

# Sex education of adolescents with autism spectrum disorders in Poland

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The aim of this article is to present the results of research into how mothers of individuals with ASD perceive school sex education. The article aims to contribute to the discussion on the need to introduce changes in the Polish education system as far as the area of sexuality is concerned. The study was carried out in two parts, at time intervals. The results were obtained only from mothers, which corresponds with the conclusion that mothers talk about matters of sexuality more often than fathers do and with daughters rather than with sons. The results indicate that mothers want to influence the sex education of their children, at the same time having no knowledge of what topics they are pursuing or can pursue with their child during formal sex education at school (education for living in a family).

KEY WORDS: autism spectrum disorders, adolescents, sex education

#### 1. Introduction

Topics related to sexuality are – almost always – demanding and sensitive ones. They seem to be particularly significant in terms of persons with autism spectrum disorders who have difficulty making interpersonal relations, understanding the social world, reading and

reflecting on the emotions of others, related directly to disturbances in the theory of mind.

Analysing the diagnostic criteria (see ICD-10, DSM-5)<sup>1</sup> and subject literature<sup>2</sup>, one can notice that the greatest difficulty during the school education period of adolescents with autism spectrum disorders is making and maintaining contact with another as well as establishing relations based on mutual advantages and social exchange<sup>3</sup>.

This originates from disturbances in the theory of mind and the failure to understand that feelings, thoughts and convictions are not the precise and real reflection of reality. These shortcomings in terms of "reading the mind" gain particularly significant momentum in the context of making and maintaining relations that are romantic, preintimate and intimate in character<sup>4</sup>.

<sup>&</sup>lt;sup>1</sup> Diagnostic and statistical manual of mental disorders. Fifth edition. DSM-5. American Psychiatric Association 2013.

<sup>&</sup>lt;sup>2</sup> E. Fein, Making Meaningful Worlds: Role-Playing Subcultures and the Autism Spectrum "Culture, medicine and psychiatry" 2015, no. 39, pp. 299-321; V. Bitsika, Ch.F. Sharpley, The Association Between Social Responsivity and Depression in High-Functioning Boys with an Autism Spectrum Disorder, "Journal of Autism and Developmental Disorders" 2016, no. 28, pp. 317-331; N.L. Matthews, Ch.J. Smith, E. Pollard, S. Ober-Reynolds, J. Kirwan, A. Malligo, Adaptive Functioning in Autism Spectrum Disorder During the Transition to Adulthood, "Journal of Autism and Developmental Disorders" 2015, no. 45, pp. 2349-2360.

<sup>&</sup>lt;sup>3</sup> N. Bauminger, M. Solomon, S.J. Rogers, *Predicting Friendship Quality in Autism Spectrum Disorders and Typical Development,* "Journal of Autism and Developmental Disorders" 2010, no. 40(6), pp. 751-761; C.C. Peterson, M. Garnett, A. Kelly, T. Attwood, *Everyday social and conversation applications of theory-of-mind understanding by children with autism-spectrum disorders or typical development,* "European Child & Adolescent Psychiatry", 2009, no. 18(2), pp. 105-115; O. Curry, M.J. Chesters, *Putting Ourselves in the Other Fellow's Shoes': The Role of 'Theory of Mind' in Solving Coordination Problems.* "Journal of Cognition & Culture" 2012, no. 12(1/2), pp. 147-159; K. Akagi, *The Meaning of a Developmental Stage Theory in Studies of Developmental Disorder*, "Japanese Journal of Developmental Psychology" 2011, no. 22(4), pp. 381-390.

<sup>&</sup>lt;sup>4</sup> M. Aston, Maxine. Asperger syndrome in the bedroom. "Sexual & Relationship Therapy", 2012, no. 27(1), pp. 73-79; S. Strunz, C. Schermuck, S. Ballerstein, Ch. J. Ahlers, I. Dziobek, S. Roepke, Romantic Relationships and Relationship Satisfaction Among Adults With Asperger Syndrome and High-Functioning Autism, "Journal of Clinical

It is thus so important for adolescents with autism spectrum disorders to participate in classes related to sexuality, because it is very difficult to gain these abilities during involuntary sexualisation in case of these types of disorders.

Despite the fact that sexuality is an innate attribute of man, and sexual needs one of the fundamental ones, this sphere still seems to be a difficult topic. To a certain extent, this stems from the fact that everyone has their own experiences in terms of sexuality – collected since childhood, verified or becoming fixed patterns, however, present and frequently disclosed. It thus becomes the greater a challenge to speak about sexuality neutrally, without any own biased perspective, restrictive ethical assessments or moral judgements pretending to be objective voices on a particular matter – voiced on the basis of the lack of knowledge.

Sexuality is also a challenge in a world full of changes, liquid meanings and transforming standards. The internet has changed sexuality in all its dimensions – with respect to its education, sexual health, pathology, behaviour spectrum. Slipping out of control and being available for anyone at any time, usually depending on the users – it is a source of information, entertainment – but also crime, abuse and human suffering. This is the reason for the enormous significance of sexual education. In the year 2018, the World Health Organisation has released the *International technical guidance on sexuality education*. An evidence-informed approach).

It stresses the fact that:

Comprehensive sexuality education (CSE) is a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. It aims to equip children and young people with knowledge, skills, attitudes and values that will empower them to: realize their health, well-being and dignity; develop respectful

Psychology" 2017, no. 73(1), pp. 113-125; E.K. Cridland, S.C. Jones, P. Caputi, *Being a Girl in a Boys' World: Investigating the Experiences of Girls with Autism Spectrum Disorders during Adolescence*, "Journal of Autism and Developmental Disorders" 2014, 44(6), pp. 1261-1274.

social and sexual relationships; consider how their choices affect their own well-being and that of others; and, understand and ensure the protection of their rights throughout their lives<sup>5</sup>.

Throughout the entire document totalling 185 pages, the world *disability* is found only 18 times. Certain summaries seem stunning, and the use of this word may be misleading:

- Other examples include: sexual intercourse; scientific information about prevention of pregnancy; the SRH needs of young people living with disabilities or HIV; unsafe abortion and harmful practices such as CEFM and FGM/C; or discrimination based on sexual orientation or gender identity<sup>6</sup>;
- Adolescent girls suffer a significant and disproportionate share of deaths and disability from unsafe abortion practices compared to women over 20 years of age<sup>7</sup>.

Elsewhere in the document it is stated that:

- historically, people with disabilities have often been perceived as either asexual or sexually uninhibited, and sex education has generally been considered unnecessary or even harmful;
- Existing education for young people with disabilities often depicts sex as dangerous, echoing past constructions of disabled people's sexuality as problematic (Rohleder and Swartz 2012);
- disabled people are statistically more frequently at risk of sexual violence and HIV infection<sup>8</sup>.

Polish-language subject literature includes papers by only a few authors who handle issues of sexual activity of the disabled, which

<sup>&</sup>lt;sup>5</sup> UNESCO, http://www.who.int/reproductivehealth/publications/technical-guidance-sexuality-education/en/, s. 16.

<sup>&</sup>lt;sup>6</sup> Ibidem, s. 18.

<sup>&</sup>lt;sup>7</sup> Ibidem, s. 23.

<sup>&</sup>lt;sup>8</sup> K. Hughes, M. Bellis, L. Jones, S. Wood, G. Bates, L. Eckley, E. McCoy, C. Mikton, T. Shakespeare, A. Officer, *Prevalence and risk of violence against adults with disabilities:* A systematic review and meta-analysis of observational studies, "The Lancet" 2012, no 379(9826), pp. 1621-1629.

means that this topic is not explored broadly9. Publications are also lacking by Polish authors that are devoted to sex education of persons with autism spectrum disorders in the changing socio-political reality of our country. In Poland sexuality is still related to intimate interaction in the realm of a formal relationship between a man and a woman. Such vision of sexuality, promoted in the regulations of the Polish minister responsible for education, and then in school curricula and in textbooks, is frequently completely useless for many youths - not only those with disabilities or autism spectrum disorders. Parents burdened by the dilemma of sexuality of their disabled children are left alone, mothers in particular. The majority of them declares that they are aware of the fact that their children will probably not marry, start families or that it will not be normative. Perhaps this is one of the reasons, why school sex education in Poland, described as 'Education for living in a family' is so strongly reduced in scope for people with disabilities and disorders.

The issues of people with autism spectrum disorders are decidedly broader than those discussed in the context of the disabled. This group includes people who on the one hand function with different levels of mental disorders and on different levels of speech disorders, yet on the other hand it includes people within the intellectual norm and with correct speech development (DSM-5). Due to such diversity of functioning of persons with ASD it seems necessary to adapt the knowledge to the capacities of the individual. Inasmuch as literature focusing on sexuality of mentally disabled persons shall also be applicable to persons with ASD coupled with mental disabilities, this material will not apply to high-functioning persons with autism. Subject literature contains materials concerning efficient education of ASD students<sup>10</sup>. Such material is also available

<sup>&</sup>lt;sup>9</sup> R. Kijak, Seksualność człowieka z niepełnosprawnością intelektualną a rodzina, PZWL, Warszawa 2014; M. Kościelska, Niechciana seksualność, Czarna Owca, Warszawa 2004; I. Fornalik, Mam autyzm. Mam seksualność. I co dalej?, Fundacja JIM, Łódź 2017.

<sup>&</sup>lt;sup>10</sup> J.K. Harrower, L.G. Denti, M. Weber-Olsen, *Educating Students With Autism Spectrum Disorder*. A Model for High-Quality Coaching, Plural Publishing, United States 2016.

at Polish higher education facilities in the form of brochures for academic teachers. Due to all of this, society has the feeling that such people only require limited support in learning, however, if early interpersonal training, social development support and support in terms of their own sexuality is lacking, a student making it to a higher education facility will neither be ready to play the role of a student nor a colleague from the same group.

Such training, particularly for persons with ASD in the intellectual norm and with correct speech development, should apply to training with respect to the theory of mind. As numerous studies show, children, youths and adults with ASD have it difficult to evaluate the behaviour of others in terms of body language, body posture, intonation and voice modulations, the gestures aimed at them, facial expression (including the eye expression in the "Eye test"), ambiguous messages due to irony, sarcasm or metaphor or vernacular. All these difficulties prevent a person with this level of disability from entering correct interpersonal relations<sup>11</sup>.

Sexual education in Poland is conducted since the 1990s under the name of 'Education for living in a family' The curriculum foresees for each school year for pupils in the 4th-6th form of primary school (2nd stage of education) 14 hours, including five hours for separate group of girls and boys. The parent, in line with the assumptions of the legislator, should be informed about the topics in the course during the first parent-teacher conference, and should they not consent to their child participating in the class – they should express this via a written declaration.

In the latest regulation of the Polish Minister of National Education of June 2nd, 2017<sup>12</sup>, p. 1. subitem b, we read: "Pupils with mod-

<sup>&</sup>lt;sup>11</sup> M.C. Pino, M. Mazza, M. Mariano, S. Perreti, D. Dimitriou, F. Masedu, M. Valent, F. Franco, *Simple Mindreading Abilities Predict Complex Theory of Mind: Developmental Delay in Autism Spectrum Disorders*, "Journal of Autism and Developmental Disorders" 2017, no. 47(9), pp. 2743-2756.

<sup>&</sup>lt;sup>12</sup> Regulation of the Polish Minister of National Education of June 2nd, 2017, amending the regulation on the mode of school education and the scope of topics concerning human sexual life, the rules of conscious and responsible parenting, the

erate or significant mental disability, including pupils with compound disabilities of which one would be moderate or significant mental disability follow the curriculum as described in section 1 within the scope of compulsory classes set out in the curriculum of general education for pupils with moderate or significant mental disability. These pupils do not take classes described in section 1". This means that persons with autism spectrum disorders attending other schools than general ones shall not participate in classes most related to sex education – from the school class timetable.

Abandoned without help are also parents who do not have Polish-language materials to conduct home sex education for their children.

Hence, the sphere of sexuality becomes filled with trouble and uncertainty for parents and youths with autism spectrum disorders. Sexuality is not just about the mechanics and dynamics of the sexual act, it is not just biology and physiology, it is an entire range of interpersonal behaviour – suggesting a meeting, continuing or ending it. Sex education is there to serve sexual health, which – in line with the working definition of the WHO – is there to contribute to more comprehensive development of man.

These classes seem particularly significant for persons with autism spectrum disorders for whom it is difficult to establish interpersonal relations, understand the social world, read and reflect the emotions of others – a fact directly related to disorders of the theory of mind.

Analysing the diagnostic criteria (ICD-10, DSM-5) and subject literature, one may notice that during the school period, teenagers with autism spectrum disorders find themselves in the most difficult period to make and maintain contact with others as well as to establish relations based on mutual advantages and social exchange. This results from disorders to the theory of mind and the lack of

value of the family, life in the pre-natal stage as well as the methods and resources of conscious procreation, included in the general education curriculum, Polish Journal of Laws of 2017, item no. 1117.

understanding that feelings, thoughts and convictions are no precise and real reflection of reality. The inability to "read one's mind" is particularly important in the context of shaping and maintaining romantic and intimate relations. It is thus important for teenagers with autism spectrum disorders to participate in classes dealing with sexuality, as persons with this disorder have a very difficult time acquiring these abilities in the scope of compulsory socialisation.

Sex education is hence a significant topic, and this is indicated by the following data:

- 1. A meta-analysis of 66 comprehensive sex education programmes for youths irrespective of their ASD diagnosis, conducted in the year 2012, had shown that the curricula reduce the frequency of unprotected sexual activity, improve protection (condoms and/ or hormonal contraception), reduce the risk of pregnancy and reduce the risk of transfer of sexually-transmitted diseases<sup>13</sup>.
- 2. Advantages of sex education include self-development, better self-esteem and provide a range of other positive aspects, which is particularly significant during emotional development in adolescence, when sexual identity and many values are at a significant point of development and subsequently continuation. Issues related to sexuality are difficult to explain to fully able people. The more so, persons suffering from ASD require more comprehensive education that is clear and specific. In line with the assumptions of the "theory of mind", the majority of people with ASD will not be able to intuitively understand the internal states of their partners, and they will

<sup>&</sup>lt;sup>13</sup> H.B. Chin, T.A. Sipe, R. Elder, S.L. Mercer, S.K. Chattopadhyay, V. Jacob, H.R. Wethington, D. Kirby, D.B. Elliston, M. Griffith, S.O. Chuke, S.C. Briss, I. Ericksen, J.S. Galbraith, J.H. Herbst, R.L. Johnson, J.M. Kraft, S.M. Noar, L.M. Romero, J. Santelli, The effectiveness of group-based comprehensive risk-reduction and abstinence education interventions to prevent or reduce the risk of adolescent pregnancy, human immunodeficiency virus, and sexually transmitted infections: Two systematic reviews for the guide to community preventive services, "American Journal of Preventive Medicine" 2012, no. 42, pp. 272-294.

- need to be told, how others will perceive their own actions and words, and they shall also need to be provided with clear indications to evaluate how their partner is feeling<sup>14</sup>.
- 3. Countering the problem of sexual abuse by other persons with mental disabilities. It is a fact that these people are both perpetrators as well as victims of sexual abuse. It is less likely, in turn, that they had received proper sex education that could be gained formally in class or informally by participation in social events. In addition, young people, children and youths are usually identified with the objective group of persons potentially at risk of emergence of risky behaviour, with one type of these being risky sexual behaviour<sup>15</sup>.
- 4. Other data applies to abuse and neglect. They indicate that the disabled are frequently at risk of sexual abuse at locations that are supposed to provide them with help<sup>16</sup>.
- 5. A study covering a group of mothers of children with Asperger syndrome and disabilities in learning social behaviour (n = 411) found that 94% of these caretakers voiced that their child was the victim of abuse by their siblings and peers. Children from this sample were described as "perfect victims" due to their deep insufficiency of social skills<sup>17</sup>.

<sup>&</sup>lt;sup>14</sup> J.D. Goldman, An exploration in health education of an integrated theoretical basis for sexuality education pedagogies for young people, "Health Education Research" 2011, no. 26, pp. 526-541.

<sup>&</sup>lt;sup>15</sup> I. Chrzanowska, Zagrożenie nowymi formami zachowań ryzykownych wśród dzieci i młodziej z niepełnosprawnością – uzasadnienia dla zainteresowania problematyką, "Studia Edukacyjne" 2014, no. 33, pp. 36.

<sup>&</sup>lt;sup>16</sup> C. White, E. Holland, D. Marsland, P. Oakes, P., *The identification of environments and cultures that promote the abuse of people with intellectual disabilities: A review of the literature*, "Journal of Applied Research in Intellectual Disabilities" 2003, no. 16, pp. 1-9.

<sup>&</sup>lt;sup>17</sup> R.B. Pfeffer, Autistic and at-risk: the public and personal safety of children with autism spectrum disorders. Abstract of dissertation Submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Criminology and Justice Policy in the Graduate School of Social Sciences and Humanities of Northeastern University, November 2012, https://repository.library.northeastern.edu/files/neu:1024/fulltext.pdf [access: 07.01.2019].

- 6. Teenagers with ASD exhibit atypical interpersonal behaviour that are not understood by the social environment, and persons with ASD themselves do not have at their disposal a different range of behaviour that would make it easier for them to commence interaction, all of which can lead to rejection, painful emotions or even mental illnesses<sup>18</sup>.
- 7. Sex education of persons with ASD can reduce the risk of improper behaviour through explanation of social norms in a manner that is clear and understandable for persons with ASD. It seems that education is required both for the general society as well as persons with ASD. It would be particularly useful to provide members of the community wo might come across persons with ASD (e.g. law enforcement, teachers) with precise information on the sexual vulnerabilities and threats that this population might cause. The needs in terms of sex education of patients with autism spectrum disorders (ASD) are unique and rarely properly included in existing curricula. There exists a limited volume of data concerning sex education, sexual health and persons with ASD. Many of them have not received suitable education and treatment that is necessary to fulfil the basic WHO guidelines on sexual health. The great chasm is that there are no results of studies concerning the influence of sex education on the sexual health of teenagers and adults with autism. Some available data suggests that sex education for persons with ASD is both advantageous as well as needed19.
- 8. L.G. Holmes and M.B. Himle have concluded that only 10% of the studied persons with ASD established partner relations

<sup>&</sup>lt;sup>18</sup> M. Lasgaard, A. Nielsen, M.E. Eriksen, L. Goossens, Loneliness and social support in adolescent boys with autism spectrum disorders, "Journal of Autism and Developmental Disorders" 2010, nr 40, s. 218-226; L.A. Livingston, E. Colvert, P. Bolton, F. Happe, Good social skills despite poor theory of mind: Exploring compensation in autism spectrum disorder, "Journal of Child Psychology and Psychiatry" 2018, no. 60(1), pp. 102-110.

<sup>&</sup>lt;sup>19</sup> R.L. Loftin, S.A. Hartlage, *Sex Education, Sexual Health, and Autism Spectrum Disorder.* "Pediatrics and Therapeutics" 2015, no. 5(1).

- that also included sexual contacts with their partner. The significance of sex education that would include teaching social skills that are so important for the development of healthy relations must thus be stressed even more strongly<sup>20</sup>.
- 9. States that cover groups of teens with comprehensive sex education (and not just education on abstinence) have the lowest mean indicator of intimate infections among the entire population and among teenagers<sup>21</sup>.

# **3.** The research method and the characteristics of the research sample

The presented research was conducted in two parts. During the first part analysed was sexual behaviour of persons with ASD in the opinion of mothers<sup>22</sup>, in the second part – the needs in terms of sexual education of persons within the autism spectrum in the opinion of mothers. Three questions were common for the first and second parts.

The survey questionnaire was constructed based on a suggested list of topics found in the scope of the curriculum for education for living in a family currently in force at Polish schools. An important source were also discussions with mothers of youths with diagnoses of disorders within the autism spectrum conducted at diagnostic and help facilities and at schools, who see numerous shortcomings both in terms of formal as well as informal sex education aimed at youths with this disorder.

<sup>&</sup>lt;sup>20</sup> L.G. Holmes, M.B. Himle, *Brief Report: Parent–Child Sexuality Communication and Autism Spectrum Disorders*, "Journal of Autism and Developmental Disorders" 2014, no. 44, pp. 2964-2970.

<sup>&</sup>lt;sup>21</sup> M. Hogben. H. Chesson, S.O. Aral, Sexuality education policies and sexually transmitted disease rates in the United States of America, "International Journal of STD&AIDS" 2010, no. 21, pp. 293-297.

<sup>&</sup>lt;sup>22</sup> A. Wojciechowska, A. Gulczyńska, *Sexual behaviuour of children and teenagers with autism spectrum disorder. Pilot study results,* "Interdisciplinary Contexts of Special Pedagogy" 2017, no. 19, pp. 91-108.

#### 3.1. Research group

100 parents were asked to complete the on-line questionnaire; they were informed about the topics of the survey and the mode of filling it out by therapists, speech therapists or teachers of children in course of individual discussions. As a result, the anonymous survey was filled in by 32 mothers, some of the other people declared discomfort related to a study on sexual topics (which was repeated in the first part of the study).

The children of the studied mothers are youths aged 11-14 (30 boys, two girls), in their second stage of education (4th-6th form). 12 people attended general schools, integration schools/ classes were attended by ten pupils and special schools by eight. Two pupils attended individual education at the school premises.

#### 3.2. Research problems

The objective of the presented study results is the presentation of the opinion of mothers on the topic of sex education aimed under school conditions for adolescents with autism spectrum disorders and of their expectations as to the topics covered during the classes.

The following research problems were posed:

- 1. How are the classes for education for living in a family organised at their children's school?
- 2. In the opinion of the mothers, what topics are covered during classes for education for living in a family?
- 3. What are the sources of knowledge about their own sexual development for children and adolescents with autism spectrum disorders?
- 4. What are the topics that the mothers would suggest if they could influence the topics covered in course of education for living in a family?

## 4. Study results

The described youths learn at primary schools: special schools, general schools or in integration classes. Sex education classes are conducted for 31.25% (10 pupils), not provided for 50% (16 pupils), and over 18% of those responding (six mothers) have no knowledge on this topic. At the same time 30 women stated that it is important for topics related to sexuality, in particular with respect to puberty, to be covered both in course of education pr therapy as well as rehabilitation. 22 mothers stated that their child does not participate in such classes, and almost 70% (23 persons) indicated that nobody asked for their consent for the participation of their child in classes on education for living in a family (sex education). None of the mothers knew even one of the topics that could be covered as part of education for living in a family.

The question on where their children get knowledge on sexual development allowed mothers to provide more than one option.

The most common response was the Internet (22 answers), then television (18 answers), literature (10), then: therapists and teachers (six) and other children (two answers).

Table 1. Sources used by children to obtain knowledge on their sexual development

Category	Number of people
Internet	22
Television	18
Literature	10
Therapists, teachers	6
Other children	2

Source: own work

The next question that was posed was how do you as a parent (caretaker) provide knowledge on sexuality. This question also allowed parents to provide more than one response.

The results were as follows: 28 responses – the parent discusses sexual development, eight – indicates literature, four – asks therapists or teachers to conduct a discussion on sexuality, and four mothers declared that they do not provide children with this information (no reason given).

No mother uses materials concerning sex education, utilising information found on websites.

Category Number of people

Discussion 28

Selection of literature 8

Asking therapists and teachers 4

No information provided 4

Table 2. More of transfer of information about sexuality

Source: own work

The issues covered most frequently in discussions with children and related to sexuality, are: loudly stating content that is sexual in character and public undressing – ten answers each; then: looking for pornographic content on the Internet – eight responses; hugging and kissing others as well as masturbation received six responses each.

The subsequent question was as follows: If you could decide on the topics of sex education in primary school, which topics would you chose to be covered as part of the class "education for living in the family" that would be significant for your child (you can choose more than one option)? Please add your own suggestions of topics that were not covered in the list, and then evaluate using the following scale: 1 – decidedly not, 2 – rather not, 3 – rather yes, 4 – decidedly yes.

The mothers indicated the following topics:

**Table 3.** Topics in sex education

Category	Number of people
The right of a person to intimacy and protecting this right;	
assertive attitudes	32
Physical and mental changes during puberty; varied, indi-	
vidual development tempo	32
Puberty hygiene	28
The significance of friendship, mutual respect, providing	
help, cooperation, empathy	28
Fundamental knowledge on the structure and functioning of	
the human reproductive system	28
Pregnancy, development of the foetus, accepting the child as	
a new family member	24
Family ties, emotional bonds and other family relations;	
conflicts and solving them	24
Differences and similarities between boys and girls; identify-	
ing with the own gender; acceptance and respect for the body	24
Motherhood and fatherhood	22
Basic functions of the family, stressing the place of the child	
in the family	20
Conveying values and traditions in the family, spending	
holidays together, spending free time	20
Insitutions working for the child and the family	14
Responsibility for the own development; self-upbringing	14
Mass media - rules and criteria of choice of newspapers,	
films and television shows	14

Source: own work

Additional topics that were mentioned as an amendment: teaching how to set and adhere to boundaries, teaching to recognise the intentions of others in the sexual sphere (one person); boundaries: what is acceptable where and when, and what isn't (one person); understanding your body and the ability to control one's needs (one person), anatomy (one person), individual adaptation of topics to the level of disability of the child (their capacity to comprehend the topic) (one person).

#### 4. Discussion

The name of the topic itself – "Education for living in a family" – describes the general structure of the class and the direction of the content on the value of sexuality in the context of the family being created, understood in Poland as a pair of a woman and man living in a formal, matrimonial relationship, having a child or more children. An analysis of textbooks concerning education for living in a family<sup>23</sup> conducted as part of a general Polish analysis of textbooks in terms of their sensitivity to gender issues had shown that

textbooks describe relationships between white, healthy, heterosexual persons of medium socio-economic status that are catholic and hold conservative views. Young, disabled people, those from incomplete families or missing a parent, who are not heterosexual, after sexual initiation, actual or declared atheists, from other backgrounds or having a different skin colour will not find themselves here<sup>24</sup>.

The reality described in the books is not an experience that can be useful for persons with autism spectrum disorders. It seems as though it is also material that is useless for teachers or parents of persons with this disorder. This is because they are not able to obviously and clearly adapt the content of books to the needs, reqire-

<sup>&</sup>lt;sup>23</sup> The three-volume report, authored by an interdisciplinary scientist team, presents the results of the research project "Gender in Texbooks", which had the purpose of a critical analysis of models and concepts of femininity, masculinity as well as relations between girls/ women and boys/ men as promoted in the Polish curriculum and Polish textbooks approved for school use. The selection of the analysed textbooks represents all school subjects and all levels of education at various types of schools. The Polish research project "GENDER IN TEXTBOOKS" was conducted by the Interdisciplinary Centre for research on the cultural gender and identity of the Adam Mickiewicz University, Poznań, in cooperation with the Feminoteka foundation as part of the project "Women and men, boys and girls".

<sup>&</sup>lt;sup>24</sup> J. Dec-Piertowska, E. Paprzycka E., Wychowanie do życia w rodzinie – raport przedmiotowy, [in:] Gender w podręcznikach, projekt badawczy. Raport, vol. 3, ed. I. Chmura-Rutkowska, M. Drurda, M. Mazurek & A. Sołtysiak-Łuczak, Fundacja Feminoteka, Warszawa 2016, pp. 127-173.

ments or diversities of people found within the autism spectrum diagnosis.

The results were only obtained from mothers, corresponding with the conclusion that topics of sexuality are generally more frequently covered by mothers than by fathers<sup>25</sup>. The results show that mothers want to influence the sex education of their children, however, without the knowledge of that topics does their child covers or can cover in course of formal sex education in school. A certain inconsequence arises, observed in studies from other countries as well<sup>26</sup>, bordering on neglect<sup>27</sup>, as well as the failure to properly assess or just plain ignorance for the scope of sexual experience of adolescent sons<sup>28</sup>.

This may probably stem from the fact that mothers of children with autism spectrum disorders, having much difficulty and limitations that determine their lives, do devote sufficient time to the topic of sex education<sup>29</sup>.

Sex education is (in the common opinion of most adult representatives of Polish society) considered to be learning about the mechanics and dynamics of sexual reactions rather than the interpersonal sphere or sexuality – being an integration of biological, psychological, social or spiritual factors serving full development of one's personality. In any case, in Poland, just like it is reflected in conclusions from studies in other countries, it is insufficient<sup>30</sup>.

<sup>&</sup>lt;sup>25</sup> L.G. Holmes, M.B. Himle, op. cit.

<sup>&</sup>lt;sup>26</sup> Ibdem.

<sup>&</sup>lt;sup>27</sup> N.A. Gougeon, Sexuality and autism: A critical review of selected literature using a social-relational model of disability, "American Journal of Sexuality Education" 2010, no. 5, pp. 328-361.

<sup>&</sup>lt;sup>28</sup> J. Dewinter, R. Vermeiren, I. Vanwesenbeeck, Ch. Van Nieuwenhuizen, *Parental Awareness of Sexual Experience in Adolescent Boys With Autism Spectrum Disorder*, "Journal of Autism and Developmental Disorders" 2016, no. 46, pp. 713-719.

<sup>&</sup>lt;sup>29</sup> M.S. Ballan, *Parental perspectives of communication about sexuality in families of children with autism spectrum disorders*, "Journal of Autism and Developmental Disorders" 2012, no. 42, pp. 676–684.

<sup>&</sup>lt;sup>30</sup> L.A. Hannah, S.D. Stagg, *Experiences of Sex Education and Sexual Awareness in Young Adults with Autism Spectrum Disorder*. "Journal of Autism and Developmental Disorders" 2016, no. 46, pp. 3678-3687.

The studied youths, as indicated by the work of P. Mehzabin and M.A. Stokes<sup>31</sup>, has less access and less advantages from traditionally undertaken sex education – both formal as well as informal.

Perhaps it would be worthwhile to consider a certain transfer of curricula from other countries – as an additional educational offer. The question remains, however – whether it should take place in a formal, school-based education system, or through foundations, associations. The conducted research shows the reasonability of parallel programmes – for parents and children from the autism spectrum, which bring about measurable advantages for every participant group<sup>32</sup>. The authors of the indicated studies conclude that future research should continue to focus on the development and implementation of specialised sex education programmes to promote the positive passage through this development period and stage for teenagers with autism spectrum disorders.

In the described Polish studies, only few mothers were informed about the content of sex education classes, they were also unable to indicate exaplne topics, a fact that could perhaps the insufficient support for parents of children with ASD in terms of education of these as reported in other study results<sup>33</sup>.

The conducted research expands the knowledge on expectations of mothers in terms of school sex education of their children with ASD, yet indicate that mothers would like to influence the selection of topics with particular focus on the human right to intimacy and the safeguarding of this right, on assertive attitudes in the area of sexuality as well as the diversification of the individual tempo of psychological and physical development. The authors are hopeful that this publication becomes the vantage point for the introduction

<sup>&</sup>lt;sup>31</sup> P. Mehzabin, M.A. Stokes, *Self-assessed sexuality in young adults with high-functioning autism,* "Research in Autism Spectrum Disorders" 2011, no. 5(1), pp. 614-621.

<sup>&</sup>lt;sup>32</sup> L.L. Corona, S.A. Fox, K.V. Christodulu, J.A. Worlock, *Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents*, "Sexuality and Disability" 2016, no. 34, pp. 199-214.

<sup>33</sup> M.S. Ballan, op. cit.

of other forms of sex education of youths with ASD even in the extracurricular area.

The conducted research was also very limited. Results were collected only from a group of volunteers, who, encouraged by their children's therapists and teachers - decided to complete the on-line questionnaire. Due to the anonymity of the questionnaire and it being filled under individual conditions, it was assumed that all persons did in fact fill it in voluntarily. The issue of to what extent the personality of the mother (e. g. certain obsessive-compulsive traits) or the level of liking of the therapist/ teacher of the child influenced the actual readiness to fill in the survey questionnaire was neither tested nor controlled. The small research sample results in the fact that correlation between selected variables and sociodemographic variables, which could permit a more comprehensive description of results, was also not checked. Due to the small research sample, the results could in no way generalised to cover the entire population. During a critical autoanalysis of the process of execution of the methodological procedure, certain facts had arisen, e.g. parent remarks concerning the range of questions, that they considered to be insufficient, and the need to allow more space in order for parents to be able to share their emotions and experiences that are important for them in the context of sex education.

To summarise, it is worth noting that the topic of sex education of persons with autism spectrum disorders is one that is insufficiently studied, insufficiently executed as part of "Education for living in a family" at education facilities as well as insufficiently adapted to the needs and capacities of functioning of children and adolescents with ASD. This area requires thus an expansion of studies both among parents as well as teachers and therapists of persons with ASD.

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