

# SEXUALITY OF ADULTS WITH INTELLECTUAL DISABILITIES AS DESCRIBED BY SUPPORT STAFF WORKERS

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**Abstract:** *Historically, people with intellectual disabilities have been labeled as asexual or as perpetrators or victims of sexual abuse (McDaniels, Fleming, 2016). They often face discrimination because of their sexuality, regardless of whether they live within residential facilities or family homes (Wingles-Yanez, 2014). This paper presents research results from qualitative studies of the sexuality of adults with intellectual disabilities. Applying a phenomenographic method (Paulston, 1993), the authors conducted 16 interviews with professionals at several daycare and residential centres in north-eastern Poland who work with intellectually disabled people. The specific research aims were to answer the following questions: (1) How do support staff workers perceive sexuality and intimate relationships of adults with intellectual disabilities? (2) Which factors contribute to the sexuality and intimate relationships of adults with intellectual disabilities according to support staff workers? (3) What kinds of support related to sexuality and intimate relationships do support staff workers think is essential for people with intellectual disabilities? The authors focus on presenting the professionals' perceptions of sexuality and intimate relationships of adults with intellectual disabilities and to depict the discourse those workers use. Implications for practice are also discussed, especially the need to provide sexuality support to adults with intellectual disabilities, their therapists and parents.*

**Key words:** *intellectual disability, sexuality, support staff workers*

## INTRODUCTION

Historically, persons with intellectual disabilities (ID) have been labeled as asexual or as perpetrators or victims of sexual abuse (McDaniels & Fleming, 2016). Practices such as segregated institutionalisation and sterilisation to prevent their childbearing have been common (Zaremba Bielawski, 2011). The past several decades have seen increasing support for persons with ID to access normalised life experiences (Nirje, 1972), but this support has focused more on employment, living conditions or recreation, whereas sexuality has remained a neglected sphere (Gilmore & Chambers, 2010). The Convention on the Rights of Persons with Disabilities (2006), which was ratified in Poland in 2012, states that parties are obliged to 'take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage,

family, parenthood and relationships, on an equal basis with others' (Art. 23). Yet, a number of prejudices, myths and stereotypes about the sexuality of people with ID are still present among health practitioners, families and caregivers (Kramers-Olen, 2016), which may limit the access of people with ID to opportunities for expressing sexuality and establishing intimate relationships.

Attitudes towards people with ID and their sexuality can act either as a barrier or a facilitator of inclusion in society. As Sankhla & Theodore (2015) point out, a number of studies have found that the lay public and care staff at public service centres hold generally moderately positive attitudes towards different aspects of sexuality in adults with ID, but that those attitudes are less positive than the same respondents' attitudes towards sexuality of people without disabilities. This may be due to sexuality-related obstacles and systemic barriers

to sexual health of people with ID, which include increased HIV/AIDS risk; vulnerability to sexual abuse and exploitation; reduced access to privacy, sexual health care, sexual education and sexuality-related information; fewer opportunities to find sexual partners (Di Giulio, 2003); and low levels of sexual knowledge of people with this type of disability (Galea et al., 2004, Kelly et al. 2009, Author, 2012). Other factors that influence an individual's attitudes towards sexuality of people with ID include the individual's age, gender, religious beliefs and ethnic origin, as well as whether the individual has an immediate family member with ID. For example, studies have shown that more conservative attitudes are more likely to be held by people who are older (Cuskelly & Bryde, 2004, Cuskelly & Gilmore, 2007), more religious (Meaney-Tavares & Gavidia-Payne 2012), male (Pebdani, 2016) or female (Meaney-Tavares & Gavidia-Payne 2012), and - in the case of aspects of sexual control and sexual rights - South Asian or White Western (Sankhla & Theodore, 2015).

Most of the abovementioned studies are based on quantitative data. Since there are few enquiries which attempt to get a deeper insight regarding carers' perspective on sexuality and intimate relationships of adults with ID, the authors made an attempt to fill this gap.

## OBJECTIVES

The aim of this study was to gain in-depth insight into how professionals working with adults with ID view sexuality and intimate relationships of adults with ID. In addition, we also reviewed the needs of support staff workers, adults with ID and their parents as well as the factors contributing to the sphere of sexuality and relationships from the perspective of the target group. The following research questions were created:

1. How do support staff workers perceive sexuality and intimate relationships of adults with ID?
2. Which factors contribute to sexuality and intimate relationships of adults with ID, according to the support staff workers?
3. What kinds of support with sexuality and intimate relationships do support staff workers think are essential for people with ID?

## METHOD

The research reported in this paper is qualitative, helping to explore the research questions in all their complexity and variability. In order to acquire a more comprehensive perception of the phenomenon, an interpretivist paradigm (Husserl, 1989) was chosen and a phenomenographic approach (Paulston, 1993) was applied in the study. The focus of phenomenography is on the second-order perspective and different ways that individuals can experience the same phenomenon (Assarroudi & Heydari, 2016). The second-order perspective allows one to answer the question of 'how a thing is perceived'. It differs from the first-order perspective, which is typical of phenomenology and which concentrates on the question of 'what a thing really is' (Marton, 1981).

The method used for data collection involved individual interviews, since an interview is a well-recognised method of gathering participants' thoughts, beliefs, experiences, and perspectives on a particular area of interest to the researchers (Hsieh & Shannon, 2005), which, in the present case, was the phenomenon of sexuality of adults with ID. It was essential for the authors to focus on the significance of therapists' perception of sexuality of adults with ID and the possible impact such perception may have on therapists' actions.

## Participants

The participants were purposively selected from five day-care institutions (three Occupational Therapy Workshops and two Community Self-Help Centres) and two residential units whose tenants were adults with ID. The institutions were situated in north-eastern Poland. The sample consisted of 16 support staff workers (therapists) of both genders (14 women and 2 men). The mean age of the workers who participated in the study was 40.44 (minimum = 29, maximum = 58), and 14 of them completed tertiary education, while the remaining two completed secondary education. Two participants occupied management positions at their institutions.

Names of the participants have been changed to preserve confidentiality and anonymity. Quotations in this study are attributed using a modified name

of the interviewee, one-letter sex descriptor (F or M) and age.

### Collecting and processing the data

The interviews were semi-structured, consisted of open questions and followed a guide created by the authors. The areas covered in the interviews included support staff workers' perception of sexuality of adults with ID, policies related to sexual behavior of people with ID in their institutions, barriers and facilitators of sexuality among adults with ID, and the needs for support related to sexuality and intimate relationships of people with ID. The interviews were conducted from October to December 2016. Each of them was previously arranged, lasted approximately 1-1.5 hours and took place in venues that guaranteed comfort and quiet, usually in rooms in the participants' institutions. A total of 13.5 hours of recording was collected and transcribed verbatim. All participants gave written consent to having the interviews recorded, transcribed, coded, stored and reported in this paper (Rapley, 2010). Interview transcripts were encrypted, encoded and anonymised. Following the rule of 'bracketing', which derives from a requirement for phenomenography to be sensitive to the individuality of conceptions of the world (Ashworth & Lucas, 2000), the researchers made an effort to avoid transferring their own assumptions about the topics that emerged during the meetings. In order to maximise the trustworthiness of results, the authors asked the interviewees to read the transcripts for accuracy following interviews.

Transcripts were coded line-by-line in a three-stage process based on grounded theory methods. The three stages were initial coding, focused coding and theoretical coding (Charmaz, 2009).

## RESULTS

### **Research Question 1: How do the support staff workers perceive sexuality and intimate relationships of adults with ID?**

Analysis of the interviews allowed the authors to distinguish three major categories of perceiving and experiencing *sexuality and intimate relationships of adults with ID* among the professionals as (1) a right of people with ID, (2) a means to

enhance the quality of life of people with ID or (3) as a problem (or challenge).

### **A. Sexuality and intimate relationships as a right of people with intellectual disabilities**

The interviewees whose narratives fall into this category paid attention to the rights of people with ID to express their sexuality, to enter into a relationship with someone, to marry and/or to have children.

*Personally, I've got nothing against it [expression of sexuality by people with ID]. I'm for [it] because everybody has the right to love, closeness, feeling of security – that's the need of everyone* (Lena, F, 30).

*In my opinion love is the most valuable feeling and it's not humanitarian to take the right to love away from someone* (Diana, F, 44).

*They're adults and they can make their own decisions* (Maria, F, 37).

Such perception often seems to be very personal (*Personally, In my opinion*). Acknowledging the rights of people with ID to fulfill their sexual needs, have an intimate relationship and start a family is usually accompanied by expressing positive feelings and emotions towards this sphere of their lives.

It is worth noting that the interviewees treated the rights of people with ID in the sphere of sexuality as rights common to every human being, not just to a group of people with (a specific type of) a disability. The support staff workers described themselves as people who do not make or apply any stereotypes of adults with ID or their sexuality:

*I don't differentiate people. There's nothing like 'able-bodied – disabled'* (Diana, F, 44).

*I'm an open and forthright person and I perceive people with disabilities as persons who have their own needs (like everyone) and one of these needs is sexuality* (Anna, F, 35).

In their statements, most professionals declared they did not think of adults with ID stereotypically. Rather, they claimed that they understood these

people and tried not to put them into any classifications.

### **B. Sexuality and intimate relationships of people with ID as a means to enhance their quality of life**

This category of description – similarly to the previous one – is connected with positive emotions among support staff workers about sexuality and intimate relationships of adults with ID. The two categories differ in the perspective taken by the interviewees. In the first category, they take the perspective of the professionals and/or society in general, which can be treated as a subject that allows or rejects certain rights. In the second category, the interviewees take the perspective of adults with ID.

*I'm really in favour of their relationships. They really function better when they are in a relationship. They've got someone to live for (Monika, F, 34).*

*Well, maybe it's because of the spring now [laughter], but they fall in love so easily and you can see how it makes them happy (Iwona, F, 58).*

### **C. Sexuality and intimate relationships of people with ID as a problem/challenge**

This category of description occurred when interviewees discussed aspects of their work, perspectives of adults with ID and perspectives of the adults' parents. The interviewees spent most time talking about aspects of their work. Some therapists stated that they were not always certain how to deal adequately with some sexual behaviours of their clients (e.g. masturbation), and that they remained cautious about discussing sexuality matters with people with ID. This was due to several reasons: feelings of incompetence, lack of formal preparation in sexuality at the university level and fear that discussions would invade their clients' privacy.

*Sometimes it can be really difficult. In one group we had a man who just had to go to the toilet several times a day to masturbate. His parents were really open, they went to a sexologist and we tried to find some ways to limit and postpone this, but not eliminate. But there were some colleagues*

*who didn't understand it at all and didn't feel like cooperating with us on the problem (Beata, F, 29).*

In order to deal with the problem of sexual expression and/or unwanted pregnancy of adults with ID, some institutions employed certain rules.

*Our manager had a great strategy. She took them [people with ID] to a gynaecologist and all got [contraception] plasters. If you don't have a plaster, you can't attend the Centre. Because one day they will have sex. It's certain! They're normal people who have their needs so we can't allow unwanted pregnancy (Monika, F, 34).*

Some interviewees perceived sexuality and intimate relationships as a problem also for people with ID and their parents.

*And there's also the 'risk' that they'll have children and this is very difficult because when they are born, they're harmed... (Iwona, F, 58).*

*[...] there is a question of pregnancy, because if a child is born, then probably a grandmother will get custody of the baby, right? Because if this person is not autonomous enough to get by, then a grandma has a 'double' problem (Adam, M, 47).*

The statements show that some professionals seemed to understand negative attitudes and restrictive behaviours of parents towards sexuality of their adult children, showing that their concerns were sometimes reasonable and understandable.

### **Research Question 2: Which factors contribute to the sexuality and intimate relationships of adults with ID, according to support staff workers?**

Analysis of therapists' narratives about factors that contribute to the sexuality and intimate relationships of adults with ID allowed us to distinguish several barriers and facilitators that – according to the interviewees – have an impact on the phenomenon.

The **barriers** reported by the interviewees can be classified into two categories: environmental (referring to the environment of a person with an ID) and personal (referring to certain qualities, skills, abilities and experiences of a person with this type of disability). The therapists emphasised

the importance of the first category. According to them, the main environmental barriers include:

- Family members' attitudes towards sexuality of adults with ID

*There are two groups of parents. In the case of those whom I call 'normal', who function well intellectually, the problem of sexuality is usually much bigger than in pathological families. For normal families, this is taboo, they don't want to talk about it and don't allow their adult children to start relationships [...]. But in pathological families there is also a problem – they don't care whether their child is in a relationship, so there are no such bans, but they don't support them at all (Karina, F, 40).*

*Lots of parents interfere with their lives. They don't give them freedom and that's the main obstacle (Renata, F, 40).*

*They often reject this sexuality. They're focused on disease and all their energy is put into rehabilitation and care, providing some stuff, buying a new wheelchair etc. [...]. They refuse to think of their children's needs to have a relationship one day. (Adam, M, 47).*

- Discriminatory attitudes toward people with ID in society

Although some interviewees noticed positive changes in social attitudes, they also pointed out negative stereotypes, beliefs and reactions in society toward adults with ID.

*I think one of the biggest barriers is social non-acceptance [...]: 'They can hold their hands, but nothing more...' (Beata, F, 29).*

*I can see two trends in society at the moment. On the one hand, we're opening the door to them [people with ID], supporting, helping [them] grow up and live in the world of adults. On the other, there are campaigns to eliminate them before they are born or exclude them from normal life (Daniel, M, 55).*

- Lack or low quality of systemic support from government (including discriminatory legal policy), local authorities and/or community

*I feel sorry that we've got such a terrible system in Poland, that there's no supported living... Lots*

*of our clients would get by with some support of a social worker. [...] I can't understand why the council prefers sending these people to big residential units even though it's more expensive than supported living in the community (Karina, F, 40).*

*The problem is that they have no opportunities to become independent. They either live with parents or in big single-sex institutions without any chances of entering into a relationship (Beata, F, 29).*

*There's a problem that they can't legalise their marriage. Some of them are really devastated because of that [...] It would be great if they had the right. They'd have an aim (Monika, F, 34).*

- Restrictions in institutions for people with ID

*There is a rule that they can't close the door when there aren't any carers with them (Maria, F, 37).*

It is worth noting that some support staff workers admitted that they did not feel comfortable with imposing restrictions on their clients. Although they often claimed that they reacted openly and positively to their clients' relationships, they noted that various environmental barriers made them behave contradictory to their opinions.

*I was in such a situation once when there was a couple – a man and a woman who felt close to each other [...] And I knew that their parents didn't want them to get any closer, not even to be friends, call or text each other in the afternoon [...] So I was and felt like a guard who doesn't allow them to caress, hold each other's hand, hug... [or] have this relationship [...] It was a very unpleasant experience for me – I felt so ambivalent (Adriana, F, 35).*

The barriers classified as personal referred to clients' limited skills, experiences and qualities. Interestingly enough, the interviewees rarely talked about limitations in intellectual functioning of adults with ID. Only one therapist noticed that there are differences in expressing sexuality depending on the level of ID.

*People with a profound ID act quickly and very straightforwardly. They're less able to control themselves. If they feel like masturbating, they simply do it [...]. And when you work with people with moderate or mild ID, you can talk to them about social norms and they are aware of them themselves (Beata, F, 29).*

Other personal barriers included certain traits described by the interviewees as typical of people with ID (e.g. helplessness, tendency to fall in love easily, emotionality, shyness, infantility), lower skills in certain areas (e.g. communication skills, social skills, daily living skills), abilities to control sexual behavior and sex (men were sometimes described as less able to control their sexual needs).

*Please, don't get me wrong... But I'm not so much into getting so obsessed about sexuality and sexual education as we see today. This is very serious and should be treated seriously. And you know... When you're retarded, you function like a child and they treat you like a child. (Iwona, F, 58).*

Interestingly, although the interviewees usually described adults with ID as a very diverse group (*We have people of different ages, different emotional levels, in different phases of development, with or without any experiences with intimate or sexual contacts;* Adriana, F, 35), some of them noticed specific typical qualities, e.g. on the one hand, hyper-sexuality, hyperactivity and emotionality or, on the other hand, sexual withdrawal.

*They're so hyperactive. I can see here that they do everything, and want everything here and now and they frequently fall in love, so sometimes it's like all of us... [...] Or some of them are in the phase of physical sexuality only (Martha, F, 34).*

*In their behaviour I can see the needs but also great fears, probably brought from home. These fears are so strong that their sexual drive is blocked (Diana, F, 44).*

Much more often, however, therapists referred to clients' limited experiences when describing personal barriers.

*They don't know life, they have no other patterns of behaviour. There's one route only: home – workshops – home, with no social life afterwards (Adriana, F, 35).*

*I know some couples who live independently. They think that they're doing right, that they're not hurting anyone, but they are... [This is] because they were raised the same way themselves (Teresa, F, 59).*

The support staff workers reported the following **facilitators**, which were classified according to their source:

- Facilitators originating with professionals: (1) empathy and positive attitudes towards people with ID and their sexuality, (2) taking part in training, (3) cooperation with specialists (psychologists, sexologists)

*It's important for a therapist to have empathy and be sensitive to the needs of these people. Of course some formal preparation is useful but not as much as the ability to understand them (Karolina, F, 32).*

*I cooperate with a psychologist, [...] we regularly solve problems together (Beata, F, 29).*

- Facilitators originating with the therapists' institutions: liberal policy guidelines that support sexuality and address hetero-normative biases

*We don't have any rules that would forbid intimate relationships of men and women. [...] Such relationships are inevitable. They're adults [...] They lock the door and have their intimacy, they can hug, kiss, whatever comes to their mind. [...] I believe that if we forbade this, the effect would be opposite. They'd just hide (Lena, F, 30, works in a residential centre).*

- Facilitators originating with adults with ID: (1) personal characteristics (e.g. responsibility, punctuality, diligence), skills and abilities (e.g. ability to control oneself sexually), (2) taking part in sexual education, training, and classes that develop social skills and raise awareness about sexuality and (3) having access to support in doing daily activities, including activities connected with sexuality.

*We don't have problems like masturbation or sexual abuse here. They are internally convinced that such behaviour shouldn't occur in front of others. (Diana, F, 44).*

*Like everyone – they are able to love, [...] they can definitely establish stable relationships (Lila, F, 58).*

- Facilitators originating with parents: (1) positive attitudes towards sexuality of their adult children, (2) advocacy of parents fighting for the rights of people with ID

*We've got such a group of parents – leaders, very open, moving forward, aware of their chil-*

*dren's needs – not just eating or drinking but also sexual ones. And they attended this training session [on sexuality of people with ID] and then encouraged others to join it as well (Beata, F, 29).*

### **Research Question 3: What kinds of support related to sexuality and intimate relationships do support staff workers think are essential for people with ID?**

According to the professionals, support with sexuality and intimate relationships of people with ID should be directed at three groups of stakeholders: (1) adults with ID, (2) their parents or legal guardians and (3) their therapists. Interviewees mentioned two types of support targeting adults with ID:

- Increasing the scope and access to education and training (e.g. in sexuality and relationships as well as social, practical and vocational skills) in order to prepare adults with ID to live independently, maintain a sustainable relationship with another person and/or raise children. Such training services could be offered in institutions (day care and residential centres for people with ID) and in their homes (with the support of family assistants, social workers and/or psychologists).
- Systemic support from government and/or local authorities to offer adequate living arrangements (e.g. financial assistance to develop supported housing) and employment opportunities (e.g. legislation that would guarantee the right to receive a pension even when a person is employed).

*For me, the biggest problem and need, actually in every phase of life – since early childhood to adulthood – is the lack of appropriate sexual education. [...] And it's not just about sexuality. For them it's difficult to talk to a person of the opposite sex. So they really need basic stuff – not just developing academic or manual skills, but social ones – establishing different relationships with people (Beata, F, 29).*

*When they live independently, have children, then there's a need for a family assistant [...] They often can't count on their own families, so it's really important (Adam, M, 47).*

Another group of stakeholders that requires support, the interviewees stated, are parents or caregivers of adults with ID. They need training in discussing and supporting the sexuality of their adult children.

*For me, the biggest need is the therapy which should be started with parents. Because they don't know that they do something wrong. [...] Now that's a tragedy! [...] There's a mom who's always holding his adult son's hand (Renata, F, 40).*

*Parents should be involved in training. Because we won't do anything on our own [...] Sexuality can't be rejected by parents. We need to speak one voice and make parents aware that this is an important sphere of their dreams (Adam, M, 47).*

Last but not least, the therapists believed that they made up a professional group that needs support regarding their clients' sexuality and intimate relationships. They felt that this support should occur at (1) the personal level (information support from specialists through university education and trainings), and (2) the institutional level (rules on expression of sexual behaviour at their institutions).

*Most often we behave intuitively. [...] But there are sometimes situations that require support. We aren't sure how to behave in certain situations (Martha, F, 34).*

## **DISCUSSION**

The current research shows that support staff workers have generally positive perceptions of sexuality and intimate relationships of adults with ID. The results are consistent with previous studies (Cuskelly & Bryde, 2004, Aunos & Feldman, Bazzo et al. 2007, Gilmore & Chambers, 2010, Wilkinson, et al., 2015). For example, similarly to the results by Wilkinson et al. (2015), the therapists in the present study seemed caught between different perceptions. On the one hand, they presented people with ID as 'normal' and having the same rights as others; and on the other hand, they subscribed to societal ideas about their functional deficits, perceiving their sexuality as a problem. This, as Wilkinson et al. (2015) argue, supports social constructionist theories in which identity

development is perceived as a construct continually renegotiated through interaction with others.

The present study has also enabled the authors to identify several factors contributing to sexuality among adults with ID and to their establishment of intimate relationships. With respect to personal factors originating within the individuals with ID, support staff workers rarely focused on deficits in intellectual functions. Rather, they paid attention to their hypersexuality, consistent with the study by Aderemi (2014), as well as to their sexual withdrawal and to some psychosocial traits described by the interviewees as characteristic of people with ID: helplessness, emotionality, shyness, infantility, vulnerability, lower communication, social and practical skills. It needs to be emphasised, though, that the participants also focused on positive features of their clients that predispose them to establish and maintain stable intimate relationships, e.g. ability to love, ability to control sexual behaviour, responsibility, punctuality and diligence. As a result of these skills and traits and – as some interviewees noted – with adequate support from the environment, people with ID have opportunities to start families. These results are consistent with previous studies (Schwier, 1994, Kijak, 2016) describing couples with ID living in satisfactory relationships and raising children.

An important result of the present research is identifying contextual barriers and facilitators for people with ID to experience a normalised sex life. The interviewees referred mostly to environmental barriers, which include certain systemic constraints as well as negative attitudes and incorrect beliefs about people with ID held by the families and communities in which those people live. The interviewees claimed that the most essential barrier was connected with parental attitudes towards their adult children's sexuality. Parental overprotection and/or tendency to control many aspects of their adult children's lives may lead to dependency, withdrawal, infantilism and the adult child's passive acceptance of his or her role as an asexual being. This is consistent with other studies indicating that parents tend to have more conservative and reserved views about the sexuality of people with ID (Cuskelly & Bryde, 2004), whereas support staff attitudes are

more liberal (Cuskelly & Bryde, 2004, Bazzo et al., 2007).

The results of the present research are consistent with studies that recommend trainings to equip teacher/therapists with skills to deliver sexual education to people with ID and to address negative attitudes and misconceptions among teacher/therapists about the sexuality of their clients (Aderemi, 2015). Although the interviewees in the present research were generally positive about issues related to the sexuality and intimate relationships of their clients, some mentioned having little or no competency to react adequately to sexuality issues and therefore suggested that there was a need to cooperate with specialists, to receive appropriate trainings and to work in institutions with appropriate policies and procedures. Unfortunately, as Gilmore & Chambers (2010, p. 27) stated, 'comprehensive policies and procedures for addressing sexuality issues seem to be rare in disability services'. In the absence of specific guidelines, it is likely that employee responses and reactions to sexuality issues are influenced to some extent by their personal attitudes and beliefs (Christian et al., 2001). If therapists are to support people with ID effectively in this sphere of life, elaboration of comprehensive policies and provision of employee trainings seem to be essential.

## CONCLUSION

This study used the qualitative approach to provide an in-depth understanding of support staff workers' perceptions of sexuality and intimate relationships of adults with ID. Their narratives of such sexuality and intimate relationships as a right, as a means to enhance quality of life and as a problem/challenge, show that professionals are conflicted in the sense that, on the one hand, they perceive people with ID as 'normal' individuals with the same rights and needs as others while, on the other hand, they perceive people with ID as having deficits and living in restrictive environments in which their sexuality is understood as a problem.

We believe that understanding therapists' perceptions of sexuality of adults with ID and understanding the barriers and facilitators to intimate relationships among such adults is essential for sev-

eral reasons. First, professionals shape the quality of life of the clients where they work. According to Gilmore & Chambers (2010), the attitudes of caregivers and support workers directly influence people with ID. Certain perceptions, emotional reactions and behaviours of professionals concerning the sexuality of adults with ID may act either as a barrier or a facilitator to those adults' expressing their needs and feeling more or less free to talk about those needs.

Second, the attitudes of professionals definitely affect the relationships of those professionals with their clients' parents or caregivers. Trainers and health professionals can provide various types of educational and rehabilitation support around the issue of sexuality in people with ID in order to increase parents' or caregivers' awareness, knowledge and skills in this area. Such programs, as Kok & Akyuz (2015) state, can enhance parents' self-efficacy in addressing their children's sexual needs.

Last but not least, the existence of negative attitudes and misconceptions about the sexuality of individuals with ID among professionals can lead those individuals to internalise such attitudes and misconceptions. As a result, the presumption of asexuality may become a self-fulfilling prophecy and lead people with disabilities to retreat from intimacy and sexuality (Di Giulio, 2003). Conversely, positive attitudes of support staff and other people in the community 'have the potential to influence opportunities for normalised life experiences in the area of sexuality' (Gilmore & Chambers, 2010, p. 22).

The study has some potential implications for disability services that provide support to people with ID. As the participants of the study expressed, there is a great need for systematic support related to sexuality of adults with ID that should be addressed to all three stakeholders involved: the adults themselves (education on sexuality and rela-

tionships, as well as on improving living arrangements and employment opportunities), their parents (sexuality trainings) and employees of institutions working with the adults (sexuality trainings, establishing policy guidelines in institutions). One of the crucial issues seems to be to create more favourable attitudes among therapists towards the sexual rights of individuals with ID. As Pebdani's (2016) study indicates, there are two ways to fulfill this task: (1) provide in-service training on sexuality for employees and (2) establish policies related to sexual behaviour of consumers in institutions. Both ways are achievable for educators and administrators. The needs in this sphere were also expressed by the therapists in the current research.

Clearly, there are also several limitations of the study as well. First of all, although the authors made an attempt to bracket their preconceptions about the phenomenon of sexuality and relationships of people with ID both during data gathering and analysis, it remains uncertain whether the task was fulfilled adequately (Webb, 1997). Second, general limitations of attitude research should be emphasised, particularly when attitudes towards sensitive subjects like disability and sexuality are concerned. It is plausible that interviewees had a tendency to report socially correct responses whereas their actual, nonverbal attitudes which actually translate into their behaviours remain unknown. Additional research methods, e.g. experiments or observations of social workers at work, would be of value. Third, the qualitative character of the study does not allow any generalisations. The participants of the research constitute a relatively small group of support workers in institutions for adults with ID in Poland. It is reasonable to believe that the results of the research conducted among support staff employed in institutions for children and youth as well as therapists in other countries could be different.

## REFERENCES

- Aderemi, T. (2014): Teachers' Perspectives on Sexuality and Sexuality Education of Learners with Intellectual Disabilities in Nigeria, *Sexuality & Disability*, 32(3), 247-258.
- Ashworth, P., & Lucas, U. (2000): Achieving Empathy and Engagement: a practical approach to the design, conduct and reporting of phenomenographic research, *Studies in Higher Education*, 25(3), 295-308.
- Assarroudi, A., & Heydari, A. (2016): Phenomenography: A Missed Method in Medical Research, *Acta Facultatis Medicae Naissensis*, 33(3), 217-225.
- Aunos, M., & Feldman, M. A. (2002): Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 15, 285-296.
- Bazzo, G., Nota, L., Soresi, S., Ferrari, L., & Minnes, P. (2007): Attitudes of social service providers towards the sexuality of individuals with intellectual disability, *Journal of Applied Research in Intellectual Disabilities*, 20, 110-115.
- Charmaz, K. (2009): *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*. Warszawa: Wydawnictwo Naukowe PWN.
- Christian, L., Stinson, J., & Dotson, L. A. (2001): Staff values regarding the sexual expression of women with developmental disabilities, *Sexuality and Disability*, 19, 283-291.
- Convention on the Rights of Persons with Disabilities (2006); Retrieved 30 April, 2017 from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.
- Cuskelly, M., & Bryde, R. (2004): Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample, *Journal of Intellectual & Developmental Disability*, 29, 255-264.
- Cuskelly, M., Gilmore, L. (2007): Attitudes to sexuality questionnaire (individuals with an intellectual disability): scale development and community norms, *Journal of Intellectual & Developmental Disability*, 32, 214-221.
- Di Giulio, G. (2003): Sexuality and people living with physical and developmental disabilities: A review of key issues, *The Canadian Journal of Human Sexuality*, 12(1), 56-38.
- Galea, J., Butler, J., & Iacono, T. (2004): The assessment of sexual knowledge in people with intellectual disability, *Journal of Intellectual & Developmental Disability*, 29(4), 350-365.
- Gilmore, L., Chambers, B. (2010): Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees, *Journal of Intellectual & Developmental Disability*, 35(1), 22-28.
- Hsieh, H.-F., & Shannon, S.E. (2005): Three approaches to qualitative content analysis, *Qualitative Health Research*, 15, 1277-1288.
- Husserl, E. (1989): *Nastawienie nauk przyrodniczych i humanistycznych. Naturalizm, dualizm i psychologia psychofizyczna*. In: Krasnodębski, Z. (Ed.), *Fenomenologia i socjologia* (pp. 53-74). Warszawa: PWN.
- Kelly G., Crowley H., Hamilton C. (2009): Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted', *British Journal of Learning Disabilities*, 37, 308-315.
- Kijak, R. (2016): *Dorośli z głębszą niepełnosprawnością intelektualną jako partnerzy małżonkowie i rodzice*, Kraków: Wyd. Naukowe UP.
- Kok, G., Akyiz, A. (2015): Evaluation of Effectiveness of Parent Health Education About the Sexual Developments of Adolescents with Intellectual Disabilities, *Sexuality & Disability*, 33(2), 157-174.
- Kramers-Olen, A. (2016): Sexuality, intellectual disability, and human rights legislation, *South African Journal of Psychology*, 46(4), 504-516.
- Marton, F. (1981): Phenomenography – describing conceptions of the world around us, *Instructional Science*, 10, 177-200.

- McDaniels, B., Fleming, A. (2016): Sexuality Education and Intellectual Disability: Time to Address the Challenge, *Sexuality & Disability*, 34(2), 215-225.
- Meaney-Tavares, R. & Gavidia-Payne, S. (2012): Staff characteristics and attitudes towards the sexuality of people with intellectual disability, *Journal of Intellectual & Developmental Disability*, 37 (3), 269–273.
- Nirje, B. (1972): The right to self-determination. In: Wolfensberger, W. (Ed.), *Normalization: the principle of normalization*. National Institute on Mental Retardation (pp. 176-200). Toronto: National Institute on Mental Retardation.
- Paulston, R.G. (1993): Pedagogika porównawcza jako pole nakreślenia konceptualnych map teorii paradygmatów. In: Kwieciński, Z., Witkowski, L. (Ed.), *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach* (pp. 25-50). Warszawa-Toruń: IBE, Edytor.
- Pebdani, R.N. (2016): Attitudes of Group Home Employees Towards the Sexuality of Individuals with Intellectual Disabilities, *Sexuality & Disability*, 34(3), 329-339.
- Rapley, T (2010): *Analiza konwersacji, dyskursu i dokumentów*. Warszawa: PWN.
- Sankhla, D., Theodore, K. (2015): British Attitudes Towards Sexuality in Men and Women with Intellectual Disabilities: A Comparison Between White Westerners and South Asians, *Sexuality & Disability*, 33, 429-445.
- Schwier, K.M. (1994): *Couples with Intellectual Disabilities Talk About Living and Loving*, Rockville, MD: Woodbine House.
- Webb, G. (1997): Deconstructing deep and surface: Towards a critique of phenomenography, *Higher Education*, 33(2), 195-212.
- Wilkinson, V.J., Theodore, K., Raczka, R. (2015): ‘As Normal as Possible’: Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood, *Sexuality & Disability*, 33(2), 93-105.
- Wingles-Yanez, N. (2014): Why All the Talk About Sex? An Autoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability, *Sexuality & Disability*, 32(1), 107-116.
- Zaremba Bielawski, M. (2011): *Higieniści. Z dziejów eugeniki*. Wołowiec: Wydawnictwo Czarne.

## SEKSUALNOST ODRASLIH OSOBA S INTELEKTUALNIM TEŠKOĆAMA IZ PERSPEKTIVE OSOBLJA ZA PODRŠKU

**Sažetak:** *Kroz povijest osobe s intelektualnim teškoćama bile su smatrane aseksualnima ili pak počiniteljima ili žrtvama seksualnog nasilja. Zbog svoje seksualnosti ove se osobe često susreću s diskriminacijom, kako u institucijama, tako i u obiteljskom domu. U ovom su radu prikazani rezultati kvalitativnog istraživanja seksualnosti odraslih osoba s intelektualnim teškoćama. Primjenivši fenomenografsku metodu, autori su proveli 16 intervjua s osobljem koje radi s osobama s intelektualnim teškoćama, iz nekoliko institucija u sjeveroistočnoj Poljskoj. Ciljevi istraživanja bili su dati odgovore na sljedeća pitanja: 1) kako osoblje za podršku percipira seksualnost i intimne odnose odraslih osoba s intelektualnim teškoćama? 2) Koji čimbenici, prema mišljenju osoblja, doprinose seksualnosti i intimnim odnosima odraslih osoba s intelektualnim teškoćama? 3) Koja je vrsta podrške, prema mišljenju osoblja, ključna za seksualnost i intimne odnose osoba s intelektualnim teškoćama? Razmatraju se praktične implikacije dobivenih rezultata, osobito potreba za pružanjem podrške glede seksualnosti odraslima s intelektualnim teškoćama, njihovim terapeutima i roditeljima.*

**Ključne riječi:** *intelektualne teškoće, seksualnost, osoblje za podršku*