

**Self-Advocates with Intellectual Disabilities Talk about Love and Relationships:
A Focus-Group Research Report**

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Abstract: The paper focuses on the view and experiences of self-advocates with intellectual disabilities towards love and intimate relationships. Although sexuality is considered to be a significant aspect of human life, people with intellectual disabilities are rarely given opportunities to explore and develop it as well as to express their opinions about it. The paper presents research results conducted with self-advocates with intellectual disabilities using a qualitative study based on interpretative paradigm and focus group technique. The authors made an attempt to answer two main research questions: 1) How do self-advocates' with intellectual disabilities perceive love? 2) What contributes to their sphere of intimate relationships and sexuality? 31 self-advocates with moderate and mild intellectual disabilities took part in six focus group interviews. In the interviews several themes emerged: perceptions of love, personal experiences in the sphere of intimate relationships and sexual behaviors undertaken by the participants, their needs and environmental constraints on the way to fulfill the needs. Through the voices of 31 adults, it is shown what they consider to be important in areas such as love and intimate relationships with others. Implications for practice are discussed, including the need for sexual education and professional support for adults with intellectual disabilities.

Keywords: intellectual disability, self-advocates, love, relationships, sexuality

Introduction

Sexuality is considered to be a significant aspect of human life (Kijak, 2013). Nonetheless, people with intellectual disabilities experience discrimination in this sphere (Wingles-Yanez, 2014) and are rarely given opportunities to explore and develop it as well as to express their opinions about it (Azzopardi-Lane & Callus, 2015). For a long time, they have been labeled as ‘eternal children’, asexual, perpetrators or victims of sexual abuse (Fornalik, 2002; McDaniels & Fleming, 2016; Kramers-Olen, 2016; Ditchman, Easton, Batchos, Rafajko, & Shah, 2017). The last several years seem to bring some changes. In Poland, as in most parts of the western world, the process of deinstitutionalisation and ideas of normalization have significantly influenced the lives of people with intellectual disabilities (Krause, Żyta, & Nosarzewska, 2010, Löfren-Mårtenson, 2004). Most of them are not separated from families and local communities in large institutions but live with their parents, other family members, in small group homes with external support or assistance (supported living), independently or with a partner.

People with intellectual disabilities often have adverse socialization experiences of frustration and deprivation, including the area of sexual life and emotional relationships. This population, as in the case of non-disabled people, is characterized by the differentiation of sexual preferences, ways of their implementation, as well as the occurrence of disorders and difficulties in this area. The peculiar character of sexuality of people with disabilities is not usually connected with life choices of these people, but it results from limited life opportunities. Research confirms that love and friendship are of great value for individuals with intellectual disabilities (Rushbrooke, Murray, & Townsend, 2014). They usually associate love with emotional well-being, want to have an intimate relationship and need an understanding of their sexuality (Bogenschutz, Novak, & Amado, 2016). These people however – if compared to the non-disabled – have fewer opportunities to choose a partner, maintain relationships or resign from them in a situation where they do not meet their expectations. In addition, they have fewer opportunities to formalize relationships and fulfill the role of a spouse or a parent (Walker-Hirsch, 2002; Parchomiuk, 2016).

Although the access to normalized life experiences (Nirje, 1972) of persons with intellectual disabilities seems to be continually increasing, sexuality tends to remain a neglected sphere (Gilmore & Chambers, 2010). To date, views and experiences of this group of people related to intimate relationships are under-represented in the literature of the subject (Rushbrooke, et al., 2014). This study aims to put some contribution to fulfilling this gap,

Method

The aim of the present study was to gain insight into self-advocates’ with intellectual disabilities perception and experiences associated with love and intimate relationships. Two research questions were formed:

1. How do self-advocates’ with intellectual disabilities perceive love?
2. What contributes to their sphere of intimate relationships and sexuality?

In order to answer the questions, qualitative research based in interpretivist paradigm (Husserl, 1989) was designed. The authors' objective was to show the complexity and variability of the subject of the study.

The method of data collection involved focus groups interviews (Morgan, 1997), a method that allows gaining a deeper understanding of the research subject (Barbour, 2011). Three focus groups were established and each of them participated in two focus group meetings during which interviews were conducted. This led to six focus group interviews. In each group there were from seven to twelve participants. The meetings took place in occupation therapy workshops (day centres) for adults with intellectual disabilities between March 2017 and March 2018.

As far as the participants are concerned, in the current project purposeful sampling, which is widely used in qualitative studies for the identification of information-rich cases related to the research subject (Palinkas et al., 2015), was applied. The sample was chosen following three main criteria:

1. Being a member of a self-advocacy group in one of three centres located in one of three towns of north-eastern Poland,
2. Being an adult with an intellectual disability (mild or moderate degree), and
3. Giving a consent (written – in case of literate participants or oral) – based Rapley's (2010) proposal – to take part in the research, record and transcribe the interviews and use them for scientific purposes.

Overall, 31 self-advocates (13 females and 18 males) with moderate and mild intellectual disabilities took part in focus group interviews. It needs to be emphasized that in Poland, as opposed to some other countries, e.g. Croatia, self-advocacy groups of people with intellectual disability are not usually run independently, but within bigger organizations. In case of the participants of the current study, all of them attend day support centres called occupational therapy workshops which are run by the Polish Association on Persons with Intellectual Disability. Their age varies from 20 to 59 (mean age: 34) and most of them (16 participants) were below 30. Majority of them (24 people) do not live independently – they live with their parents, siblings or other family members who usually take care of them and/or control them in some spheres (e.g. economic) of their lives. Others live in their apartments or houses on their own, with partners or some family members (e.g. an adult nephew or a child). The vast majority of the participants receive disability payments from the state and three work part-time. All self-advocates involved in the research had a legal capacity.

In the process of analysis of the present research coding and categorization proposed by Flick (2010), Kvale (2010) and Gibbs (2011) were used. The process involved five steps: 1) coding of words generated from verbatim data of transcripts of six focus group interviews, 2) categorization of the codes generated into broader categories, 3) comparison of categories and examination of their relations to the research questions, 4) categorization of the data according to the research questions, and 5) presentation of the results in a text (Kvale & 2010; Bartnikowska, Ćwirynkało, & Borowska-Beszta, 2017).

Findings

The process of the analysis of the verbatim data started with generating the codes and grouping them into broader categories. They included: (1) perceptions of love, (2) personal experiences in the sphere of intimate relationships and sexual behaviors undertaken by the participants, as well as (3) their needs and environmental constraints on the way to fulfill the needs.

Category 1: Perception of Love. The findings illustrate how people with intellectual disabilities describe love. Describing the notion, they almost solely associated it with an intimate relationship between a woman and a man. For the participants of the study love is perceived as something desirable, something which makes them feel special, and something they want to experience:

“Love is... Well, to tell the truth, it means that you’re number one!” (Daniel)

“I want to find my love. I could talk to somebody...” (Jan)

Love is also referred to certain activities (e.g. supporting each other), attitudes and other feelings (e.g. respect):

“Love is helping each other, supporting. When you love someone, you do everything for this person. I’d like to have such a person who would do anything for me. And I would, too...” (Mike)

“It means that we’re faithful, respect each other and support each other in difficult moments. Like I supported Adam when his Mum died...” (Joanna)

In their statements about love some self-advocates associated it with the sexual embrace. Love was perceived as an introduction or a necessary condition before sexual intercourse:

“You know... When you want to have a drink or some wine, then it’s like... When there’s a girl you love, you touch her legs, and... [...] And if you can kiss the girl, you kiss her. And that’s love.” (Damian)

There were also interviewees who, while describing love, gave examples of couples from their close environment:

“For example in my home... Because I’ve got a sister who’s much older than me and she’s got a very good relationship with her husband. They’ve been together for fifteen years now. And they created a great love together because they’ve got two children.” (Emil)

The findings also indicate that for some participants love and intimate relationships seem to be restricted only to personal ties between a man and a woman:

“I saw two men kissing each other once, in the street. It’s wrong cause they can’t have children.” (Anna)

Others, however, disagree:

"I don't mind. There are different couples." (Eric)

"Times are different now. It's the 21st century [laughing]." (Michael)

Several self-advocates referred to maternal love for a child and their own feeling towards close family members:

You have to love your mother. She gave birth to you, right? She's the most important and you can't hurt her. (Mark)

Category 2: Personal Experiences in the Sphere of Intimate Relationship and sexual behaviors. Another theme that emerged during the meetings was connected to personal experiences in the sphere of intimate relationships and sexual behaviors undertaken by the participants. This was, as they convinced, a sphere of vital importance for them, although, only hardly a half of them admitted that they were (or had been in the past) in such a relationship:

I'm in a relationship here [at the Workshops]. Yes, I've got a girlfriend. When I came here, we started talking to each other. [...] I've been here for six years now and we're still going out together. We give presents to each other. We like cleaning together. We hang out around. There's a feeling between us... (Paul)

I had a fiancé once. I met him at the Workshops in B. He also was disabled. I was young, 22-23 years old. And stupid... [...] At first it was all fine, but then it all messed up. He didn't help with the child and I had to do everything on my own. He was just yelling and beating, right? So I left... (Maria)

Category 3: The needs and environmental constraints. Although the stories described by some self-advocates showed that the experiences might be negative, the desire to have someone close with who they could be in an intimate relationship was common.

"Maybe in some time in the future... Maybe I'll also be lucky? I would like to. He [ex-boyfriend] has a girlfriend now... And maybe I'll also find someone cool for me..." (Julia)

When they talked about their dreams and plans for the future, they often expressed their needs to have a partner (husband or wife), an apartment in which they would live independently, work and – not that often though – children:

"I'd like to have a wife and a house. I'd just want to support my family."

"Work." (Adam)

How will I live in ten years' time? Interesting... I'd love to live in my own home, have my own work, be with my own partner and my own family... You know, parents won't live forever... Everyone has to get by somehow. [...] I must become self-reliant. Maybe at first it would be difficult, but we would learn. With an assistant maybe... (Martha, moving on a wheelchair)

"Yeah, you can learn a lot when you really want. Once I was alone at home so I took some washing powder, poured some water into the sink and washed the sock all by myselfs. So you can do it!" (Jonas, a blind person)

Some interviewees seemed to be skeptical about their dreams. On the one hand, they expressed what they would like their future to be like, on the other, paid attention that the dreams might not come true:

I don't know... I mean I thought about it but I don't know... I thought about a girlfriend but I'll probably live with my parents cause where else? I'd also like to work but I don't know... I would have to remember at this work... and my memory is... Hard to say. (David)

In their desire to be involved in an intimate relationship, however, most participants reported being constrained. There were several reasons why they felt this way, e.g. overprotective or restrictive attitudes of parents, lack of privacy (at home and/or at workshops), lack of or limited finances, lack of a place to live independently, dependence on others (especially in case of participants moving on wheelchairs but also when partners did not have legal capacity). The sphere in which they felt restricted in the predominant way was their sexuality. One of the participants complained about it but, at the same time, tried to excuse his parent:

We sometimes meet at my home, but very rarely, cause Mum couldn't stand it when we were alone in the room, so now we meet here [at the workshops]. We couldn't do it there because of Mummy was stressed and she gave birth to me and raised me so I need to respect her. I don't want her to be stressed because of me. [...] I wanted to see Eve but I saw how difficult it was for Mum and didn't want her to watch it and get depressed. (Paul)

Another place where some self-advocates also see restrictions is their workplace at workshops:

"You can't kiss each other here." (Cathrine)

Yeah, there are some rules what you can and can't do here. [...] But when no one sees, I can touch my partner and stand next to her. And you can sit next to each other! But you can't catch her from behind... Just like I said, such things only secretly. (Paul)

It is worth noting, however, that the interviewees were aware that their sexual behaviours – just like in case of everyone else – are supposed to be controlled by some social mores and regulations:

"There are policies at the Workshops but it's good." (Mark)

"Yeah, so that no one hurt anyone. Some things are forbidden. The manager told us so." (Paul)

I mean that we come here to work. We can't do things like that [kissing] here. Because we're at work. Later on, when we're in town, that's a different thing. The same when there are parents around – you have to think about it. (Peter)

It is also evident that the self-advocates are cognizant of their rights and freedom of choice in the sphere of sexuality. As Joanna and Paul asserted:

There was such a situation once. I'll not say the name but he tried to touch me at Music classes. I told him, 'Don't do that or I'll tell the manager'. [...] And it was ok then. (Joanna)

“We are self-advocates and we need to protect our rights and the rights of every person with a disability! This is what we learnt here.” (Paul)

“If someone can’t protect himself or herself, they’ll attack him or her.” (Martha)

As far as the sources of knowledge about sexuality are concerned, the participants reported the following: friends, family members (parents, siblings, cousins, and aunts), Internet, television and professionals (e.g. gynecologists). Some of them also mentioned trainings organized at workshops and – depending on the focus group, which was organized in different towns – they were more or less satisfied with them:

We had such trainings here. They told us what is wrong and when to say ‘no’. (Joanna)

Yeah, there was something like that. But they only showed us some cartoons, you know...

Not real actors. (Daniel)

In any case, however, the self-advocates seemed to be interested in this sort of trainings.

Research Question 1: How do self-advocates’ with intellectual disabilities perceive love?

The next step in data analysis was to formulate answers to the research questions. As far as the first one is concerned (*How do self-advocates’ with intellectual disabilities perceive love?*), the findings indicate that both love is considered by self-advocates with intellectual disabilities as a very significant sphere. The participants talked about it in a vivid way and described as something desirable. Most of the interviewees admitted that they dreamt of having a partner/husband/wife in the future and it was obvious to them that people with intellectual disabilities have the right to be involved intimate relationships and to express their sexuality. Nonetheless, they also seemed to be aware of various environmental constraints in the sphere.

Research Question 2: What contributes to the sphere of intimate relationships and sexuality of self-advocates’ with intellectual disabilities?

The analysis of the research material also allowed answering the second research question: *What contributes to their sphere of intimate relationships and sexuality?* Four categories of contributors to the sphere of love and intimate relationships of adults with intellectual disabilities were distinguished: (1) the participants’ personal characteristics and activities, (2) participation in social life, (3) environmental facilitators and (4) environmental barriers. They are characterized below.

Personal characteristics and activities of the participants (1) were usually perceived as facilitators, not barriers in the sphere of intimate relationships. Talking about this subject, the participants focused on their positive personal characteristics, e.g. self-confidence, abilities to learn to live independently and protect their own rights. Also, gaining knowledge on sexual behaviour (e.g. during trainings organized in occupational therapy workshops) and preparing for vocational activities can be treated as facilitators in forming and maintaining relationships. There were only a few participants who emphasized their personal characteristics as barriers in this sphere. These characteristics, however, did not refer to their intellectual abilities but to their state of health. This was illustrated by David, who admitted that he would not have children due to his

epilepsy and Martha who was aware that moving on a wheelchair can make it difficult for her and her future partner to live independently.

It is also clear that the interviewees' active participation in social life (2) (e.g. social events, being a member of a theatre group or a self-advocacy group) plays a vital role in enabling this group to form and maintain an intimate relationship as well. When the self-advocates talked about their current or previous experiences in the sphere of sexuality and intimate relationships, they usually mentioned that they had met their (ex-) partners at occupational therapy workshops which they regularly attended. It is certain that for all the participants day centres are important (sometimes the most important) places for having social life (making friends, meeting peers, finding a partner). Being a consumer of the workshops also gives opportunities to take part in various social events organized for people with intellectual disabilities, e.g. trips, sports competitions or dances. For some consumers this is the only chance to actually be involved in social life as otherwise they would stay at home. Furthermore, all the participants were members of self-advocacy groups. Except for giving an opportunity for social contacts, it is plausible that participation in self-advocacy meetings had an impact on their way of thinking on their rights, also in the sphere of sexuality. A few interviewees were also involved in art groups (a theatre group, a band), which enabled them not only to keep in touch with group members, but also with the public (during performances) and other people they met on tours. Thanks to recreation and leisure activities as well as thanks to contacts with different people, especially peers, adults with intellectual disabilities can observe various social situations, observe couples, develop social skills and sometimes experience their own infatuations, relationships, love.

Environmental facilitators (3) refer to trainings, positive attitudes of professionals and other people from the participants' close environment. Thanks to trainings, the participants can acquire new skills (e.g. social skills) and gain knowledge (e.g. on their rights and obligations, on sexuality). Positive attitudes of other people were usually connected with certain activities which enabled the participants to be engaged in an intimate relationship (for example parents allowing couples to meet at home).

Environmental barriers (4) were associated with negative (overprotective or restrictive) attitudes of parents (in the sphere of sexuality and intimate relationships) and material (including financial) factors (having no apartment, limited finances based on disability payments). Both of these barriers often led to lack of privacy (having no place and/or no money to spend time with a partner) and reliance on others, usually parents or other family members.

Discussion

The analysis of the content of verbatim material gathered in the interviews shows that love and intimate relationships constitute a sphere of vital importance to adults with intellectual disabilities. In the study the participants showed awareness of their sexuality and their desires to be loved. The findings are in line with the results of studies by Löfren-Mårtenson (2004), Grütz (2007), Arias, Ovejero and Morentin (2009), Rushbrooke, Murray and Townsend, (2014) and Mattila et al. (2017). The first one suggests that the majority of people with intellectual disabilities express their need for love and sexual expression, the second indicates that intimate relationships are desired and important to these persons and the third shows that individuals with

mild intellectual disabilities describe love as emotions and concrete acts and consider it crucial for everyone's well-being. Also, in the current study four main contributors to their sphere of sexuality and intimate relationships were recognized: (1) personal characteristics and activities, (2) participation, (3) environmental facilitators and (4) environmental barriers. The analysis of the research material indicates that adults with intellectual disabilities rarely see the barriers in themselves. Much more common – from their perspective – are barriers located in the environment, especially in their close family members who restrict their privacy. The findings align with the research results obtained by other authors (Healy et al., 2009; Kelly, Crowley and Hamilton, 2009; Abbott 2013), which indicate that, although adults with intellectual disabilities are aware of their sexual rights, they perceive a number of social and cultural barriers in fulfilling these rights. Similar results were obtained by Ćwirynkało, Byra and Żyta (2017), whose study suggests that also therapists perceive overprotective or controlling behaviors and attitudes of parents of people with intellectual disabilities as one of the main barriers in developing their sexuality.

Conclusions and Recommendations

In this paper an attempt has been made to present how self-advocates with intellectual disabilities perceive love and sexuality. In order to gain an in-depth view on the subject an inclusive project was designed in which self-advocates during focus groups meetings were asked to express their opinions and share their experiences. The analysis of the content of verbatim material gathered in the interviews shows that love and intimate relationships constitute a sphere of vital importance to adults with intellectual disabilities. In the study the participants showed awareness of their sexuality and their desires to be loved. The findings are in line with the results of studies by Löfren-Mårtenson (2004), Rushbrooke et al. (2014) and Mattila et al. (2017). The first one suggests that the majority of people with intellectual disabilities express their need for love and sexual expression, the second indicates that intimate relationships are desired and important to these persons and the third shows that individuals with mild intellectual disabilities describe love as emotions and concrete acts and consider it crucial for everyone's well-being. Also, in the current study four main contributors to their sphere of sexuality and intimate relationships were recognized: (1) personal characteristics and activities, (2) participation, (3) environmental facilitators and (4) environmental barriers. The analysis of the research material indicates that adults with intellectual disabilities rarely see the barriers in themselves. Much more common – from their perspective – are barriers located in the environment, especially in their close family members who restrict their privacy. Similar results were obtained by Ćwirynkało, Byra & Żyta (2017), whose study suggests that also therapists perceive overprotective or controlling behaviors and attitudes of parents of people with intellectual disabilities as one of the main barriers in developing their sexuality.

The research has several implications both in the field of possible future research and practice. In the field of research, we suggest conducting further studies with adults with intellectual disabilities. Focus group interviews turned out to be a useful technique of gathering research material from these participants so other research subjects can also be explored this way. However, we believe that using additional aids (like pictures, films) that would facilitate expressing opinions could be of value, especially in a group of participants who have difficulties with communication. Furthermore, the selection of participants of focus groups can be discussed.

Perhaps, results would differ if the meetings were restricted to single-sex groups, especially in case of such sensitive subjects like sexuality.

In the field of practice we recommend providing support for adults with intellectual disabilities in the sphere of intimate relationships. The support could be provided by different stakeholders out of which two groups seem to play a crucial role: parents (or sometimes other family members) and professionals, e.g. doctors, teachers, therapists, also working at occupational therapy workshops). They should be responsible for developing social skills and self-determination of adults with intellectual disabilities as well as facilitating their contacts with other people on a social basis. The research findings also suggest that trainings on sexuality for adults with intellectual disabilities and establishing policies related to sexual behaviour in institutions for these people are essential. It is worth noting that similar needs are also expressed by therapists who work in such institutions (Ćwirynkało, et al., 2017). The present study indicates that also the consumers of these institutions want to participate in such trainings and are in favour of having regulations concerning sexual behaviour there. Another recommendation is to organize trainings or meetings for parents of adults with intellectual disabilities during which their children's needs in the sphere of intimate relationships could be discussed.

Clearly, although the findings of the current study are of value, there are also some limitations. First, the qualitative character of the study does not allow any generalizations. The group of participants was relatively small (31 participants) and they all came from the same north-eastern region of Poland. Perhaps, results gathered from a bigger sample living in different places would be different in some ways. Second, it is possible that the interviewees in the study tried to report socially correct responses and had a tendency to hide their actual opinions and experiences which – according to them – could not be appreciated by others.

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