Unsuccessful Developmental Experiences of People with ID and ASD as Risk Factors for Disorders in Psychosexual Functioning

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Abstract: The article presents an analysis of the general characteristics of negative psychosocial experiences and their possible impact on the psychosexual sphere of children and adolescents with intellectual disabilities and autism spectrum disorders. Seeking such factors, the focus was on the family environment. Particular attention was paid to parental attitudes towards the child with indicated developmental disabilities and the child's sexuality. The tasks essential for the development of sexuality during childhood and adolescence were described. Possible problems and difficulties that may arise in this sphere in persons with developmental disabilities in the context of negative experiences were analyzed. General guidelines important for supporting parents were outlined, which are important from the perspective of limiting the adverse psychosocial experiences of children.

Keywords: Sexual development, psychosocial experiences, childhood, adolescence, autistic spectrum disorders, intellectual disability.

INTRODUCTION

This review article presents an analysis of unfavorable developmental experiences of people with intellectual disability (ID) and autistic spectrum disorders (ASD) relevant for their psychosexual functioning. The sexuality of persons with ID and ASD is the subject of numerous studies that indicate similarities between its trajectory of development in this group of people and persons without disabilities (neurotypical). They take into account its developmental stages from childhood, adolescence, and maturity to old age and its multidimensional determinants such as biological, psychosocial and normative factors. Numerous studies so far also show that persons in both these groups experience disorders and difficulties in sexual development and functioning, manifested about one's self, to others, and in the socio-legal context. Empirical evidence shows that the risk factors for these disorders and problems are not only the deficits in terms of criteria for defining disability (such as significant limitations in cognitive or adaptive abilities) but also negative attitudes in the living environment related to them. The purpose of the analysis is to characterize ID and ASD focusing on the family environment and to describe their possible consequences in the psychosexual sphere. A detailed investigation was conducted of 1) the trends in parents' attitudes towards the sexuality of children with ID and ASD and their etiological background 2) disorders in psychosexual functioning of persons with ID and ASD as a result of unfavorable developmental experiences. The present paper is a general theoretical overview of research in the field and not a systematic review. In general, the study organizes issues related to the topic and signals the most important problems suggesting directions for possible solutions.

PARENTS OF CHILDREN WITH ID AND ASD AND THEIR CHILD’S SEXUALITY

During childhood and adolescence parental attitudes and styles of upbringing are of key importance for awakening and developing their child's sexuality and then for its formation in an individually optimal and socially accepted form. They are co-created by mutual relations between spouses, parental competences and parents’ experiences gained from their families of procreation, their attitudes towards themselves, life and other people. Attitudes and styles determine the ability to adequately respond to the child's needs depending on their developmental phase and individual capabilities. They are crucial to building family ties, shaping a positive emotional-affective atmosphere, family socialization while maintaining the individual autonomy of family members.

Being a parent of a child with a disability is a source of requirements and stressors, often exceeding mothers' and fathers' resources, leading to disturbances in psychosocial and physical functioning [1-3]. Requirements and stressors are related to the child’s special needs, the specificity of their development and functioning, and also to social expectations. Parents of children with developmental
disabilities, compared to mothers and fathers raising non-disabled children, reveal less favorable results of stress intensity and its negative consequences in the sphere of psychosocial and physical well-being [4-7]. The specificity of parents’ functioning is described as a kind of paradox characterized by maintaining conflicting judgments about the child: loving it and at the same time wanting to erase the child’s disability, still hoping against other people's negative opinions. It is made up of contradictory experiences: pain, despair, suffering, sadness and hope, joy, happiness, and optimism [8] but also ambiguous information, advice and predictions that conflict with the parents' own observations. In the context of this complex and difficult situation, certain parental behaviours and reactions which determine the specificity of the psychosocial experiences of their child with disabilities relevant to this child’s entire development become more pronounced.

Manifestations of the parental difficulty in adaptation include: an emotional rejection of the child, perceiving the child through their disability, neglecting activities optimizing the child's development, attempts to over-compensate for the child's disability, overprotection, and social isolation. A child with a developmental disability may not experience body affirmation, closeness and love (especially physical) in the early stages of life, which creates an unfavorable atmosphere for their basic emotional competence, including their style of attachment. Generalizing the results of available, relatively numerous studies [c.f. 9-14] certain general trends in parental attitudes towards the sexuality of a child with a disability can be observed. The indicated categorization of attitudes refers to the concept created by Kościelska [11].

Desexualization (Ignoring Sexuality)

Its basic component is the stereotypical belief in the asexuality of a child with a disability, often accompanied by a lack of recognition of their growing up (remaining an eternal child). Nurturing such beliefs allows parents to avoid confrontation with the difficult reality. Children growing up and puberty which is manifested in the child's sexual behavior, changes in their psychique and physiological phenomena, can violate the "relative balance" that the family has developed. The child's cognitive and physical limitations hinder the natural process of socializing their sexuality, consequently, they require more effort on the part of caregivers, taking measures to compensate for the limitation of the child's own activity (e.g. directed at gaining information about puberty). The development of the child's sexuality provokes questions about the future, the quality of adulthood, the possibilities and consequences of taking up social roles (such as the role of a partner or a parent), and the parents' responsibility to support their child on the way. Parents do not undertake activities optimizing their child's sexuality, adequately to the child's age and abilities, such as attempts to introduce hygiene training not only to develop the child's independence but also to make them aware of the intimacy of the place and situation. Parents do not know how to use hygienic procedures (washing, changing, changing diapers) or playing with the child as an opportunity to help the child learn about their body, learn to name its parts, and gradually practice protecting their body. Ignoring the child’s sexuality may also mean ignoring the child’s gender, which parents do not see, focusing on the disability itself and its consequences. As a result, they do not emphasize the attributes of the child’s gender through clothing (buying tracksuits because it is more convenient), hairstyle (short hair makes it easier to maintain hygiene). They will also buy their child’s only the toys that can be used for rehabilitation. Children with disabilities are not informed by parents about puberty, sometimes they experience certain changes with anxiety, unconscious of their meaning (throughout their entire life, e.g. menstruation in the case of women). If they exhibit cognitive (asking questions) or instrumental activity (sexual behaviour, such as developmental masturbation), it is met with suppression or it is punished. Interestingly, in the case of children raised in such an attitude their sexual activity is less frequent: it develops less since all manifestations of the child’s autonomy are suppressed. Parents do not undertake sex education fearing they might “awake their child’s dormant sexuality.” It should be noted that this type of parental behaviour, pointing to their anxiety, helplessness and excessive concentration results from their lack of competencies and support from specialists or relatives. Intense concentration on the child is also expressed by the tendency to strongly protect the child from difficult and risky experiences (as they are seen from the parents’ perspective), which leads to limiting the child’s independence and suppressing manifestations of the child’s autonomy or self-activity. As a result, the child has limited possibilities of gaining experience to learn about themselves and the environment. Children with disabilities less often than their non-disabled peers have the opportunity to participate in diverse social groups (including peer groups), to be engaged in household activities, and to perform their age-
appropriate daily duties. A child with developmental disabilities brought up in social isolation has little opportunity to acquire social competences and assimilate models of social roles. Not given the opportunities to participate in various forms of sex-specific activity (accompanying their mother, their father, their siblings), the child cannot imitate them and learn this way.

Suppression

Parental suppression may be directed at various manifestations of their child's sexuality such as pursuing a psychosexual need in a partner relationship (heterosexual or homosexual), procreation, and seeking to formalize a relationship. The way parents deal with the manifestations of their child's sexuality (which they do not accept and do not understand), especially in the period of turbulent changes during puberty, is that they suppress their child's sex drive through pharmacological agents prescribed by physicians. Suppressing sexuality can also be manifested by having the child sterilized, motivated by difficulties in maintaining hygiene during the menstrual period, and in the long term by protection against pregnancy [15, 16]. Parents, as in the case of the previous attitude, react inadequately to the manifestations of their child's sexuality, but the strength of their repressions may be greater due to the potentially greater activity of the child. At the heart of parental practices are their helplessness, anxiety and a strong need to protect their child. It seems, however, that parents striving to suppress their child's sexuality are more aware of their child's needs in this sphere compared to parents who desexualize their child. On the other hand, desexualization does not exclude extensive parental awareness and knowledge and maybe a manifestation of a defense mechanism.

Acceptance

Parents recognize sexuality as a natural attribute of human beings, a positive characteristic, an expression of normality. It is possible, though, that this attitude will be tainted. Parents may have a limited image of their child reduced to perceiving only the child's physicality that is not disturbed (e.g. in ASD), and as such can compensate for deficits in other spheres. Parents' actions can be focused on the child's body and appearance, emphasizing attributes of the child's beauty or overexposing the child's sexuality. Manifestations of the child's sexuality become a "normalizing" element that indicates that the child's development in this sphere does not deviate from the norm. In this context, there is a threat of instrumentalizing the sexual sphere, pursuing the sexual need without its integration with the cognitive, emotional and social spheres. In this parental attitude symptoms of tolerance may occur. Such an attitude may indicate that the child is not accepted as they are, with their limitations.

To summarize, the following categories of negative experiences of children with disability can be indicated: lack of satisfaction of basic psychosocial needs; failure to take actions optimizing manifestations of sexuality, such as hygiene training, preparation for developmental changes, introduction to social roles, sex education; not looking for possible causes of abnormal behaviors (like persistent masturbation); suppressing the child's sexuality verbally and non-verbally and using punishment; taking exaggerated compensatory measures in the sexual sphere perceived as the only sphere unaffected by disability, which can lead to promiscuity and lack of compliance with social norms.

The potential of children and adolescents with developmental disorders (DD) manifested in their own activity, dynamics of development and the ability to fulfill age-appropriate tasks can be significantly reduced.
by cognitive and physical deficits, including those with the organic background. Some persons with DD will not be able to achieve the competencies expected at particular stages of development (e.g. gender awareness, ability to establish deep emotional-affective relationships). However, the child's psychosocial experiences, which are largely provided in the family environment, may either compensate for developmental limitations or deepen their negative effects. Educational activities of parents who have a child with developmental disorders require greater determination and effort, greater optimism and more time - often beyond the period of adolescence. Human sexual development (including persons with disabilities) depends to a large extent on biological factors, which vary in each individual. They, among others, decide about an individual's intensity of sexual needs. In the case of non-disabled children, this biological potential is successfully realized in adulthood, even when the child has not received proper support from the nearest environment when manifestations of their sexuality were punished and suppressed in different ways [17]. In the case of children with ID or ASD, with several cognitive, emotional or physical disorders, such possibilities are rare.

CONSEQUENCES OF NEGATIVE PSYCHOSOCIAL EXPERIENCES

Problems with sexuality can manifest themselves in the interpersonal and intrapersonal aspect and sexual/intimate behaviors at every stage of an individual's life:

a. Gender identity disorders: lack of self-awareness / incomplete awareness; poor knowledge (in the sex and gender dimension); lack of awareness of intimate parts of the body and the need to protect them; lack of self-acceptance (cases of gender-dysphoria) [14, 18-23].

b. Lack of sexual-emotional integration: inability to establish close emotional-erotic contact; seeing oneself as a low-value and unimportant person; emotional-sexual immaturity manifested in childlike behavior in adulthood, such as striving for constant closeness with a significant person (parent, caregiver, therapist), dependence of mood on the significant person's behavior and seeking for their favors, striving for physical contact beyond the age and moral norms, no sense of natural shame (public exposure, public masturbation) and normative awareness in this respect, immaturity of emotions and behaviors in the form of, for example, childish coquetry or preferring treatments related to the body [14, 24, 25].

c. Lack of sexual competencies: lack of sexual knowledge or selective, false, and unordered knowledge; negative emotions associated with manifestations of sexuality (feelings of shame, guilt, fear, and humiliation); negative evaluation of sexual activity as harmful and immoral [14, 23, 26-31].

d. Difficulties in taking and fulfilling social roles related to sexuality: difficulties in establishing successful partner relationships including friendly and intimate ones; problems in relationships; problems in fulfilling parental responsibilities; limited competencies in regulating one's fertility [14, 32-39].

e. Negative attitude towards one's own sexuality which is an element of an unfavorable self-image: unawareness of one's own sexuality; anxiety associated with puberty, lack of acceptance of manifestations of biological changes in the body (first menstruation, nocturnal emissions); low self-esteem; problems with shaping one's own personal and social identity [2, 29, 40, 41].

f. Improper fulfillment of sexual needs; difficult behavior of a sexual nature: sexual need expressed in the form of difficult behaviors, socially unacceptable, having a negative impact on the individual (self-harm, exposure to sexual exploitation and legal consequences); masturbation that meets the criteria of compulsive behavior, masturbation in public places; paraphilic behaviors; multi-conditioned offensive behavior of a sexual nature [42-48].

Low competences in the form of selective and disordered knowledge about one's own sexuality and human sexuality as such, difficulties in understanding manifestations of one's own sexuality and their control and subordination to social norms, limited opportunities for establishing intimate social relationships (sexual and non-sexual) to realize psychosexual needs which may result in the individual resorting to difficult behaviors that bring about negative personal and socio-legal consequences. "Challenging behaviour is culturally abnormal behaviour(s) of such intensity,
frequency and duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of or result in the person being denied access to ordinary community” [49, p. 108]. In the population of people with ID at different ages, especially with more severe degrees of ID (although the severity of ID itself is not a determining factor here), masturbation occurs, which, due to its etiology, manifestations and consequences, is categorized as a difficult behavior [50]. Masturbation can be a manifestation of the experienced disturbances caused by unfavorable external psychosocial factors such as, negligence, deprivation, restrictions, and violence, which generally involve not meeting psychosocial needs, and in turn, lead to frustration and stress. Negative emotions are discharged in the most accessible way - through masturbation, which leads to its consolidation and dependence on masturbation as an effective mechanism. If masturbation results from experienced conflicts (e.g. caused by feelings of guilt), intrusive and obsessive thoughts or even psychosomatic symptoms, becomes a compulsion in the face of a limited repertoire of other measures to reduce emotional tension, and becomes one of the individual's main activities, it can be treated as a compulsive behaviour [51]. Among the multiple causes of masturbation in people with ID Kościelska [11] lists: neurotic masturbation, performed to cope with anxiety; masturbation used to reduce muscle tension resulting both from the sense of neurotic anxiety and the inability to express emotions in a publicly acceptable way; masturbation as a form of auto stimulation in situations of cognitive deprivation; masturbation leading to withdrawal, is a form of defense against the outside world. Public masturbation can become a tool for achieving the desired attention of a significant person, a way to provoke interest, even if this interest is related to a negative reaction [11]. Masturbatory behaviors of people with ID may lead to self-injury [52]. The circumstances of masturbation, especially its public manifestation, lead to repressive behavior of the environment, aimed at eliminating the behavior by punishing, scaring, instilling guilt or using medication that weaken the sex drive. Such practices do not lower the frequency of masturbation and may result in an unintended increase in its intensity, while medication has negative side effects for health [50]. In people with ASD, masturbation can be a mechanism for dealing with anxiety, uneasiness; a form of self-stimulation when they experience deprivation of their needs [53]. Chronic masturbation which produces strong sensations, even pain, may also occur due to hyposensitivity [40]. It may be accompanied by using various objects, which increases the risk of self-harm [37]. Lower functioning or younger people with ASD may undertake masturbation in public places [54].

In the context of socio-legal problems in the sexual functioning of people with ID and ASD, sexual violence is also an issue. Buchanan I Wilkins [in 55, p. 69] distinguish between, sexual abuse, understood as “cases of incest, rape and other types of violence”; sexual exploitation, referring to situations in which a person is unable to give informed consent due to lack of knowledge about sexual activities and their consequences; and professional abuse, defined as “situations in which a person commits abuse in order to satisfy their sexual needs using their authority and violating trust in the relationship with the ward”. Many studies show that people with ID and ASD are victims of sexual violence; they are abused by their relatives, acquaintances, specialists, random persons, and in the institutional life conditions - other persons with disabilities [27, 56-60]. Analyzes of the risk factors of violence in the population of persons with ID were the basis for creating the concept of vulnerability. Key personal characteristics of vulnerability include: high level of physical and emotional dependence, limited assertiveness, excessive submissiveness, low control over one's own life, increased need for social approval, lack of self-image stability, internalization of devaluing opinions resulting in a lower self-worth, poor knowledge about potential threats, weaker internalization of social and legal norms, difficulties in communication [61]. Besides, deficits in health and fitness, including motor and sensory deficits, chronic diseases, addictions [62]. In this concept, interactions between deficits that result directly from individual disorders with specific environmental factors, such as economic problems are emphasized (e.g. poverty, homelessness, limited access to services and social benefits, lack of support, social devaluation of the person with a disability) [62]. Hollmotz [63] writes that it is important how the close and distant environment “reacts to disability”, i.e. what actions they take compensating the deficits that accompany disability. In this case, it is about support in sexual development, sex education, development of social competences, including assertiveness and control over one's own body, and suitable reactions in situations when the individual is threatened or has problems in realizing their sexuality. In the case of people with ASD, significant risk factors for violence include: deficits in communication, limitations of social...
The undertaken interventions are met with a sense of not intended to harm others and violate norms [23]. Caused by paraphilic disorders. Many of these acts are that many of them may be risk factors for committing socialization experiences of people with ASD indicates of disorders or mental disorders [69]. Analysis of the problems or the use of medicines, e.g., in the treatment own and other people’s behavior; neg desirable behaviors related to establishing relationships, and the lack of social acceptance, sometimes result in behaviors that are difficult for the environment and harmful to the individual, who is perceived to have deviant tendencies or intensified sexual needs [see 72]. The abovementioned problems constitute autistic spectrum disorders, however, they may be to some extent weakened or compensated by learning the desirable behaviors during childhood and adolescence [14]. Acquiring the desired sexual and social behavior will be hindered by the lack of sex education which could correct misconceptions about human sex life. These misconceptions are shaped by the media (as well as pornography) and peers. Another barrier in successful sexual and social development is limited social relations, especially with peers of both sexes and the related difficulties in acquiring social competencies [40, 73]. Antisocial and unlawful sexual behavior of persons with ASD, such as the lack of intimacy in communicating matters related to their own or other people’s sexuality (e.g., asking questions about details of intimate life), very direct behavior, stalking, the use of child pornography, voyeurism, specific interest in parts the body of another person (e.g., feet) with attempts to act without this person’s consent are associated with deficits, such as theory of the mind impairment, lack of emotional distance, incomplete knowledge of one’s own sexual orientation, but also lack of social competences to establish relationships with peers [53, 67, 71, 73]. In the population of persons with ID and ASD, there are individuals whose behavior meets the criteria of paraphilic disorders. Paraphilia is referred to as “sexual behavior that most people reject as abominable, unusual or abnormal; it is different from genital sex with a normal conscious adult” [75, p. 622]. Paraphilic disorders are the ones that “cause a person to suffer or limit their functioning” [75, p. 622]. Diagnostic criteria include: qualitative nature of paraphilia (e.g., erotic interest in children) - criterion A, and negative consequences (distress, injury, injury to others) - criterion B; both criteria need to be met. Duration (at least 6 months) and the presence of strong sexually stimulating fantasies, impulses and behaviors are important in the diagnosis of paraphilia [76]. Research in this area is limited and often includes case studies. Voyeurism, pedophilia, sadomasochism,
masochism, transvestite fetishism and exhibitionism were observed in people with ID [44, 77-79] and fetishism, transvestite fetish, sadomasochism, voyeurism, pedophilia were observed in the population of persons with ASD [37]. The genesis of paraphilia includes biological and psychosocial factors. Childhood experiences, including destructive ones, such as violence and sexual abuse, personality disorders, physical disorders and diseases (related to the functioning of the brain), the quality of experiences gained in partner relationships are all important. Case studies report a number of traumatic events including sexual abuse by foster parents, rape by a cohabitant in the institution, early homosexual experiences (8 years old), the use of pornographic materials, unfavorable tendencies in the parental relationship in the form of the dominant sexual position of the father, his strong possessiveness, and his intense sexual needs realized by his wife without mutual satisfaction [79]. In the case of people with ASD, certain behaviors can be stimulated by sensory (and other) disorders (eg, tactile or olfactory), without any sexual component. If these behaviors are associated with pleasurable sexual experiences, they may become fixed, though [67]. There are few studies of this issue because of the difficulties in diagnosing and disclosing paraphilic disorders, thus, more general conclusions regarding the etiology of paraphilic disorders and their consequences cannot be drawn.

SUGGESTIONS ON OPTIMIZING PARENTS’ ATTITUDES TOWARDS CHILDREN WITH ID AND ASD

Taking into account the genesis of parental attitudes which are the source of unfavorable experiences of children and adolescents with ID and ASD, it can be concluded that the optimization of development will require providing comprehensive support to parents and their cooperation with other entities important in the process of socialization. In the view of parental lack of sexual knowledge and their inability to teach it to their child with special needs, focus on the child’s disability, the associated sense of loneliness, fear, and helplessness, it is crucial to:

a) Help parents increase their sexual competencies to the extent necessary to facilitate their child’s positive everyday developmental experiences, such as developing a body image and gender awareness. Teach parents how to educate their child appropriately to the child’s needs, respond appropriately to the symptoms of the child’s sexuality and compare these symptoms to the developmental norm. Early parental support, widely described in the literature and implemented in many countries, also based on legislative guidelines, must be focused on experiences related to sexuality, many of which belong to the group of fundamental experiences for the child’s emotional, cognitive and social development. In this regard, the help of psychologists, pedagogues and sex therapists working in social institutions (counseling centers), as well as institutions providing early developmental support seems indispensable.

b) Parents’ constant support especially in periods crucial for the child’s sexual development such as puberty and maturity. Parental support seems to be important in the case of developmental difficulties, such as persistent masturbation, specific interests, excessive sexual arousal, but parents can also take more concrete actions to prepare the child to deal with manifestations of their own sexuality such as menstruation or nocturnal emissions. Such support should also be provided by sex therapists, sex educators, psychologists or specialist physicians (gynecologist), and educational or rehabilitation facility to which the child attends could organize and coordinate it. Using such organized (non-accidental) help will foster parents’ trust. The mentioned specialists who are coordinated by the school must have specialist knowledge of developmental disability.

c) Organizing long-term cooperation between parents and education and rehabilitation institutions to unify sexual education activities and procedures for dealing with problem situations. The roles of the school pedagogue, psychologist, and sex educator are of key importance. Parents must be aware that the sexual development of every child, including a child with a disability, is an element of the whole of the child’s functioning, consequently, its support requires a comprehensive approach, in most cases - long-term, sometimes across a lifetime.

d) Parents must be able to increase their sense of security associated with the social consequences of their developing child’s sexuality. Issues of current and future relationships, including formal ones, fulfilling
family roles, including parental ones (with the necessary support) must be undertaken as part of transition plans. Hopefully, specifying possible solutions in such plans eg. spouses with ID or ASD moving in together, receiving support in everyday activities and counseling regarding procreation and birth control, will increase parents’ sense of safety. This may result in them being more open to their child entering partner relationships and perceiving the positive contribution such relationships may have to the child’s quality of life.

CONCLUSION

The analysis made here were necessarily limited to selected issues, due to the wide scope of the subject. Issues of sexual abuse in the family environment were not discussed. The analysis of psychosocial experiences during childhood and adolescence in this paper focused mainly on family relations and parental attitudes. Experiences gathered in the wider environment, especially the peer environment, are also important though. The peer community, as defined in general in the characterisation of developmental tasks, plays a role in sex education, the development of social competences, sexual experimentation aimed at socializing the sexual need, and satisfying psychosocial needs. It is significant in preparing the child to undertake developmental tasks of adulthood. This topic is important for supporting people with developmental disabilities in successful psychosexual development. Activities supporting persons with ID and ASD in experiencing their sexuality positively should be integrated, i.e. they should be consistent across different environments of their functioning, they should include informal issues (socialization through participation in everyday situations) and formal issues (planned education and support).

This study is not a systematic analysis. It signals several issues important for the socialization of children with ID and ASD in the family, focusing on how they affect the child's psychosexual development. It is a discussion based on the available empirical research and the author's own research conducted for many years in the subject area [38, 80-84].

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