of both groups felt it easy to teach sexual education to their children. The family should fulfill this role, regardless of

any physical or intellectual disabilities of her child. Research into these problems, which begins with this study, will help to initiate discussion and scientifically explore the issues of sexual education of young people with intellectual disabilities. Nevertheless, more studies and surveys are needed to target social and cultural circumstances in our country so that any sex education programs can meet the needs of our social and cultural reality.

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